Nueva York, Estados Unidos, el 23 de enero de 2020

Respetada Magistrada

CRISTINA PARDO SCHLESINGER

MAGISTRADA PONENTE

Corte Constitucional

E.S.D.

REF: Expedientes acumulados D-13575 y D-13585

Demanda de inconstitucionalidad contra la Ley 1996 de 2019 "Por medio de la cual se establece el régimen para el ejercicio de la capacidad legal de las personas con discapacidad mayores de edad"

Accionantes: Edier Esteban Manco Pineda (D-13575), Grupo de estudiantes de la Facultad de Derecho de la Universidad de Manizales (D-13585).

Nosotros,

- el **Profesor Michael Ashley Stein**, ciudadano estadounidense en ejercicio y Director Ejecutivo del Harvard Law School Project on Disability de Cambridge, Massachusetts, Estados Unidos;
- la **abogada Cathy Costanzo**, ciudadana estadounidense en ejercicio y Directora Ejecutiva del Center for Public Representation de Northampton, Massachusetts, Estados Unidos;
- la **Profesora Leslie Salzman**, ciudadana estadounidense en ejercicio y Profesora Clínica de Derecho del Colegio de Derecho Benjamin N. Cardozo y Co-Directora del Cardozo Bet Tzedek Civil Litigation Clinic, de Nueva York, Nueva York, Estados Unidos;
- la **Profesora Rebekah Diller**, ciudadana estadounidense en ejercicio y Profesora Clínica de Derecho del Colegio de Derecho Benjamin N. Cardozo y Co-Directora del Cardozo Bet Tzedek Civil Litigation Clinic, de Nueva York, Nueva York, Estados Unidos;

- la **Profesora Natalie Chin**, ciudadana estadounidense en ejercicio y Profesora Asociada de Derecho y Co-Directora del Disability & Aging Justice Clinic de la Universidad de la Ciudad de Nueva York, de Nueva York, Nueva York, Estados Unidos; y
- la **Profesora Kristin Booth Glen**, ciudadana estadounidense en ejercicio y Profesora Universitaria en la Universidad de la Ciudad de Nueva York de Nueva York, Nueva York, Estados Unidos,

nos permitimos dirigirnos a Usted, con el fin de solicitarle de la manera más respetuosa nos permita, como organizaciones y miembro de la sociedad civil, presentar una intervención en el presente proceso, amparándonos en el artículo 242 de la Constitución Política, el cual dispone que *"[c]ualquier ciudadano podrá (...) intervenir como impugnador o defensor de las normas sometidas a control en los procesos promovidos por otros"*.

La presente intervención se organiza en la siguiente manera. Primero, presentamos brevemente los intereses y experticias de las organizaciones y el individual suscritos. Luego, resumimos el objetivo de esta intervención, antes de aportar tres consideraciones de fondo relevantes a la cuestión de constitucionalidad frente a la Corte. Estas son, primeramente, que la experiencia de los Estados Unidos con respecto de las sentencias de interdicción es que éstas han ocasionado abusos, explotación y disminución de la capacidad funcional de las personas interdictas. En contraste, los sistemas de apoyo para la toma de decisiones, una alternativa a la interdicción, ha tenido resultados positivos en las vidas de personas con discapacidad intelectual. Por lo tanto, el tránsito desde un régimen de sustitución de voluntad a uno basado en sistemas de apoyos reflejado en la Ley 1996 de 2019 busca evitar los defectos de los sistemas de interdicción y promover acceso a una alternativa que ha sido correlacionada con mayores beneficios para las personas involucradas. Últimamente, adjuntamos varios anexos citados en nuestra intervención, que podrían resultar de utilidad.

DECLARACIÓN DE INTERESES

El Harvard Law School Project on Disability ("HPOD") es un centro global de derecho y políticas públicas sobre discapacidad ubicado en Cambridge, Massachusetts, Estados Unidos, que provee apoyo técnico a gobiernos, instituciones protectoras de derechos humanos, organizaciones no gubernamentales y organizaciones representantes de personas con discapacidad, para promover la efectiva implementación de la Convención sobre los Derechos de las Personas con Discapacidad de la Organización de las Naciones Unidas (CDPD). Su director ejecutivo, el Profesor Michael Ashley Stein, fue uno de los actores principales en las negociaciones de dicho instrumento. HPOD ha trabajado en más de 40 países, asesorando procesos legislativos, llevando a cabo investigaciones académicas y apoyando litigios estratégicos, incluso mediante la presentación de escritos de *amicus curiae* en numerosos casos sobre derechos de personas con discapacidad ante órganos internacionales, regionales y nacionales, incluso el Comité sobre los Derechos de las Personas con Discapacidad de las Naciones Unidas (el "Comité CDPD"), la Corte Interamericana de Derechos Humanos y el Tribunal Europeo de Derechos Humanos.

El Center for Public Representation (el Centro de Representación Pública, o "CPR") es un bufete de abogados de interés público que ha ayudado a personas con discapacidades por más de 40 años. El CPR utiliza estrategias legales, iniciativas de reforma sistémica y promoción de políticas para hacer cumplir los derechos civiles, ampliar las oportunidades para la inclusión y la plena participación de la comunidad y capacitar a las personas con discapacidad para que puedan tomar sus propias decisiones en todos los aspectos de sus vidas. El CPR ha impulsado litigio estratégico en más de 20 estados y ha presentado escritos de *amicus* en la Corte Suprema de los Estados Unidos, tanto en varios tribunales federales de apelación estadounidenses, para hacer cumplir los derechos constitucionales y estatutarios de las personas con discapacidad. El CPR estableció el primer proyecto piloto sobre la toma de decisiones con apoyo en los Estados Unidos en el año 2015. Desde entonces, ha coordinado el establecimiento de cinco programas adicionales en Massachusetts y actualmente gestiona un centro nacional de capacitación y asistencia técnica, inclusive un sitio web dedicado a la toma de decisiones con apoyo, disponible en: www.supportedecisions.org.

El Cardozo Bet Tzedek Civil Litigation Clinic, del Colegio de Derecho Benjamin N. Cardozo (la "Clínica Cardozo"), con sede en Nueva York, Nueva York, Estados Unidos, es una clínica jurídica en materia de derecho civil que brinda asesoría jurídica a los adultos mayores y personas con discapacidad con respecto de asuntos civiles. El eje de la clínica es proteger y garantizar los derechos civiles de sus clientes así como sus derechos a recibir servicios y apoyos para que puedan vivir plena e independientemente en la comunidad. La Clínica Cardozo promueve el derecho a la capacidad jurídica al ayudar a los clientes encontrar alternativas a la interdicción y al representar a los individuos sujetos a sentencias de interdicción para que remuevan éstas sentencias y restauren sus derechos.

El Disability & Aging Justice Clinic ("DAJC") de la Universidad de la Ciudad de Nueva York ("CUNY"), la más grande universidad pública urbana en los Estados Unidos, brinda asesoría jurídica a los neoyorquinos con discapacidad y adultos mayores en varios asuntos civiles, incluyendo discriminación en el acceso a programas y servicios, los derechos de presos, acceso a servicios de salud, alternativas a la interdicción y los procedimientos de interdicción. La misión del DAJC es promover y proteger los derechos civiles, así como la personalidad y autodeterminación de los individuos con discapacidad y adultos mayores. La interdicción, o más bien las alternativas a ella, como el apoyo para la toma de decisiones, son temas esenciales para el DAJC, ya que la interdicción obstaculiza el derecho de los adultos con discapacidad intelectual y otros adultos con limitaciones cognitivas a mantener su dignidad, autodeterminación y personalidad con respecto de las decisiones que más afectan sus vidas.

Profesora Kristin Booth Glen de CUNY es una experta sobre el ejercicio de la capacidad jurídica, habiendo publicado más de cinco artículos académicos al respecto y habiendo estado invitada a intervenir como experta ante la Oficina del Alto Comisionado para los Derechos Humanos de las Naciones Unidas, así como para dar lecturas a asociaciones de jueces en diversos países, incluyendo Bulgaria, Escocia, Georgia, Islandia, y Tanzania, y diversos estados de los Estados Unidos. Desde hace 11 años, ha operado como jueza estatal en la Ciudad de Nueva York con jurisdicción sobre los procedimientos de interdicción relativos a las personas con discapacidad intelectual tanto aquellos relativos a los adultos mayores, y emitió los primeros fallos en los Estados Unidos aplicando la CDPD en este tipo de procedimiento. Actualmente, dirige el proyecto piloto llamado "Supported Decision-Making New York", el más grande sobre el apoyo para la toma de decisiones en el país, el cual desarrolló y está implementando un modelo novedoso destinado a ayudar a más de cien personas con discapacidad a elaborar acuerdos de apoyo escritos, con financiamiento desde el estado de Nueva York. Más información sobre el proyecto está disponible en: www.sdmny.org.

RESÚMEN

Este escrito de *amici curiae* tiene por objetivo dar a conocer a esta Honorable Corte la experiencia estadounidense en cuanto a la operación actual de la figura de interdicción y la implementación de sistemas de apoyo para la toma de decisiones. La interdicción contraviene los preceptos de la CDPD, como ha esclarecido el Comité CDPD de manera repetida en su observación general y conclusiones finales sobre los informes de estados partes, tanto como han hecho varios tribunales nacionales y subnacionales de diversos países, inclusive en los

Estados Unidos. La contradicción entre la interdicción y los derechos de las personas con discapacidad no es una mera cuestión doctrinal. Al contrario, cada día más aumenta la conciencia de los abusos y violaciones de derechos que la interdicción ha ocasionado. Precisamente para encontrar una alternativa que puede ayudar a evitar tales abusos, actualmente en los Estados Unidos se están implementando varios programas pilotos diseñados a ayudar las personas con discapacidad intelectual a celebrar acuerdos de apoyo para la toma de decisiones.

Además, jueces en varios estados han emitido al menos 26 fallos judiciales en los cuales se consideraron los sistemas de apoyo para la toma de decisiones más aptos que la interdicción, mientras al menos 8 estados y el Distrito Federal de los Estados Unidos han expedido decretos legislativos con el fin de difundir el uso y conciencia de los sistemas de apoyo para la toma de decisiones. En contraste con la interdicción, los sistemas de apoyo han sido correlacionados con efectos positivos en las vidas de las personas con discapacidad, urgiendo reemplazar los regímenes de interdicción con sistemas que promuevan dichas alternativas. Visto que la Ley 1996 de 2019 "Por medio de la cual se establece el régimen para el ejercicio de la capacidad legal de las personas con discapacidad mayores de edad" busca implementar las directrices de la CDPD y su Comité e incorpora la flexibilidad necesaria para modificar la *praxis* en cuanto a los sistemas de apoyo conforme al surgimiento de nuevas lecciones e innovaciones, se debería declarar que la Ley 1996 de 2019 es EXEQUIBLE e instarse a las entidades del Estado correspondientes a que aseguren su cabal cumplimiento.

FONDO

1. En los Estados Unidos, las sentencias de interdicción han ocasionado abusos, explotación y disminución de la capacidad funcional de las personas interdictas.

Históricamente, la imposición de interdicción por orden judicial se ha justificado en la protección de una persona vulnerable, sea por discapacidad, vejez, u otro motivo. Sin embargo, la experiencia reciente estadounidense ha demostrado que, en vez de cumplir con el objetivo de protección, en muchos casos la interdicción paradójicamente ha expuesto a dichas personas a un mayor grado de vulnerabilidad. Al transferir los derechos de una persona a un tercero, contrariamente al objetivo de protegerla, se le quita las herramientas para protegerse sí mismo, resultando en un estado de desprotección.

Conforme a la organización gubernamental federativa estadounidense, los estados y no el gobierno federal son competentes a regular la interdicción. Estos han expedido normas y desarrollado procedimientos al respeto que varían desde estado a estado[1]. Los defectos en dichos sistemas estatales han permitido un rango de abusos por los tutores, los cuales se dieron a la luz en los 1980s[2], y subsecuentemente provocaron reformas a la normatividad en muchos estados[3]. Si bien las reformas en gran parte eran exitosas en cuanto a impulsar nuevas legislaciones destinadas a detectar los conflictos de intereses, así como a limitar el alcance de la autoridad de los tutores, no llegaron a eliminar la interdicción por completo[4]. Como resultado, dichas reformas no extirparon las causales subyacentes de la problemática, visto que siguen dándose a la luz abusos y maltratos en el mismo sentido[5].

Más recientemente, la generalización de abusos también ha servido como una llamada a acción para el Gobierno federal, aun si formalmente dentro el sistema federativo estadounidense carece de competencia para promulgar legislación o reglamento con respecto de la interdicción. Tres veces, en 2004, 2010 y 2016, el Congreso ha solicitado que la Oficina de Fiscalización Federal ("GAO", por sus siglas en inglés) elaborara un informe para investigar los abusos y explotación experimentados por personas sujetas a la interdicción. El informe de 2010 documentó cientos de casos de abuso físico, negligencia y explotación financiera por tutores entre los años 1990 y 2010[6]. El GAO atribuyó que defectos en los sistemas judiciales de monitoreo y control eran al menos parcialmente responsables por el alcance del riesgo de abuso. Los abusos sucedieron no sólo cuando el tutor no tenía relación familiar con la persona interdicta—un estudio sobre casos de explotación financiera por un tutor en el estado de Minnesota confirmó que 24 de los 31 casos examinados involucraron tutores quienes eran familiares las personas interdictas.

El informe del GAO de 2016 concluyó que a pesar del deber de los tribunales estatales, al imponer una sentencia de interdicción, de monitorear el estado de la persona interdicta, en

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[1] *Véase* Government Accountability Office (GAO), *Guardianships: Collaboration Needed to Protect Incapacitated Elderly People*, Nro. GAO-04-655, pág. 9 (2004).

[2] *Véase por ejemplo* Fred Bayles y Scott McCartney, "Guardians of the Elderly: An Ailing System Part II: Many Elderly Never Get Their Day in Court", *Associated Press* (20 de septiembre de 1987), *disponible en:* http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-II-Many-Elderly-Never-Get-Their-Day-In-Court/id-8ea94c1c992fd97e7eea7fe72a924f73 [https://perma.cc/5YRP-7FQK].

[3] *Véase* A. Frank Johns, "Ten Years After: Where is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?", *Elder Law Journal*, vol. 7, pág. 79 (1999).

[4] *Véase* Rebekah Diller, "Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making", *Fordham Urban Journal of Law*, vol. 43, pág. 505 (2016).

[5] *Véase por ejemplo* Rachel Aviv, "How the Elderly Lose Their Rights", *The New Yorker* (2 de octubre de 2017), *disponible en:* https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights.

[6] GAO, *Guardianships: Cases of Financial Exploitation, Neglect and Abuse of Seniors*, Nro. GAO-10-1046, pág. 2 (2010).

muchos casos no lo hacían eficazmente[7]. Muchos tribunales no solo carecían de los recursos financieros o humanos para conducir actividades de monitoreo eficaces, sino la extensión de las actividades de monitoreo era limitada. Por ejemplo, frecuentemente los secretarios de acuerdos revisaran informes financieros (si los recibían), pero no monitorearan el estado de salud o bienestar de la persona interdicta o investigar si deriva mayores beneficios desde la interdicción que alternativas a ella[8]. Es decir, aunque el estado, a través del tribunal, optó a intervenir en la vida de una persona para transferir sus derechos a otra persona, no adoptaba las medidas mínimas de control para asegurarse si su intervención conllevaba beneficios a la persona supuestamente necesitando un mayor grado de protección. Asimismo, el informe señaló que los tribunales estatales al cargo de garantizar la protección de las personas interdictas no contaban con datos sistemáticos sobre la población bajo su supervisión[9], a pesar de varias iniciativas lideradas por el gobierno federal diseñadas a fomentar la recopilación y reparto de datos.

Aparte de los daños físicos y pecuniarios causados por ciertos tutores, varios estudios han demostrado que la interdicción de por sí conlleva impactos psicosociales negativos en todas las personas interdictas, aún si son más sutiles.[10] El informe del 2018 del Consejo Nacional sobre Discapacidad ("NCD", por sus siglas en inglés) catalogó dichos estudios, y al sintetizarlos concluyó que la interdicción está correlacionada con los siguientes efectos:

- impactos negativos en la capacidad funcional, salud y bienestar de una persona,
- aislamiento social,
- disminución de confianza y aumento de sentimientos de desesperanza,
- sentimientos de estigmatización social, y
- preocupación que el tutor podría abusar su autoridad[11].

Es decir, la transferencia de derechos tiene efectos no sólo legales sino sociales y psicólogos, generando una forma de "aislamiento social construido", efectivamente dejando muchas

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[7] GAO, *Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults*, Nro. GAO-17-33, pág. 22 (2016). *Véase también* National Center for State Courts, Center for Elders and the Courts, *Adult Guardianship Court Data and Issues Results from an Online Survey*, pág. 25 (2010), *disponible en:* http://aja.ncsc.dni.us/pdfs/GuardianshipSurveyReport_FINAL.pdf.

[8] *Véase* National Center for State Courts, *idem*, pág. 26.

[9] Government Accountability Office, *Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults*, Nro. GAO-17-33, pág. 6 (2016).

[10] *Véase por ejemplo* A. Frank Johns, "Person-Centered Planning in Guardianship: A Little Hope for the Future," *Utah Law Review*, vol. 3, pág. 1543 (2012).

[11] National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities*, págs. 118-123 (2018).

personas interdictas en situaciones de mayor vulnerabilidad a abuso.[12] Además, la interdicción puede fomentar estigmatización de las persona interdictas por parte de terceros, quienes erróneamente les perciben como deficientes, incompetentes e incapaces a causa de su estado legal[13], así reforzando su aislamiento y poniéndole en un estado de mayor vulnerabilidad.

2. Los sistemas de apoyos para la toma de decisiones han sido correlacionados con resultados positivos en las vidas de personas con discapacidad intelectual, provocando tendencias judiciales y legislativas que favorecen esta alternativa a la interdicción.

Dos proyectos pilotos sobre la toma de decisiones con apoyo han demostrado que esta alternativa a la interdicción conlleva ciertos beneficios a las personas con discapacidad intelectual, en adición de no exponerlas al grado y tipo de vulnerabilidad que haría una sentencia de interdicción. Los resultados emergiendo de estos pilotos, así como la conciencia de los sistemas de apoyo en general, han influenciado a varios jueces en diversos estados del país a someter la interdicción a un escrutinio más estricto que harían tradicionalmente. Luego, para respaldar los esfuerzos judiciales para transitar desde las prácticas basadas en la sustitución de la voluntad hacia arreglos diseñados a brindar los apoyos necesarios para suplirla, las asambleas legislativas de diversos estados del país han expedido reformas para fomentar y acelerar dicha transición.

(a) Resultados positivos de los proyectos pilotos

Desde el 2015 al 2016 Center for Public Representation y Nonotuck Resource Associates, Inc., ambas organizaciones no gubernamentales sin fines de lucro, conjuntamente dirigieron el primer proyecto piloto en los Estados Unidos, con el propósito de ayudar a nueve personas con discapacidad intelectual a ejecutar acuerdos de apoyo para la toma de decisiones y utilizar los sistemas de apoyo notariados en dichos acuerdos para tomar sus propias decisiones. Utilizaron los apoyos estipulados para tomar decisiones grandes y pequeñas, y los apoyos se utilizaron más frecuentemente para decisiones entorno a la salud, y secundariamente con decisiones financieras[14]. Preocupaciones con respecto de esta índole de decisiones—de la salud y los bienes—son precisamente aquellas que influencian a familiares o proveedores de servicios de solicitar la interdicción. Después del segundo año, un evaluador independiente

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[12] Leslie Salzman, “Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?”, *Saint Louis University Journal of Health Law & Policy*, vol. 4, págs. 289–293 (2010).

[13] National Council on Disability, *Turning Rights into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities*, pág. 72 (2019).

[14] Elizabeth Pell y Virginia Mulkern, *Supported Decision Making Pilot: Pilot Program Evaluation Year 2 Report*, pág. 5 (2016).

elaboró un informe describiendo los cambios que se evidenciaron en los participantes, las cuales incluyeron aumentos en orgullo, auto estima, alegría, disponibilidad de probar cosas nuevas, mayor protagonismo con respecto de su propia salud física y mental, mayor iniciativa a ayudar a otros[15]. Más importante, nadie experimentó abuso, negligencia o explotación financiera como resultado de utilizar a apoyos, causando los participantes a pensar que la estructura de los sistemas de apoyo para la toma de decisiones disminuyen los riesgos que pueden afectar a las personas interdictas[16].

Además, se realizó un informe de medio camino con respecto de un proyecto piloto en el estado de Nueva York llamado "Supported Decision-Making New York", o "SDMNY". Hasta la fecha, ha ayudado a 10 personas con discapacidad intelectual a celebrar acuerdos para la toma de decisiones, tras completar un programa riguroso que se compone de tres fases y por medio del cual se conocen sus derechos y se sensibiliza a sus apoyadores. Al entrevistar los apoyadores relacionados con 20 personas con discapacidad que habían ejecutado sus acuerdos o que habían avanzado en el programa, la evaluadora independiente contratada por parte del proyecto notó los siguientes cambios positivos en las personas con discapacidad:

- más contento,
- mayor entusiasmo de responsabilizarse por sus decisiones,
- aumentada autoestima y abogacía,
- fortalecidas habilidades de independencia,
- reforzada confianza en sus habilidades,
- menos ansiedad y más madurez[17].

Es decir, al juicio de los apoyadores, las personas con discapacidad intelectual se volvieron *más capaces* de tomar decisiones como resultado de su participación en el proyecto SDMNY. Además, los apoyadores mismos se beneficiaron como resultado de su participación en el programa, ya que reportaron haber dado más libertad a las personas con discapacidad de tomar sus propias decisiones, haber observado más autoexpresión y protagonismo por parte de las personas con discapacidad, haber tenido más oportunidades de conversar abiertamente de asuntos importantes y haber sentido menos miedo acerca del futuro de las personas con

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[15] *Idem*, págs. 32–33.
[16] *Idem*, pág. 26.
[17] Elizabeth Pell, *Supported Decision-Making New York: Evaluation Report of an Intentional Pilot*, págs. 68–71 (2019).

discapacidad[18]. En otras palabras, los apoyadores resultaron más sensibilizados y dispuestos de buscar a suplir y complementar la voluntad de las personas con discapacidad en vez de sustituirla, equipándoles así con redes de apoyo suficientes para que ejerzan su capacidad jurídica y obviando cualquier necesidad de protección anteriormente percibida.

Los resultados de estos dos proyectos estadounidenses son consistentes con los beneficios observados en los participantes de otros proyectos pilotos en otros países. Por ejemplo, un proyecto búlgaro demostró que los sistemas de apoyo están correlacionados con aumentos en autodeterminación, relaciones interpersonales y desarrollo personal[19]. Los evaluadores independientes de un proyecto israelí observaron que el uso del apoyo para la toma de decisiones fortaleció la capacidad de las personas con discapacidad intelectual involucradas a comprender sus métodos de tomar decisiones, así como sus habilidades en cuanto a implementar y dar a seguimiento a sus elecciones[20]. En el mismo sentido, varios proyectos pilotos realizados en Australia han documentado beneficios relacionados con el uso del apoyo para la toma de decisiones. Aumenta la confianza de las personas con discapacidad en su capacidad de tomar sus propias decisiones[21], conlleva al desarrollo de nuevas estrategias y más sofisticadas habilidades relacionadas con la toma de decisiones[22] y estimula a la persona con discapacidad a no sólo desarrollar habilidades específicamente relacionadas con la toma de decisiones, sino asumir mayor responsabilidad para otras áreas de su vida, como para realizar tareas diarias que anteriormente realizaron familiares o profesionales[23].

Así, los reportes desde los primeros intentos de implementar los sistemas de apoyo para la toma de decisiones indican que estos son correlacionados con mayores beneficios para las personas involucradas, en contraste con los muchos casos de abusos que han sido documentados con respecto de las personas interdictas.

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[18] *Idem.*

[19] Radoslava Lalcheva y Miryana Malamin, *Cost Benefit Analysis of Supported Decision-Making*, págs. 12–15 (2014), *disponible en:* http://bcnl.org/uploadfiles/documents/Cost%20Effectiveness_SDM.pdf.

[20] Tal Cahana y Shira Yalon-Chamovitz, “Article 12 Supported Decision Making Pilot: Summary of assessment study findings”, en *Supported Decision-Making Service for Persons with Disabilities: Service Model*, pág. 45 (2016), *disponible en:* https://www.beitissie.org.il/kb/digital/decision/files/assets/common/downloads/publication.pdf.

[21] WestWood Spice, *My life, my decision: An independent evaluation of the Supported Decision Making Pilot*, págs. 52–53 (2015), *disponible en:* https://sdmny.org/download/westwood-spice-my-life-my-decision-an-independent-evaluation-of-the-sdm-pilot-2015.

[22] Margaret Wallace, *Evaluation of the SDM Project*, págs. 4-5 (2012), *disponible en:* http://sdmny.org/download/margaret-wallace-evaluation-of-the-sdm-project-2012.

[23] Community Matters Pty Ltd, *HCSCC Supported Decision Making Program 2014-15: Evaluation report*, págs. 5-6 (2015), *disponible en:* http://www.hcscc.sa.gov.au/wp-content/uploads/2015/11/HCSCC-SDM-Project-2015-Evaluation-Report1.pdf.

(b) Nueva reticencia de los jueces competentes a imponer la interdicción

En años recientes, conforme al aumento de conocimiento de los beneficios correlacionados con los sistemas de apoyos, varios jueces estadounidenses han negado solicitudes de sentencias de interdicción que anteriormente solían otorgar. Ya que la CDPD aún no ha sido ratificada por el gobierno estadounidense, los jueces estadounidenses no se encuentran obligados a considerar sus preceptos al decidir imponer una sentencia de interdicción o no. No obstante, cada día más jueces estatales, quienes conforme al derecho estadounidense tienen jurisdicción sobre cuestiones de relacionadas con el ejercicio de capacidad jurídica, están procurando a promover los sistemas de apoyo para la toma de decisiones por vía jurisprudencial.

En un fallo parteaguas emitido en el 2012, la jueza neoyorquina Kristin Booth Glen decidió que Dameris L., una mujer con una discapacidad intelectual (de grado leve a moderado), era capaz de ejercer su capacidad jurídica, a razón de su red de apoyo informal, con el apoyo de otros. Por lo tanto, revocó la sentencia de interdicción que le había impuesta tres años atrás, la cual nombró la madre de Dameris y su esposo como sus tutores[24]. En el intervalo entre la emisión de la sentencia y la revisión judicial de la misma, surgió una crisis de vivienda para Dameris, que le obligaba a mudarse y ejecutar un nuevo contrato de arrendamiento. Empero, en aquel momento su tutora se encontraba en el extranjero y no podía contactarse, por lo cual las demás personas involucradas en su vida se movilizaron para facilitar su mudanza bajo supervisión judicial a pesar de la ausencia de la tutora.

La red de apoyo de Dameris era conformada por su esposo, sus vecinos (quienes además consintieron a ser los padrinos de su hija), y la esposa del primo de su esposo. Esta última venía a la casa rutinariamente y le ayudaba con decisiones cotidianas, por ejemplo, a traducir documentos desde español a inglés o darse de alta en clases comunitarias de alfabetización, así como decisiones más significativas, como la de someterse a un procedimiento de ligadura de trompas. Por ello, la jueza concluyó que Dameris, *"ha demostrado que puede ejercer su capacidad jurídica, esto es, para tomar y implementar sus propias decisiones, con la asistencia de su red de apoyo, la cual se ha materializado luego de la primera vez ella había acudido a este tribunal. El acto de revocar la sentencia previa designando . . . sus tutores, se los reconoce a la vez como personas que asisten y apoyan a su autonomía en vez de sustituirla. El acto de*

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[24] *Matter of Dameris L.,* 38 Misc. 3d 570, Surrogate Court del condado de Nueva York, 31 de diciembre de 2012.

revocar la sentencia de interdicción reconoce y afirma los derechos constitucionales así como los derechos humanos de Dameris".

En los siete años después del fallo, *Matter of Dameris*, al menos cinco otros jueces neoyorquinos han fallado en manera parecida en más de 15 casos, sea para revocar sentencias o negar solicitudes, al haberse convencido que el sistema de apoyos para la toma de decisiones se alinea mejor con la protección de los derechos de las personas tradicionalmente a riesgo de interdicción, aún en la ausencia de una obligación legal de hacerlo:[25]

Nro.	Título	Fecha	Referencia
1.	*Matter of Capurso*	26 de marzo de 2019	63 Misc. 3d 725
2.	*Proceeding for the Appointment of a Guardian for Chenel D.*	14 de enero de 2019	2019 NYLJ LEXIS 125
3.	*Matter of Eli T.*	5 de diciembre de 2018	62 Misc. 3d 638
4.	*Matter of Michael J.N.*	27 de diciembre de 2017	58 Misc. 3d 1204(A)
5.	*Guardianship of K.L.*	29 de junio de 2017	2017 NYLJ LEXIS 1757 / 1695
6.	*Matter of Zachary W.*	30 de marzo de 2017	2017 NYLJ LEXIS 901
7.	*Estate of Caitlin*	16 de marzo de 2017	2017 NYLJ LEXIS 1043
8.	*Estate of Albert J.*	27 de febrero de 2017	2017 NYLJ LEXIS 475
9.	*Estate of Hilton*	3 de febrero de 2017	2017 NYLJ LEXIS 284
10.	*Sean O.*	30 de septiembre de 2016	2016 NYLJ LEXIS 3647
11.	*Matter of Michelle M.*	22 de julio de 2016	52 Misc. 3d 1211(A)
12.	*Matter of Hytham M.G.*	14 de abril de 2016	52 Misc. 3d 1211(A)
13.	*Matter of D.D.*	28 de octubre de 2015	50 Misc. 3d 666
14.	*Guardian for A.E.*	17 de agosto de 2015	2015 NYLJ LEXIS 4377
15.	*Proceeding for the Appointment of a Guardian for Akiva & Moshe*	9 de mayo de 2013	2013 NYLJ LEXIS 3334

Aún si los jueces del estado de Nueva York se han demostrado líderes en cuanto a sus contribuciones al desarrollo de la jurisprudencia estadounidense con respecto de la toma de decisiones con apoyo, no son los únicos. En 2013, un juez del estado de Virginia revocó la sentencia de interdicción de Margaret Hatch, una mujer con síndrome Down, a favor de su red de apoyos informal[26]. En 2015, un juez de Massachusetts restauró los derechos a Cory Carlotto, un hombre con diagnosis de autismo, desorden obsesivo compulsivo y ansiedad, en luz del

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[25] Como que el gobierno federal de los Estados Unidos todavía no ha ratificado la CDPD, los jueces estatales no se encuentran obligados de aplicar el tratado en los casos que resuelven.

[26] *Ross v. Hatch,* Nro. CWF-120000-426-DP (Virginia Circuit Court, 2 de agosto de 2013), *disponible en:* http://supporteddecisionmaking.org/sites/default/files/ross_hatch_trial_court_decision.pdf.

acuerdo para la toma de decisiones con apoyo que celebró con sus apoyos[27]. En 2016, un juez del Distrito Federal revocó la sentencia de Ryan King, Jr.[28], y otro del estado de Florida hizo lo mismo en el caso de Michael McCreight[29]. En 2017, tres jueces de los estados de Nevada[30], Vermont[31] y North Carolina[32] también revocaron sentencias de interdicción, y a continuación, en 2018 dos más jueces de los estados de Maine[33] e Indiana[34] terminaron interdicciones, así como un juez de Kentucky[35] el año pasado. En total, a partir del fallo *Matter of Dameris,* surgieron al menos 25 más fallos revocando sentencias de interdicción o negando solicitudes para ella, aún en la ausencia de un estándar legal vinculante como la CDPD, basándose en pruebas fáticas que las personas con discapacidad intelectual en los procedimientos estaban utilizando los sistemas de apoyo para la toma de decisiones, sea informalmente o con un acuerdo escrito, y que estos estaban en sus mejores intereses en vez de la interdicción.

(c) Tendencia legislativa a dar reconocimiento legal a los acuerdos escritos para la toma de decisiones con apoyo

En ningún de los casos anteriormente citados estaba vigente legislación estatal obligando al juez a considerar la toma de decisiones con apoyo en vez de la interdicción. Empero, esta situación está cambiando. Desde el 2015, ocho estados—Alaska, Delaware, Indiana, Nevada, North Dakota, Rhode Island, Texas y Wisconsin[36]—y el distrito federal han

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[27] *Véase* Center for Public Representation, "Meet Cory", *SupportedDecisions.org, disponible en:* http://supporteddecisions.org/cory.

[28] *In re Ryan Herbert King, Jr.*, Nro. 2003 INT 249 (D.C. Superior Court 2016), *disponible en:* http://supporteddecisionmaking.org/sites/default/files/ryan-king-order.pdf.

[29] *Véase* Disability Rights Florida, *2016 Annual Report*, pág. 4, *disponible en:* http://www.disabilityrightsflorida.org/documents/Disability_Rights_FL_2016_Annual_Report.pdf.

[30] *Order after September 5, 2017 Hearing; Order Terminating Guardianship; Decree of Discharge, In re A Protected Person*, Nro. PRO3-00264 (Nevada Judicial District Court 2017).

[31] *Véase* Vermont Department of Disability, Aging and Independent Living, *Annual Report*, pág. 2 (diciembre de 2017), *disponible en:* https://dail.vermont.gov/sites/dail/files//documents/DDSD_Supported_Decision_Making.pdf.

[32] *Véase* Thomas Goldsmith, "Adult guardianship group to propose changes in law, practice to NCGA", *North Carolina Health News* (4 de marzo de 2019), *disponible en:* https://www.northcarolinahealthnews.org/2019/03/04/adult-guardianship-group-to-propose-changes-in-law-practice-to-ncga.

[33] *Order of Termination of Guardianship, In re Strong*, Nro. 2002-0082 (Maine Probate Court, 6 de junio de 2018), *disponible en:* http://supporteddecisionmaking.org/sites/default/files/Strong-Order-of-Termination-of-Guardianship.pdf.

[34] *Véase* Marilyn Odendahl, "Indiana woman makes judicial history by seeking supported decision making agreement", *The Indiana Lawyer* (12 de junio de 2018), *disponible en:* https://www.theindianalawyer.com/articles/47278-indiana-woman-makes-judicial-history-by-seeking-supported-decision-making-agreement.

[35] *Véase* "Freed from Guardianship: A Kentucky First: Woman Wins Her Rights in Court Using SDM", *Exceptional Family KY*, págs. 14–15 (verano de 2017), *disponible en:* http://www.supporteddecisionmaking.org/impact-stories/freed-guardianship-kentucky-first-suzie-wins-her-rights-court-using-sdm.

[36] Para un listado de dichas leyes, incluyendo las referencias, véase Supported Decision-Making New York, "Supported Decision-Making Laws", https://sdmny.org/sdm-laws (último acceso el 15 de enero de 2020).

adoptado legislación dando reconocimiento legal a los acuerdos para la toma de decisiones con apoyo. Visto que los gobiernos estatales son los empoderados a expedir normas sobre la interdicción, es probable que el avance de legislación continuará, a saber: proyectos de ley similares están pendiendo en cuatro más estados—Connecticut, Kansas, Kentucky y Massachusetts. Esta tendencia legislativa ha surgido no obstante la ausencia de una obligación federal o de rango constitucional de hacerlo, ya que la CDPD no ha sido ratificada por el gobierno federal estadounidense, por lo tanto, indica que tanto los jueces como los miembros de la sociedad civil están buscando alternativas a la interdicción no caracterizadas por la misma historia de abusos y desprotección.

A pesar de las diferencias, cada una de estas nuevas leyes fundan el reconocimiento del derecho a ejercer la capacidad jurídica de personas con discapacidad intelectual, y en algunos de los estados personas con discapacidad psicosocial y adultos mayores, en un acuerdo escrito celebrado entre la persona con discapacidad (el “principal”) y las personas de apoyo (los llamados “apoyadores”) elegidas por el principal. Permiten al principal designar ciertos apoyadores para ciertas áreas o tipos de decisiones, así como excluir ciertas áreas en las cuales no desee apoyo. Son vinculantes a los terceros, esto es, obligan a los terceros a respetar que el principal ejerce su capacidad jurídica no en aislamiento sino en conjunto con una o más personas de su confianza. Algunas leyes sancionan los actos que tienden a negar la voluntad expresada en el acuerdo. En su mayoría, prohíban expresamente a los apoyadores de sustituir su voluntad por aquella del principal, estableciendo una obligación legal de brindar el apoyo estipulado en el acuerdo y evitar conflictos de intereses. En todos casos, refuerzan la presunción de capacidad, señalando a los terceros que los apoyos estipulados en los acuerdos no son evidencia de un estado de incapacidad sino una manera diversa y específica al principal de ejercer su capacidad jurídica.

Si bien el carácter reciente de esta tendencia legislativa no ha permitido a la elaboración de estudios de campo sobre sus impactos, la tendencia en sí demuestra una conciencia creciente que los sistemas de apoyos para la toma de decisiones pueden llevar a las personas con discapacidad intelectual más beneficios que riesgos, en contraste con la experiencia muchas personas frente la interdicción.

3. **La Ley 1996 de 2019 no sólo está alineada con la tendencia estadounidense a promover normas y prácticas favoreciendo el apoyo para la toma de decisiones evidente, sino permite un grado de flexibilidad para continuar a ajustar el nuevo régimen legal a las necesidades y preferencias de las personas afectadas.**

El régimen evidente en la Ley 1996 de 2019 "Por medio de la cual se establece el régimen para el ejercicio de la capacidad legal de las personas con discapacidad mayores de edad" tiene por su objeto promover el tránsito desde el régimen anterior de sustitución a otro basado en el apoyo para la toma de decisiones, y así busca eliminar los riesgos de vulneración que se han evidenciado en las jurisdicciones que históricamente han favorecido la interdicción, inclusive en los Estados Unidos. La CDPD fue redactada con el propósito de ayudar a las personas con todos tipos de discapacidad a mantener y reforzar sus derechos en vez de concederlos a otros. La transferencia de derechos crea un estado de dependencia legal y fática en otra persona quien a veces sí, pero muchas veces no, abusa de la autoridad inmensa otorgada por orden judicial. Los acuerdos de apoyo, a la vez, permiten a sus usuarios, quienes quieren asistencia en la realización de actos jurídicos, no sólo mantener sus derechos sino elegir por sí mismo quienes le rodeen, así fortaleciendo y supliendo sus capacidades inherentes.

Para que el cambio de paradigma en progreso y evidenciado en la tendencia de promover normas y prácticas favoreciendo el uso de los sistemas de apoyo se arraigue, serán necesarios no sólo un marco normativo como aquél reflejado en la Ley 1996 de 2019, sino la posibilidad de ir ajustando el nuevo régimen conforme a las lecciones derivadas de la práctica. Para ello, resulta oportuno subrayar el ámbito de elaborar lineamientos y protocolos acerca de la valoración de apoyos prevista en el artículo 12 de la Ley 1996 de 2019, el cual expresamente permitirá al Estado colombiano desarrollar intervenciones y abordajes individualizados y a la medida de las circunstancias específicas de cada persona que desee ejercer su capacidad jurídica con la asistencia de apoyadores y establecer su voluntad en un acuerdo escrito. Los proyectos pilotos mencionados anteriormente forman parte de una gama de iniciativas emprendidas en diversos contextos para cubrir la brecha grande entre los regímenes legales y las vidas diarias de las personas con discapacidad, siempre obedeciendo los preceptos de la CDPD, inclusive las directrices del Comité CDPD al respecto. En contraste con la interdicción, dicha flexibilidad permitirá un régimen legal que corresponde a las circunstancias específicas del diverso rango de personas con discapacidad afectadas por él, y un régimen que no sólo busca evitar los abusos que en muchos casos han ocasionado la interdicción, sino responderá la evolución de las necesidades y preferencias de las personas afectadas por él.

SOLICITUD

Con base en los argumentos arriba expuestos, respetuosamente solicitamos que se declare que la Ley 1996 de 2019 es EXEQUIBLE y se inste a las entidades del Estado correspondientes a que aseguren su cabal cumplimiento.

Cordialmente,

Profesor Michael Ashley Stein
Director Ejecutivo del Harvard Law School Project on Disability

Natalie

Profesora Natalie Chin
Profesora Asociada de Derecho de la Universidad de la Ciudad de Nueva York y Co-Directora del Disability & Aging Justice Clinic

Cathy E Costanzo

Cathy Costanzo
Directora Ejecutiva del Center for Public Representation

Booth

Profesora Kristin Booth Glen
Profesora Universitaria en la Universidad de la Ciudad de Nueva York de Nueva York

Profesora Leslie Salzman
Profesora Clínica de Derecho del Colegio de Derecho Benjamin N. Cardozo y Co-Directora del Cardozo Bet Tzedek Civil Litigation Clinic

Profesora Rebekah Diller
Profesora Asociada Clínica de Derecho del Colegio de Derecho Benjamin N. Cardozo y Co-Directora del Cardozo Bet Tzedek Civil Litigation Clinic

ANEXOS

1. Government Accountability Office, *Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults*, Nro. GAO-17-33, noviembre de 2016, *disponible en:* https://www.gao.gov/assets/690/681088.pdf.
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United States Government Accountability Office

Report to Congressional Requesters

November 2016

ELDER ABUSE

The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults

GAO-17-33

GAO Highlights

Highlights of GAO-17-33, a report to congressional requesters

November 2016

ELDER ABUSE

The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults

Why GAO Did This Study

The number of older adults, those over age 65, is expected to nearly double in the United States by 2050. When an older adult becomes incapable of making informed decisions, a guardianship may be necessary. Generally, guardianships are legal relationships created when a state court grants one person or entity the authority and responsibility to make decisions in the best interest of an incapacitated individual—which can include an older adult—concerning his or her person or property. While many guardians act in the best interest of persons under guardianship, some have been reported to engage in the abuse of older adults.

GAO was asked to review whether abusive practices by guardians are widespread. This report describes (1) what is known about the extent of elder abuse by guardians; and (2) what measures federal agencies and selected state and local guardianship programs have taken to help protect older adults with guardians.

GAO reviewed relevant research, reports, studies, and other publications issued by organizations with expertise on elder abuse and guardianship issues. GAO also conducted interviews with various guardianship stakeholders including federal agencies such as HHS, six selected state courts, and nongovernmental organizations with expertise in guardianship-related issues. In addition, GAO identified eight closed cases of abuse by guardians in which there was a criminal conviction or finding of civil or administrative liability to use as nongeneralizable illustrative examples. GAO makes no recommendations in this report.

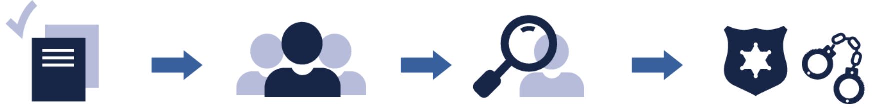
View GAO-17-33. For more information, contact Kathryn A. Larin at (202) 512-6722 or larink@gao.gov.

What GAO Found

The extent of elder abuse by guardians nationally is unknown due to limited data on key factors related to elder abuse by a guardian, such as the numbers of guardians serving older adults, older adults in guardianships, and cases of elder abuse by a guardian. Court officials from six selected states GAO spoke to noted various data limitations that prevent them from being able to provide reliable figures about elder abuse by guardians, including incomplete information about the ages of individuals with guardians. Officials from selected courts and representatives from organizations GAO spoke to described their observations about elder abuse by a guardian, including that one of the most common types appeared to be financial exploitation. Some efforts are under way to try to collect better data on elder abuse and guardianship at the federal, state, and local levels to support decision making and help prevent and address elder abuse by guardians. For example, the Department of Health and Human Services (HHS) plans to launch the National Adult Maltreatment Reporting System—a national reporting system based on data from state Adult Protective Services (APS) agency information systems by early 2017. According to HHS and its contractor, this system has the capability to collect information that could specifically help identify cases of elder abuse where a guardian was involved. GAO also identified state and local initiatives to capture key data points and complaint data as well as identify “red flags” such as unusually high guardian fees or excessive vehicle or dining expenses.

The federal government does not regulate or directly support guardianship, but federal agencies may provide indirect support to state guardianship programs by providing funding for efforts to share best practices and facilitate improved coordination, as well as by sharing information that state and local entities can use related to guardianship. State and local courts have primary responsibility over the guardianship process and, as such, have a role in protecting older adults with guardians from abuse, neglect, and exploitation. Measures taken by selected states to help protect older adults with guardians vary but generally include screening, education, monitoring, and enforcement.

Measures Used to Help Protect Older Adults with Guardians from Abuse



Screening
Courts screen prospective guardians and seek to ensure only those in need are assigned a guardian

Education
Prospective guardians may be required to complete training and education prior to assuming guardianship duties

Monitoring
Courts and other entities monitor guardian caretaking and spending activities

Enforcement
Guardians who have committed elder abuse are removed from their duties, pay fines, or face jailtime

Source: GAO analysis of selected state courts’ guardianship oversight roles. | GAO-17-33

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Abbreviations

ACUS	Administrative Conference of the United States
APS	Adult Protective Services
CFPB	Bureau of Consumer Financial Protection
HHS	Department of Health and Human Services
NAMRS	National Adult Maltreatment Reporting System
NCSC	National Center for State Courts
SSA	Social Security Administration
WINGS	Working Interdisciplinary Networks of Guardianship Stakeholders

U.S. GOVERNMENT ACCOUNTABILITY OFFICE
441 G St. N.W.
Washington, DC 20548

November 16, 2016

The Honorable Susan M. Collins
Chairman
The Honorable Claire McCaskill
Ranking Member
Special Committee on Aging
United States Senate

The Honorable Orrin G. Hatch
Chairman
Committee on Finance
United States Senate

In 2014, the U.S. Census Bureau estimated that there were over 46 million older adults—individuals aged 65 and over—in the United States. The Census Bureau predicts this number will nearly double to 88 million by 2050. When an older adult becomes incapable of making informed decisions, a guardianship may be necessary. Generally, guardianships are legal relationships created when a state court grants one person or entity the authority and responsibility to make decisions in the best interest of an incapacitated individual—which can include an older adult—concerning his or her person or property.[1] State and local courts are generally responsible for overseeing guardianship appointments. The federal government does not regulate or directly support guardianship, but federal agencies may provide indirect support to state guardianship programs by providing funding for efforts to share best practices and facilitate improved coordination. In addition, some agencies have established programs that appoint representative payees to manage

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[1] The focus of this report is older adults with guardians. While some states differentiate between various types of guardianships and conservatorships, for the purposes of this report we define guardianship broadly as a relationship created by state law in which a court gives one person or entity the duty and power to make personal or property decisions, or both, for another person—often called a ward or person under guardianship. While terminology and responsibilities vary from state to state, in this report we use the term “guardian” broadly to refer to various types of state guardians and conservators.

federal benefits for individuals who are unable to do so for themselves.[2] While many guardians act in the best interest of persons under guardianship, some have been reported to engage in the abuse of older adults.[3]

Because of your concern about the financial exploitation and other abuses of older adults, you asked us to review whether abusive practices by guardians are widespread. This report describes (1) what is known about the extent of elder abuse by guardians; and (2) what measures federal agencies and selected state and local guardianship programs have taken to help protect older adults with guardians from abuse. In addition, appendix I contains information related to coordination between federal representative payee programs and state guardianship programs.

To determine what is known about the extent of elder abuse by guardians, we reviewed relevant research, reports, studies, and other publications issued by organizations with expertise on elder abuse and guardianship issues. We also conducted interviews with various guardianship stakeholders including the following:

- Federal agencies including the Department of Health and Human Services (HHS), Bureau of Consumer Financial Protection (CFPB), and Department of Justice to discuss efforts to support to state guardianship programs. We also interviewed officials from the Social Security Administration (SSA), the Department of Veterans Affairs, and Office of Personnel Management to discuss their representative payee programs.
- State court officials that oversee or are otherwise knowledgeable on guardianship-related issues from California, Florida, Minnesota, Ohio, Texas, and Washington. These states were selected because they had the largest populations of older adults as well as at least two of the following criteria: guardian certification requirements, a Working

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[2] The Social Security Administration (SSA), the Department of Veterans Affairs, and the Office of Personnel Management have programs that appoint representative payees to manage federal benefits received by individuals who are unable to do so for themselves. We use the term “representative payee” to refer to Department of Veterans Affairs fiduciaries and SSA or Office of Personnel Management representative payees. A representative payee may also be a guardian, and some beneficiaries with a representative payee also have a guardian.

[3] For the purposes of this report, we define elder abuse as any knowing, intentional, or negligent act by anyone that causes harm or a serious risk of harm to an older adult, including physical, sexual, or emotional abuse, neglect, and financial exploitation.

Interdisciplinary Networks of Guardianship Stakeholders (WINGS) program, an independent guardianship support program, or citation during our preliminary interviews as having promising practices or known problems.[4] In addition, we spoke with an official from the Conservator Account Auditing Program, a statewide program housed in the Minnesota court system that audits the periodic accounting information certain guardians are required to provide to the court. We also interviewed prosecutors, judges, and county clerk officers from some of the six states referred to us during our interviews with other court officials and nongovernmental organizations. The observations gleaned from interviews with officials from these states are not generalizable to other states.

- Nongovernmental organizations with expertise in guardianship-related issues. Specifically, we interviewed officials from the American Bankers Association, American Bar Association, Center for Elders and the Courts, National Adult Protective Services Association, National Center for State Courts (NCSC), National Committee for the Prevention of Elder Abuse, National Association to Stop Guardian Abuse, National Guardianship Association, Center for Guardianship Certification, Uniform Law Commission, and Virginia Tech Center for Gerontology. We selected nongovernmental organizations to interview by reviewing published materials related to elder abuse by guardians, conducting a web search using terms related to elder abuse by guardians, and referrals from our preliminary interviews.

We also identified eight closed cases of elder abuse by guardians in which there was a criminal conviction or finding of civil or administrative liability in the last 5 years, to illustrate the types of abuse that guardians have been found to inflict on older adults under guardianship. Seven of these cases were identified using public-record searches, while an eighth was referred to us during one of our interviews.[5] To corroborate key information about each case, we examined court records, police reports, or other relevant documents. The illustrative examples we identified are nongeneralizable and cannot be used to make inferences about the overall population of guardians.

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[4] WINGS programs are court–community partnerships designed to affect the ways courts and guardians practice and to improve the lives of people who need help in decision making.

[5] Public-record searches included web searches for terms related to elder abuse by a guardian such as “elder abuse,” “guardianship abuse,” “convicted,” and “sentenced.” We also reviewed public websites that list disciplinary actions taken against certified guardians.

To identify measures federal agencies and selected state and local guardianship programs have taken to help protect older adults with guardians from abuse, we reviewed relevant research, publications, and other materials on elder abuse and guardianship. We also conducted interviews with the various guardianship stakeholders described above.

We conducted this performance audit from November 2015 to November 2016 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Guardianship

In general, state courts appoint a guardian for individuals when a judge or other court official determines that an individual lacks the capacity to make important decisions regarding his or her own life or property. Depending on the older adult's needs and relevant state laws, a court may appoint a "guardian of the person" who is responsible for making all decisions for the older adult, or a "guardian of the estate"—or conservator—who only makes decisions regarding the older adult's property.

When state courts appoint guardians, older adults often forfeit some or all of their decision-making powers. Depending on the terms of the court's guardianship appointment, older adults may no longer have the right to sign contracts, vote, marry or divorce, buy or sell real estate, decide where to live, or make decisions about their own health care.

Courts can generally appoint different types of guardians including the following:

- **Family guardians.** According to the Center for Elders and the Courts, courts favor the appointment of a family member or friend, often called a family guardian.[6] However, it may not always be possible to find family or friends to take on this responsibility.

- **Professional guardians.** A professional guardian may be hired for a fee to be paid by the older adult, and may serve more than one older adult at a time. Some states require that a professional guardian be certified. This requirement is described in additional detail later in this report.
- **Public guardians.** If an older adult is unable to find a capable family or friend and is unable to afford the fees and associated expenses of hiring a professional guardian, a public guardian—whose cost is funded by the state or local government—may be appointed.

Elder Abuse

Elder abuse is a complex phenomenon.[7] Table 1 describes the types of elder abuse, according to the National Center on Elder Abuse.[8] Each of these can affect older adults with guardians, as well as those without. The categories include physical, sexual, and emotional abuse, as well as financial exploitation, neglect, and abandonment, but it is not uncommon for an older adult who has been abused to experience more than one type of abuse simultaneously.

Table 1: Types of Elder Abuse

Type[a]	Description
Physical abuse	The use of physical force that may result in bodily injury, physical pain, or impairment.
Sexual abuse	Nonconsensual sexual contact of any kind with an older adult.
Psychological abuse	Also referred to as verbal or emotional abuse, psychological abuse is the infliction of anguish, pain, or distress through verbal or nonverbal acts.
Financial exploitation	The illegal or improper use of an older adult’s funds, property, or assets.
Neglect	The refusal or failure to fulfill any part of a person’s obligations or duties to an older adult.

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[6] The Center for Elders and the Courts, a project of the NCSC, attempts to increase judicial awareness of issues related to aging, and provides training tools and resources to improve court responses to elder abuse and guardianships.

[7] For recent GAO reports related to elder abuse, see GAO, *Elder Justice: National Strategy Needed to Effectively Combat Elder Financial Exploitation*, GAO-13-110 (Washington, D.C.: Nov. 15, 2012); and *Elder Justice: Stronger Federal Leadership Could Enhance National Response to Elder Abuse*, GAO-11-208 (Washington, D.C.: Mar. 2, 2011).

[8] The National Center on Elder Abuse is a national resource center dedicated to the prevention of elder abuse. Funded by the Administration on Aging in HHS, it is made up of a consortium of grantees.

Abandonment	The desertion of an older adult by an individual who has assumed responsibility for providing care for an older adult, or by a person with physical custody of an older adult.

Source: National Center on Elder Abuse. | GAO-17-33

[a] Federal and state law may define these terms differently.

The Extent of Elder Abuse by Guardians Is Unknown, and Available Information Varies by State and Locality, but Some Efforts Are Under Way to Gather More Data

Courts Lack Comprehensive Data on Older Adults in Guardianships and Elder Abuse by Guardians, but Some Courts Have Limited Information

The extent of elder abuse by guardians nationally is unknown due to limited data on the numbers of guardians serving older adults, older adults in guardianships, and cases of elder abuse by a guardian. While courts are responsible for guardianship appointment and monitoring activities, among other things, court officials from the six selected states that we spoke to were not able to provide exact numbers of guardians for older adults or of older adults with guardians in their states. Also, on the basis of our interviews with court officials, none of the six selected states appear to consistently track the number of cases related to elder abuse by guardians.

Court officials from the six states we spoke with described the varied, albeit limited, information they have related to elder abuse by guardians and noted the various data limitations that prevented them from providing reliable figures on the extent of elder abuse by a guardian.

- **California.** A court official in California stated that while the Judicial Council of California collects information about requests for restraining orders to prevent elder abuse, it does not separately identify those cases alleging elder abuse by a guardian. The council also collects the number of new guardianships filed each year statewide. The official stated the number of new adult guardianships is partially estimated because about half of the courts in the state report a combined number of guardianships for minors and adults.

- **Florida.** A court official in Florida acknowledged that the court does not collect guardianship and elder abuse information such as the number of guardians for older adults, the types of guardians currently serving in guardianship roles for older adults, and the number of elder abuse hearings conducted. This official cited lack of funding as a barrier for collecting this type of information. Detailed information on financial exploitation specifically may be available at the county level. For example, officials from one county in Florida told us that it collects data on the number of guardianships and the assets guardians control, and also identified the amount of fraud over a 4-year period.
- **Minnesota.** A court official in Minnesota told us that the state differentiates between guardianship of the person and conservatorship of the estate. The state collects figures on the (1) number of guardianship cases, (2) number of conservatorship-only cases, and (3) number of combined guardianship and conservatorship cases; and can break these figures out by minors and adults. The state also has a statewide program housed in the court system—the Conservator Account Auditing Program—that audits the financial reports that guardians of the estate (or conservators) are required to submit electronically through a system called MyMNConservator. This system can calculate the total assets under court jurisdiction in Minnesota, which are presented in an annual report. According to the annual report, the program audits accounts with assets over a certain threshold at regular intervals and upon referral by the court. However, one of these officials told us that this system does not track the age of the individuals with guardians of the estate, so the number of older adults in this arrangement is not identifiable.
- **Ohio.** An official from the Supreme Court of Ohio told us probate courts in the state report to the Supreme Court quarterly aggregate caseload data including the number of pending guardian applications for adults, the number of new applications for the appointment of guardians, and the number of guardianships closed, but the data are not classified by the age of the person under guardianship. Additionally, although local courts may do so, the Supreme Court of Ohio does not capture the number of complaints related to guardianships. Court officials directed us to state Adult Protective Services (APS) elder abuse complaint data.
- **Texas.** Court officials in Texas told us that every county is required to submit monthly information to the Office of Court Administration pertaining to active guardianships. However, officials told us that

some counties do not report any active guardianships (considered to be underreporting), and some counties overreport on active guardianships that should have actually been closed, such as when the person under guardianship is deceased.

- **Washington.** A court official in Washington stated that while she could provide the number of adult guardianships statewide, she could not provide this information specifically for older adults. Further, the state's Certified Professional Guardian Board publishes the number of grievances against professional guardians each year its annual Grievance Report, but does not identify which were for older adults.[9] This official stated that while the court has case information on abuse by professional guardians, it does not track information on abuse by family guardians.

Representatives from nongovernmental organizations we spoke with also told us that the way cases are classified in the court system makes collecting data on elder abuse by guardians difficult. For example, representatives from the Center for Elders and the Courts told us that few cases appear to be clearly labeled with phrases such as "elder abuse" in the court system, making it difficult to identify the universe of these cases. These representatives explained that cases of elder abuse may appear as other charges, such as assault, battery, or theft. Identifying all cases involving elder abuse, and more specifically that by a guardian, would require a difficult manual review of a large volume of court cases. Further, stakeholders we spoke to noted that instances of elder abuse by guardians can be difficult to prosecute, reducing the number of known cases in the legal system and presenting an additional challenge to identifying the extent of elder abuse by guardians.

Collecting reliable information about court practices related to guardianship can also be challenging. At the request of SSA, the Administrative Conference of the United States (ACUS) administered and analyzed the results of a survey of judges, court staff, and guardians to

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[9] Washington's Certified Professional Guardianship Board defines a grievance as a written document filed by any person with the board or directly by the board itself, for the purpose of commencing a review of the professional guardian's conduct under the rules and disciplinary regulations applicable to professional guardians.

review guardianship practices in state courts in 2014.[10] The survey collected information regarding appointment, monitoring, and discipline of guardians; caseloads and electronic case-management capabilities; and court interaction with federal agencies and other organizations.[11] However, in administering this survey, ACUS was unable to identify a sample of courts that were representative of the guardianship practices in all states as no comprehensive list identifying courts or judges that have oversight of adult guardianship cases exists, which makes it impossible to generalize the findings to a known universe.

In the absence of reliable data, information on individual cases can provide some insight into the types of abuse guardians have been found to inflict on older adults under guardianship. In a 2010 report, we identified hundreds of allegations of abuse, neglect, and exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010. At that time, we reviewed 20 of these cases and found that guardians had stolen or otherwise improperly obtained $5.4 million from 158 incapacitated victims, many of whom were older adults.[12] Table 2 provides a summary of eight new cases in which guardians were found to have financially exploited or neglected older adults under guardianship in the last 5 years. Seven of these cases were identified using public-record searches, while the eighth was referred to us during one of our interviews. We examined court records, police reports, or other relevant documents to corroborate key information about each case. The illustrative examples of selected closed cases of elder abuse by a guardian we identified are nongeneralizable and cannot be used to make inferences about the overall population of guardians.

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[10] ACUS is an independent federal agency that attempts to improve the administrative process through research and provides advice and recommendations for improved federal agency procedures. This study was done in response to recommendations by GAO and Congress to improve SSA's collaboration with state courts to help protect incapacitated persons and better prevent the misuse of federal funds.

[11] Administrative Conference of the United States, *SSA Representative Payee: Survey of State Guardianship Laws and Court Practices* (Dec. 24, 2014).

[12] See GAO, *Guardianships: Cases of Financial Exploitation, Abuse, and Neglect of Seniors*, GAO-10-1046 (Washington, D.C.: Sept. 30, 2010).

Table 2: Selected Closed Cases of Elder Abuse by a Guardian

Case number	Type of elder abuse	Case details
1	Financial exploitation	• According to a complaint filed by an official in the Office of the State Attorney in Florida, over the course of 21 months a family guardian spent money of the person under guardianship—an elderly disabled adult—on items unrelated to the care and welfare of that individual including personal bills, services, restaurant purchases, and cash withdrawals. • In 2013, the guardian pleaded guilty to the exploitation of an elderly or disabled adult, and was sentenced to 120 days in jail and ordered to pay over $33,000 in restitution.
2	Financial exploitation	• According to Supreme Court of Ohio documents, a professional guardian misappropriated funds from persons under guardianship—at least one of whom was elderly—to support his drug addiction. The court found that the guardian's misconduct caused harm by misappropriating more than $200,000 over a 6-year period. • In 2014, the guardian was convicted of three felony counts of theft from the elderly, and was sentenced to a 4-1/2-year prison term, and ordered to pay restitution. In 2016, he was indefinitely suspended from the practice of law in Ohio.
3	Financial exploitation	• According to a criminal complaint in Virginia, a family guardian spent money of the person under guardianship—her 83-year-old aunt—on personal expenses including an $11,645 pickup truck for a friend and $360 at a sunglasses retailer in Tennessee, and told law enforcement officials that she believes she is entitled to be taken care of using her aunt's funds. • In 2012, the guardian pleaded guilty to intent to defraud, and agreed that total losses were no less than $29,000. The guardian was sentenced to 12 months in prison and ordered to pay restitution of over $32,000.
4	Financial exploitation	• According to a criminal complaint in Virginia, the legal assistant of a professional guardian in Virginia used her unauthorized access to the bank accounts of an elderly person under guardianship to obtain more than $100,000 to support a drug habit by issuing and cashing fraudulent checks. • The guardian initially discovered the thefts but, because of a personal relationship with his assistant, he failed to remove the access to the accounts, thereby allowing the thefts to continue, and attempted to conceal the scope and extent of the thefts from law enforcement officials and others. • In 2014, the guardian pleaded guilty to misprision of a felony, agreed to repay the stolen funds, and in 2015 consented to the revocation of his law license.
5	Financial exploitation and neglect	• According to documents from the Certified Professional Guardian Board in the state of Washington, a professional guardian violated the Certified Professional Guardian Standards of Practice by (1) failing to properly manage the financial affairs of an elderly person under guardianship including the untimely filing of tax returns and payment of medication bills, (2) not providing basic clothing, (3) not visiting regularly or making arrangements for qualified visits, and (4) improperly taking guardian fees without consultation of the person under guardianship when the guardian was already being paid by the Office of Public Guardianship. • The mismanagement of the funds of the person under guardianship represented a potential loss of up to $25,000 and accounted for up to 25 percent of the person's assets. • In 2015, the state Certified Professional Guardian Board revoked the guardian's certification, and the guardian was required to pay administrative costs of approximately $20,000.

Case number	Type of elder abuse	Case details
6	Financial exploitation and neglect	• According to documents from the Texas Judicial Branch Certification Commission, a professional guardian was responsible for more than 50 persons under guardianship statewide, including at least 6 older adults in two facilities 400 miles from the guardian's home and place of business. • For the persons under guardianship in these two facilities, the guardian went months without contacting these individuals, did not provide them with shoes and clothing, was late in paying facilities, withheld moneys from their monthly stipends, and was nonresponsive to communications from their facilities. • This conduct resulted in 16 violations of provisions of Texas's Minimum Standards for Guardianship Services. On the basis of these and other unrelated violations, the guardian was required to pay an administrative penalty of over $25,000 and is not permitted to renew her guardian certification.
7	Financial exploitation	• According to court documents, a professional guardian in Nevada withdrew money from the bank accounts of persons under guardianship including over $78,000 in cash from an elderly person, falsified payments to her own company, and inappropriately used the funds of person under guardianship for other personal purchases such as jewelry items and payment to a cell-phone company. • In 2013, the guardian pleaded guilty to the exploitation of an elderly or vulnerable person, which is a felony in Nevada, and was sentenced to 8 years in prison and ordered to pay over $160,000 in restitution.
8	Financial exploitation	• According to court documents, a professional guardian in Oregon mistreated or stole money from 26 persons under guardianship including at least five older adults. • The guardian, among other things, (1) intercepted checks made out to persons under guardianship, third-party care providers, and ambulance companies to deposit them in her own personal bank account and (2) when persons under guardianship died, the guardian diverted funds to her own personal bank account. • In total, the guardian was convicted of five counts of Criminal Mistreatment in the First Degree, four counts of Aggravated Theft in the First Degree, one count of Theft in the First Degree, one count of money laundering, and one count of tax evasion. The guardian was sentenced to 48 months in prison and was ordered to pay more than $117,000 in restitution to the victims. The guardian's certification was also revoked.

Source: GAO analysis of court, police, state certifying board, and other state agency data. | GAO-17-33

Stakeholders we spoke to described their observations about elder abuse by a guardian. According to stakeholders, financial exploitation is among the more common types of elder abuse. Similarly, all eight of the closed cases of elder abuse by a guardian we found, presented above in table 2, were examples of financial exploitation. A prosecutor in one of the states we spoke to shared her observation that the majority of financial exploitation by professional guardians is done through overcharging for services that were either not necessary or were never performed. One representative commented that greed was a driving factor for guardians to financially exploit persons under guardianship. Some stakeholders we spoke to also expressed concerns that guardians may become overwhelmed by their guardianship responsibilities, or may not have the proper training and education to understand and perform their guardianship duties.

Federal, State, and Local Entities Have Some Efforts Under Way to Collect More Information on Elder Abuse by Guardians

Federal, state, and local entities have some efforts under way to try to collect better data on elder abuse and guardianship to support decision making and help prevent and address elder abuse by guardians. While state courts are responsible for overseeing the guardianship process—appointment and screening, education, monitoring, and enforcement—HHS has also taken steps to collect better data on guardianship and elder abuse. In 2011, we found that existing studies likely underestimated the full extent of elder abuse and could not be used to track trends.[13] At that time, we recommended that HHS coordinate with the Attorney General to conduct a pilot study to collect, compile, and disseminate data on the feasibility and cost of collecting uniform, reliable APS administrative data on elder abuse cases from each state, and compile and disseminate those data nationwide. HHS agreed with our recommendation.

In 2013, HHS's Administration on Aging began developing the National Adult Maltreatment Reporting System (NAMRS)—a national reporting system based on standardized data submitted by state APS agency information systems.[14] The goal of the system is to provide consistent, accurate national data on the exploitation and abuse of older adults and adults with disabilities as reported to state APS agencies. According to HHS officials and the contractor developing NAMRS, this system will have the capability to collect information that could help identify cases of elder abuse where a guardian was involved.[15] For example, NAMRS can collect information about substitute decision makers, including guardians, associated with the complaint such as whether there was a substitute decision maker at the start and end of the investigation, whether the perpetrator was the older adult's substitute decision maker, and what recommendations or actions the state APS agency initiated against the perpetrator. An official from the Administration on Aging stated that the

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[13] See GAO, *Elder Justice: Stronger Federal Leadership Could Enhance National Response to Elder Abuse*, GAO-11-208 (Washington, D.C.: Mar. 2, 2011).

[14] HHS's Administration on Aging aims to promote the well-being of older adults by providing services and programs designed to help them live independently in their homes and communities.

[15] State APS agencies receive some complaints about incidents of elder abuse, so their systems represent a potential source of information for compiling national data on elder abuse.

pilot phase of the system is complete and the agency hopes to roll it out for data submissions from all states by early 2017.[16]

Representatives from the National Adult Protective Services Association stated that NAMRS would provide important information that could inform the guardianship process once fully implemented.[17] For example, a court official from Florida suggested that having more information on elder abuse by a guardian may help guardianship programs decide whether to place more focus on screening, education, and monitoring of guardians, and enforcement of policies and laws governing guardians, as described later in this report.

In addition to this federal effort, some state and local efforts are also under way to collect better data on elder abuse and guardianship. However, some of the stakeholders we spoke to acknowledged that these efforts face funding challenges and require ongoing support.

- **Compiling data points.** Officials in one county in Florida described an ongoing project they have to extract key data points from guardianship cases, such as the reason for alleged incapacity, asset values, and time spent with a guardian, to share with other state guardianship programs. These officials expect that the data points will be used to assess the guardianship system in this county, and suggested that courts could use critical data points on guardianship such as the average time in guardianship, average burn rate of assets, or typical fees charged in order to make appropriate data-driven decisions on how to better address cases of potential elder abuse by a guardian. A court official in Florida told us that in the fall of 2016, the Chief Justice of Florida will appoint a workgroup under the state's Judicial Management Council to examine judicial procedures and best practices related to guardianship to help ensure that courts are protecting these individuals. Similarly, in Texas, the Office of

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[16] While the system was designed to be flexible enough to be able to eventually gather data from different sources besides state APS agencies, there are currently no plans to enter information from other sources into NAMRS.

[17] The National Adult Protective Services Association is a nonprofit organization whose goal is to provide APS programs a forum for sharing information, solving problems, and improving the quality of services for victims of elder and vulnerable adult mistreatment. Its mission is to strengthen the capacity of APS at the national, state, and local levels, to effectively and efficiently recognize, report, and respond to the needs of elders and adults with disabilities who are the victims of abuse, neglect, or exploitation, and to prevent such abuse whenever possible.

Court Administration started the Guardianship Compliance Pilot Project, which provides additional resources to courts handling guardianships by supplementing local staff to review compliance with statutory requirements and by developing an electronic database to monitor guardianship filings of initial inventory and annual accountings. Information collected includes the number of courts involved in the project, the number of guardianships reviewed, the number of guardianships out of compliance with required reporting, the number of guardians reported to the court for person under guardianship well-being or financial exploitation concerns, and the status of technology developed to monitor guardianship filings.

- **Collecting complaint data.** In Washington, the state's Certified Professional Guardianship Board collects complaint and grievance information about professional guardians. In its annual report, the state publishes the number of cases opened, closed, investigated, and in need of investigation. The state also discloses the number of sanctions, which can include decertification, suspension, reprimand, prohibition from taking new cases, and admonishment, imposed on professional guardians. Ohio's Disciplinary Counsel also reported the number of grievances filed regarding guardianships in 2015 and through September 2016. A court official from the Judicial Council of California told us his state tracks the number of requests for restraining orders under California's Elder Abuse and Dependent Adult Civil Protection Act, which can include those against guardians.
- **Identifying red flags.** Representatives from the National Center for State Courts (NCSC) are using data collected from Minnesota's Conservator Account Auditing Program to identify "red flags,"—or risk indicators—such as unusually high guardian fees or excessive vehicle or dining expenses that would help courts detect cases that need additional review or monitoring.[18] Representatives from the NCSC told us they are hopeful that these efforts will help courts move forward in preventing and responding to abuses.

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[18] The NCSC is an independent, nonprofit court-improvement organization that serves as a clearinghouse for research information and comparative data to support improvement in judicial administration in state courts.

Federal Agencies Provide Funding to Support Coordination and Sharing Information, While State and Local Entities Oversee the Guardianship Process to Help Protect Older Adults with Guardians from Abuse

Federal Agencies' Measures to Help Protect Older Adults with Guardians Include Providing Funding to Support Coordination and Sharing Information

While the federal government does not regulate or directly support guardianship, federal agencies, such as HHS, may provide indirect support to state guardianship programs by providing funding for efforts to share best practices and facilitate improved coordination. The federal government also shares information that state and local entities can use related to guardianship.

Providing Funding to Support Coordination

HHS has assumed a national role for funding grants to support coordination and information sharing that could help educate guardians and other parties.

- HHS has funded grants through the National Legal Resource Center to share best practices related to guardianship with states, attorneys, and other interested parties. The grant activities cover a wide range of guardianship issues related to court oversight and monitoring and illustrate the ongoing commitment to developing nationwide "Best Practice" resources on this issue. For example, grant activities have included providing technical assistance and policy guidance to states on guardianship issues, oversight and monitoring improvements, developing standards of practices for guardians, training attorneys practicing in the area of guardianship law, and developing solutions for interstate jurisdictional issues involving guardianship cases.

- HHS launched the Elder Justice Innovation Grants program in fiscal year 2016. The purpose of the program is to support foundational work to create credible benchmarks for elder abuse, neglect, and exploitation prevention and control, and for program development and evaluation. HHS expects projects funded by these grants will contribute to the improvement of the field of elder abuse prevention and intervention by developing and advancing approaches to address new and emerging issues related to elder justice, or by establishing and contributing to the evidence-base of knowledge. In 2016, HHS identified abuse in guardianship as one of the targeted priority areas for this program, and according to agency officials awarded three grants in this target area—each grant is funded at approximately $1,000,000 over 2 years, September 2016 through September 2018. At the completion of these grants, HHS expects grantees will have developed materials and information for further replication and testing.
- HHS also funds the National Center on Elder Abuse, which collects information regarding research, training, best practices, news, and resources on elder abuse, and provides this information to policymakers, professionals in the elder justice field, and the public.

In addition, the State Justice Institute has provided grants to various entities to improve coordination and develop and share best practices.[19]

- With help from funding provided by the State Justice Institute and others, states have developed Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) programs to facilitate enhanced coordination. WINGS programs bring together judges and court staff, the aging and disability networks, the public and private bar, mental-health agencies, advocacy groups, medical and mental-health professionals, service providers, family members and individuals affected by guardianship, and others to drive changes affecting the ways courts and guardians practice and to improve the lives of older adults (and others) with guardians. National Guardianship Association representatives told us that WINGS groups look at the broader picture of what is happening to address guardianship-related issues across the country and are not just focused on abuse and neglect.[20] WINGS

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[19] Congress established the State Justice Institute as a private, nonprofit corporation that awards grants to improve the quality of justice in state courts, and create solutions to common issues faced by all courts. 42 U.S.C. §§ 10701 – 10713.

[20] The National Guardianship Association is a nonprofit corporation whose mission is to advance the nationally recognized standard of excellence in guardianship.

programs can make recommendations to state supreme courts and state legislatures based on their observations. American Bar Association representatives told us one of the keys to the success of a WINGS program is ongoing communication.[21] The programs are not designed to be onetime conversations or a task force, but instead represent an ongoing communication mechanism to ensure optimal coordination. During our interviews, feedback for WINGS programs was consistently positive, and the WINGS group we spoke with emphatically encouraged other states to develop their own WINGS-like programs and expressed interest in continued funding support for its program.[22] In addition, one of the goals of grants awarded through the Elder Justice Innovation Grants program is to establish, expand, and enhance state WINGS programs to improve the ability of state and local guardianship systems to develop protections less restrictive than guardianship and advance guardianship reforms. As of September 2016, at least 14 states and the District of Columbia have adopted either WINGS programs or something that resembles these programs.

Sharing Information

CFPB has developed materials that can be used by guardians, banks, and others to help better protect older adults with guardians from abuse.

- CFPB has published numerous educational materials to help protect older adults from financial abuse and exploitation. These include guides for fiduciaries that lay out the rules and responsibilities for appropriately handling the finances of another person.[23] CFPB has also developed guidance for financial institutions. For example, in 2013, CFPB and seven other federal agencies issued guidance on privacy laws and reporting information on financial exploitation.[24] This guidance is intended to make it clear that reporting suspected financial abuse of older adults to appropriate local, state, or federal agencies does not, in general, violate the privacy provisions of the

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[21] The American Bar Association is a voluntary professional organization for attorneys that, among other things, has developed extensive research on guardianship and related matters.

[22] The American Bar Association and National Guardianship Network developed a 10-step guide for replicating WINGS programs.

[23] According to CFPB officials, these guides can be adapted to incorporate state-specific rules and terminology.

[24] Board of Governors of the Federal Reserve System, *Interagency Guidance on Privacy Laws and Reporting Financial Abuse of Older Adults* (Washington, D.C.: 2013).

Gramm-Leach-Bliley Act or its implementing regulations.[25] CFPB officials stated that they hoped the 2013 Interagency Guidance will help financial institutions better understand their ability to report suspected financial exploitation to relevant federal, state, and local agencies. Additionally, in 2016, CFPB released an advisory and related recommendations for financial institutions on preventing and responding to elder financial exploitation.

State and Local Measures Can Include Screening, Education, Monitoring, and Enforcement

State and local courts have primary responsibility over the guardianship process and, hence, have a role in protecting older adults with guardians from abuse. In 2014, the National Association for Court Management published an adult guardianship guide with detailed information about how to plan, develop, and sustain a court guardianship program.[26] This report laid out detailed suggestions for practices to effectively establish guardianships, monitor guardians, and train relevant stakeholders. Guardianship laws can also vary by state, but organizations such as the Uniform Law Commission—an organization that drafts legislation for states intended to bring clarity and stability to state statutory law—have developed model legislation to promote the uniformity of procedures for appointing guardians and conservators and strengthening due process protections for individuals in guardianship proceedings and jurisdictional conflicts. On the basis of our review of published materials and interviews with various state courts and nongovernmental stakeholders, we observed that measures states can take to help protect older adults with guardians vary but generally include screening, education, monitoring, and enforcement as shown in figure 1.

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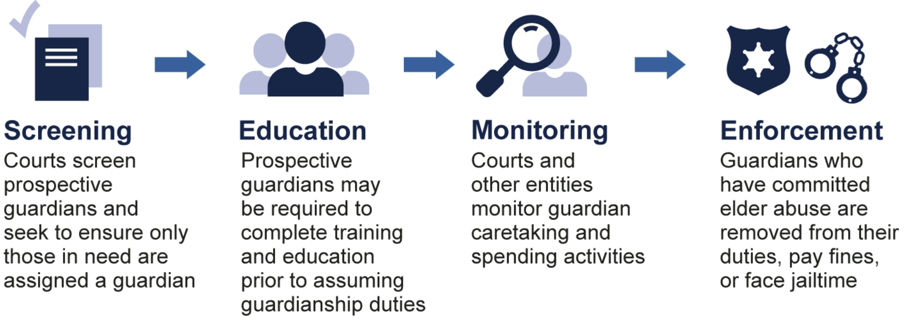
[25] Gramm-Leach-Bliley Act, Pub. L. No. 106-102, Title V, §§ 501 – 510, 113 Stat. 1338, 1436 – 1445 (Nov. 12, 1999) and 12 C.F.R. §§ 1016.1 – 1016.17.

[26] National Association for Court Management, *Adult Guardianship Guide: A guide to plan, develop, and sustain a comprehensive court guardianship and conservatorship program*, 2013-2014 Guide (Williamsburg, Virginia: 2014).

Figure 1: Measures Used to Help Protect Older Adults with Guardians from Abuse



Screening
Courts screen prospective guardians and seek to ensure only those in need are assigned a guardian

Education
Prospective guardians may be required to complete training and education prior to assuming guardianship duties

Monitoring
Courts and other entities monitor guardian caretaking and spending activities

Enforcement
Guardians who have committed elder abuse are removed from their duties, pay fines, or face jailtime

Source: GAO analysis of selected state courts' guardianship oversight roles. | GAO-17-33

Screening

According to multiple stakeholders we spoke with, an important step of the guardianship process is for a court to ensure that only those in need are appointed a guardian. Once the need for a guardian has been identified, state courts generally are responsible for screening proposed guardians to help ensure suitable individuals are appointed. On the basis of our review of published materials and interviews with various state courts and nongovernmental stakeholders, we observed the following promising practices and challenges related to screening.

- **Least-restrictive option.** Due to the loss of rights experienced when an older adult is placed into a guardianship, courts determine whether a guardian is appropriate. One representative from a state WINGS program that we spoke with expressed concern that guardianship may not be appropriate for some persons under guardianship, especially when the appointment is made for the convenience of others. To address this concern, this representative told us that courts in her state have modified court guardianship forms to encourage the use of less-restrictive alternatives to guardianship, such as a caregiver.[27]
- **Periodically reexamine guardianship.** Some courts periodically reexamine the appropriateness of the guardianship to ensure that it is working for the person under guardianship and remains appropriate, since it can be difficult for an older adult with a guardian to demonstrate that his or her capacity has been restored.
- **Criminal history and credit checks.** These types of checks provide an easy and relatively inexpensive way to ensure that potential guardians do not have a criminal history or financial concerns.

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[27] A caregiver is an individual who provides compensated or uncompensated care to an older adult who needs supportive services in any setting.

However, one of the stakeholders we spoke with described some limitations regarding background checks. For example, criminal-background check systems may not present a complete picture for various reasons, including that many elder abuse cases are not prosecuted. Even when prospective guardians have been prosecuted, a number of factors determine whether the criminal history appears in the background check. For example, a background check may not always identify a criminal history in another state.

Education

Stakeholders we spoke with agreed that education plays an important role in helping ensure that guardians understand their roles and responsibilities and appropriately perform their duties. On the basis of our review of published materials and interviews with various state courts and nongovernmental stakeholders, we observed the following promising practices and challenges related to education.

- **Educational requirements.** Education allows guardians to better understand their roles and responsibilities. For example, a court rule requires professional guardians in Washington to complete a training program developed by the state's Certified Professional Guardian Board, while a statute generally requires family guardians to complete video or web-based training. According to state officials, the professional guardian training consists of a 90-hour course offered by the University of Washington, while family guardians usually complete a 2-hour training module. Florida statutes also generally require family guardians to undergo course work on guardian responsibilities, while applying more rigorous requirements for professional guardians. These types of training requirements may help to address unintentional and nonmalicious mistreatment such as comingling assets of the guardian and the person under guardianship. Officials at the National Guardianship Association told us that education about how to be an effective guardian is very important because guardians may make bad decisions due to lack of training or education about their role, and not intentional abuse. However, educational requirements for guardians are not in place in many states.
- **Standards of practice and certification.** The National Guardianship Association has developed standards of practice that define a guardian's duty to comply with laws and regulations; the guardian's relationship with the courts, protected persons, and others; and other duties to the person under guardianship. Also, the Center for Guardianship Certification has developed a certification program that tests a prospective certified guardian's ability to apply these standards

of practice.[28] Under this certification program, certified guardians must meet continuing educational requirements to maintain their status as professional guardians. According to the Center for Guardianship Certification, 12 states require professional guardians to be certified, including 8 states that require certification via the use of Center for Guardianship Certification examinations, as of September 2016.

- **Educational materials.** Courts in all six of the selected states we spoke to post written guidance for guardians online. These guides explain the responsibilities and duties associated with becoming a guardian while providing other potentially useful information. For example, a guide from California discusses the importance of separating funds of guardian and of persons under guardianship by warning guardians that mixing their money with that of the persons under guardianship could get the guardian in serious trouble. Minnesota has also made online videos that explain the guardianship process as well as guardian roles and responsibilities. In conjunction with the NCSC, North Dakota developed a web-based information seminar that guardians can use to better understand their responsibilities. The training is scenario-based and helps the trainee understand his or her options, and was designed to be easily modified for replication in other states. One challenge that one official noted is that it can be difficult to reach family guardians to provide them with educational materials. Also, even when family guardians can be reached, one stakeholder suggested that a 30-minute training video is unlikely to radically enhance guardian performance when a guardian is faced with some of the more complicated scenarios.
- **Support for guardians.** One of the stakeholders we spoke with suggested that guardians and persons under guardianship would benefit from other initiatives, such as states providing guardians with a mechanism to ask questions and allowing guardians to receive positive feedback when something went well instead of just warnings when something went wrong. Another stakeholder told us it would be beneficial for guardians to interact with one another to finds ways to achieve better outcomes.

Monitoring

According to some of the stakeholders we spoke with, most states require guardians to be monitored, but the level of oversight and specific

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[28] The Center for Guardianship Certification was created in 1994 as an allied organization of the National Guardianship Association to enhance the quality of guardianship services through national certification. Voluntary certification through CGC is open to all guardians, not just professional guardians.

requirements vary by state. On the basis of our review of published materials and interviews with various state courts and nongovernmental stakeholders, we observed the following promising practices and challenges related to monitoring.[29]

- **In person visits and well-being checks.** To monitor the person under guardianship's personal well-being, one stakeholder told us courts in every state should periodically send a court investigator to conduct an unannounced site visit to check on that individual.
- **Examinations of guardian expenditures.** A state court official we spoke with cautioned that, without effective monitoring, guardians basically have free access to the person under guardianship's money and other officials we interviewed outlined some specific related measures. For example, an official from one organization suggested that steps should be taken to help ensure that fees are appropriate for the services rendered (e.g., attorneys should not charge attorney rates for grocery shopping), while another representative of a different organization suggested that fees should be capped to help protect persons under guardianship. Other related suggestions from various stakeholders included independent reviews of mandatory annual financial reports, an initial inventory of the person under guardianship's assets, and utilizing effective accounting controls to help protect that individual's assets. Technology can be used to support the oversight process. For example, as previously described, Minnesota monitors the state's conservators using an online program that allows auditors to flag suspicious spending patterns and other warning signs for potential abuse.

Despite the known importance of monitoring efforts, stakeholders described how challenges in monitoring guardians often arise from resource limitations. According to one of the stakeholders we interviewed, courts often do not have the resources to employ court visitors, investigators, auditors, or robust case-management systems for tracking key filings and case events. Another stakeholder told us that guardians are supposed to submit annual reports about persons under guardianship, and in many states and counties these reports are filed, but no one checks to see if the reports have been filed on time or to verify if what is reported is accurate.

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[29] In 2007 the AARP Public Policy Institute and American Bar Association issued a study on promising practices for court monitoring. See AARP Public Policy Institute, *Guarding the Guardians: Promising practices for court monitoring* (Washington, D.C.: 2007), for additional details about these practices.

In addition, other monitoring efforts can be limited. For example, a court official in Washington told us some reviews are paper audits where no one conducts a site visit to the person under guardianship to verify his or her well-being. Representatives from the National Guardianship Association told us that while guardianships have some oversight, there is significant variation in the level of oversight performed by different states. The investment in monitoring the activity of guardians is up to local counties and constrained by resources. One of the recurring themes these representatives find when they examine guardianship issues is that states would like to apply more robust oversight, but the states say that there are not enough resources available to investigate and oversee these cases.

To help overcome resource limitations, the American Bar Association and AARP have developed programs courts can use to recruit and train volunteers to help monitor guardian activities. While there are some costs associated with these programs, according to stakeholders, they can reduce the burden on courts for monitoring guardian activities.

Enforcement

Enforcement activities punish the guardian for his or her abusive actions against a person under guardianship, deter future abuse by sending the message that the abuse of older adults by guardians will not be tolerated, and at times may allow for restitution to the victim. On the basis of our review of published materials and interviews with various state courts and nongovernmental stakeholders, we observed the following promising practices and challenges related to enforcement.

- **Complaint systems.** In addition to providing educational benefits to guardians, certification systems can provide states with a mechanism for receiving complaints and addressing noncriminal guardian performance issues (e.g., not submitting required accountings), while offering other potential certification-related benefits such as screening opportunities and continuing education requirements. In states that certify guardians, complaints may also be directed to the guardianship certification board. State-operated hotlines can also help identify cases of abuse. For example, the Palm Beach County Clerk’s Inspector General set up a hotline that allows the public to report concerns about guardians via telephone, e-mail, or the Internet, or in-person. From fiscal year 2011 through February 2016, the Palm Beach County Clerk’s Inspector General reported 516 contacts, 250 of which were actionable. However, multiple stakeholders also identified some challenges related to complaints. For example, some of the representatives we spoke with stated that it may be difficult or impossible for people with diminished capacity to file a complaint about a guardian, so complaints typically originate from family members. Also, one of the stakeholders we interviewed told us it is not always clear where complaints about guardians should be sent, but that anyone with an elder-abuse related concern could contact law enforcement agencies or the state APS agency. In addition, this stakeholder told us that courts may have complaint processes, but it can be difficult to navigate these processes without effective counsel.

- **Dedicated investigative resources.** Palm Beach County, Florida, dedicated resources to independently audit guardian spending reports and also dedicated resources to the investigation and monitoring of guardianship-related activities, which has had a positive effect, according to officials there. A prosecutor that we spoke with in San Diego discussed similar efforts in his jurisdiction, but noted that law-enforcement entities in most cities do not have departments dedicated to investigating elder abuse.
- **Appropriate disciplinary measures.** Guardianship enforcement activities can range from removing guardians for poor performance to prosecution for overt criminal actions. States that apply such measures appropriately can punish bad actors, obtain restitution for victims, and deter future abuse.[30] However, there can be investigative and prosecutorial challenges associated with cases of elder abuse by a guardian. Stakeholders we spoke to highlighted obstacles that can obstruct efforts to punish abusive guardians. For example, a prosecutor in Washington noted that when abuse by guardians takes the form of overcharging an older adult for the guardian’s services, because the courts have approved the payments in question it is virtually impossible for the prosecutor’s office to file charges. This prosecutor explained that a guardian charged with financial exploitation in such a case would be able to argue that the fees he or she obtained were appropriate because they were sanctioned by the courts; this would almost certainly prevent such a guardian from being found guilty at trial. Also, a prosecutor in California opined that law-enforcement officials generally feel that when someone is in a position of trust, law enforcement officials cannot and should not get involved. Specifically, they feel it is a civil matter that should be handled in the civil jurisdiction. Other representatives we spoke with raised concerns about the cost of investigating cases of potential abuse. For example,

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[30] In some states, guardians are generally required to post a bond in an amount set by the court to allow victims to recover losses resulting from a guardian’s failure to properly perform his or her duties.

representatives from the National Guardianship Association noted the forensic analysis to identify evidence in these cases can cost $20,000 or more for just one case. Other challenges relate to the penalties associated with these crimes. For example, an official in Washington has noted the sentences tend to be insignificant and jail time can often be avoided. This official also noted that prosecutors will rarely proceed with cases that do not exceed certain dollar thresholds.

Agency Comments

We are not making recommendations in this report. We provided a draft of this report to HHS, CFPB, the Department of Justice, SSA, the Department of Veterans Affairs, and the Office of Personnel Management for review and comment. CFPB and SSA provided technical comments, which we incorporated as appropriate. HHS, the Department of Justice, the Department of Veterans Affairs, and the Office of Personnel Management had no comments on this report.

As agreed with your offices, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days from its issue date. At that time, we will send copies of this report to relevant congressional committees; the Commissioner of the Social Security Administration; the Secretary of Veterans Affairs; the Secretary of Health and Human Services; and other interested parties. In addition, the report will be available at no charge on the GAO website at http://www.gao.gov.

If you or your staff have any questions concerning this report, please contact me at (202) 512-6722 or larink@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix II.

Kathryn A Larin

Kathryn A. Larin
Acting Director
Forensic Audits and Investigative Service

Appendix I: Coordination between Federal Representative Payee Programs and State Guardianship Programs

The Social Security Administration (SSA), the Department of Veterans Affairs, and the Office of Personnel Management have programs that appoint representative payees to manage federal benefits received by individuals who are unable to do so for themselves.[1] Federal agencies are responsible for oversight of representative payees assigned under these programs, while state and local courts are responsible for oversight of guardianship appointments. A representative payee may also be a guardian, and some beneficiaries with a representative payee may also have a guardian. According to a white paper prepared for the Elder Justice Coordinating Council, the representative payee and the guardian might or might not be the same person or organization.[2] Table 3 shows the number of beneficiaries who are older adults and have representative payees, as well as the number of representative payees and court-appointed guardians or conservators that the respective federal agency is aware of.

Table 3: Counts of Older Adults Receiving Federal Benefits, and Related Number of Representative Payees and Guardians

Agency	Number of program beneficiaries over age 65	Number of beneficiaries over age 65 with representative payees	Number of representative payees[a]	Beneficiaries with a court-appointed guardian or conservator[b]
Social Security Administration (SSA)[c]	44,888,000	652,688	550,493	91,744
Department of Veterans Affairs[d]	2,413,353	121,946	108,987	2,793
Office of Personnel Management[e]	2,051,946	6,619	6,339	4,641

Source: SSA, Department of Veterans Affairs, and Office of Personnel Management. | GAO-17-33

[a] A single representative payee may assist multiple federal beneficiaries.

[b] Federal agencies are responsible for oversight of representative payees assigned under these programs, while state and local courts are responsible for oversight of guardianship appointments.

[c] SSA directed GAO to its July 2016 Monthly Statistical Snapshot to determine the number of program beneficiaries over age 65 and to its 2015 Annual Statistical Supplement to provide the number of beneficiaries over age 65 with representative payees. SSA directly provided the remaining figures as of July 2016.

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[1] We use the term “representative payee” to refer to both Department of Veterans Affairs fiduciaries and SSA or Office of Personnel Management representative payees.

[2] Erica Wood, *Statement on Federal Approaches Toward Elder Financial Exploitation by Fiduciaries—Representative Payees & Guardians*, paper prepared for the Elder Justice Coordinating Council (Oct. 31, 2012).

[d]The Department of Veterans Affairs uses the term fiduciary to describe the person who supports individuals who are unable to manage their financial affairs. The number of beneficiaries over the age of 65 with a court-appointed guardian or conservator only includes those court appointments recognized by the Department of Veterans Affairs. The Department of Veterans Affairs provided the number of program beneficiaries over 65 as of September 2015, and provided the number of beneficiaries with representative payees, number of representative payees, and number of beneficiaries with a court-appointed guardian or conservator as of August 2016.

[e]The Office of Personnel Management provided figures for all columns as of August 2016.

We have previously found that, among other things, poor communication between the courts and federal agencies has enabled guardians to chronically abuse persons under guardianship and others.[3] In 2011, we found that information sharing among federal fiduciary programs and state courts could improve the protection of older adults with guardians.[4] More specifically, we found that information about SSA's incapable beneficiaries and their representative payees could help state courts (1) avoid appointing individuals who, while serving as SSA representative payees, have misused beneficiaries' SSA payments in the past, and (2) provide courts with potential candidates for guardians when there are no others available.[5] At that time, we recommended that SSA should determine how it can, under current law, disclose certain information about beneficiaries and fiduciaries to state courts upon request, potentially proposing legislative changes to allow such disclosure. Upon review of our recommendation, SSA determined it could not disclose information about SSA beneficiaries and representative payees to state courts for the purposes of determining guardianship without written consent because legal limitations prevent the sharing of this information.

While we continue to believe that it is in the best interest of incapable SSA beneficiaries for the agency to disclose certain information about beneficiaries and fiduciaries to state courts, SSA officials with whom we

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[3] See GAO, *Elder Justice: National Strategy Needed to Effectively Combat Elder Financial Exploitation*, GAO-13-110 (Washington, D.C.: Nov. 15, 2012).

[4] See GAO, *Incapacitated Adults: Oversight of Federal Fiduciaries and Court-Appointed Guardians Needs Improvement*, GAO-11-678 (Washington, D.C.: July 22, 2011).

[5] Pursuant to 42 U.S.C. § 405(j)(2)(B)(ii), SSA maintains a centralized file of individuals whose certification as a representative payee has been revoked, who have been convicted of certain types of fraud under the Social Security Act, or who have otherwise misused certain SSA benefits. Generally, these individuals may not serve as representative payees for SSA benefits. SSA officials told us that the agency has determined that a routine use for sharing this information with state courts is not legally permissible under the Privacy Act (5 U.S.C. § 552a) because such a use is not compatible with the purposes for which SSA collected the information.

spoke in 2016 maintain that the agency cannot disclose information regarding SSA beneficiaries and representative payees to courts for the purposes of determining guardianship issues without written consent, unless a Privacy Act exception applies. SSA officials also told us they were not aware of any routine exchanges of information between state courts and their agency; however SSA does share limited information about representative payees with other federal agencies when legally authorized to do so.

Officials from state courts we spoke to also reiterated the need for increased coordination and communication with federal representative payee programs. For example, a court official in Washington explained that it is important for courts to know when there is an issue with a representative payee who is trying to become a guardian, and it is also important for SSA to know when there is a problem guardian.[6] Also, court officials in Ohio described another challenge related to their monitoring efforts that occurs when they are unaware of significant increases in the assets of the person under guardianship, caused by the receipt of sizable back payments paid by SSA.

As described in this report, the Administrative Conference of the United States administered and analyzed the results of a survey of judges, court staff, and guardians to review, among other things, court interaction with federal agencies.[7] In August 2016, SSA officials told us the agency was using the study to make improvements that will leverage the work of state courts in SSA's process for determining whether a representative payee is necessary. For example, SSA is exploring whether the agency could automatically appoint guardians—or individuals who are currently serving in a similar capacity—as representative payees. Additionally, SSA officials told us they are using the results to identify better ways to communicate with state and local courts and the guardians appointed by these entities. These efforts include providing clarification to agency

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[6] SSA officials reviewed this comment made by the Washington court official and noted that SSA's standards for representative payees differ from state guardianship standards; thus, while some problems may be helpful for SSA to know about, others may not. SSA officials also noted that under the Privacy Act, SSA must maintain in its records only such information about an individual as is relevant and necessary to accomplish the purpose of administering its programs. 5 U.S.C. § 552a(e)(1).

[7] Administrative Conference of the United States, *SSA Representative Payee: Survey of State Guardianship Laws and Court Practices* (Dec. 24, 2014).

technicians on permitted disclosures to state and local courts and legal guardians.

Appendix II: GAO Contact and Staff Acknowledgments

GAO Contact

Kathryn A. Larin, (202) 512-6722 or larink@gao.gov

Staff Acknowledgments

In addition to the contact named above, Gabrielle Fagan (Assistant Director), John Ahern, Nada Raoof, and April Van Cleef made key contributions to this report. Also contributing to the report were Lorraine Ettaro, Colin Fallon, Maria McMullen, and James Murphy.

Related GAO Products

Elder Justice: More Federal Coordination and Public Awareness Needed. GAO-13-498. Washington D.C.: July 10, 2013.

Elder Justice: National Strategy Needed to Effectively Combat Elder Financial Exploitation. GAO-13-110. Washington D.C.: November 15, 2012.

Incapacitated Adults: Oversight of Federal Fiduciaries and Court-Appointed Guardians Needs Improvement. GAO-11-678. Washington D.C.: July 22, 2011.

Elder Justice: Stronger Federal Leadership Could Enhance National Response to Elder Abuse. GAO-11-208. Washington D.C.: March 2, 2011.

Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors. GAO-10-1046. Washington D.C.: September 30, 2010.

(100389)

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GAO

Report to the Chairman, Special Committee on Aging, U.S. Senate

September 2010

GUARDIANSHIPS

Cases of Financial Exploitation, Neglect, and Abuse of Seniors

GAO

Accountability ★ Integrity ★ Reliability

GAO-10-1046

September 2010

GUARDIANSHIPS

Cases of Financial Exploitation, Neglect, and Abuse of Seniors

Highlights of GAO-10-1046, a report to the Chairman, Special Committee on Aging, U.S. Senate

Why GAO Did This Study

As individuals age, some become incapable of managing their personal and financial affairs. To protect these individuals, state laws provide for court appointment of guardians, who may be professionals or family members, to protect the incapacitated person's personal and/or financial welfare. State and local courts are responsible for overseeing guardians. In addition, federal agencies may appoint a representative payee, in some cases, the guardian, to manage federal benefits on behalf of incapacitated adults. Previous GAO reports have found that poor communication between state courts and federal agencies may allow guardians to continue abusing their victims.

GAO was asked to (1) verify whether allegations of abuse by guardians are widespread; (2) examine the facts in selected closed cases; and (3) proactively test state guardian certification processes. To verify whether allegations are widespread, GAO interviewed advocates for seniors and reviewed court documents. To examine closed criminal, civil or administrative cases with a finding of guilt or liability in the past 15 years, GAO reviewed court records, interviewed court officials, attorneys and victims, and reviewed records from federal agencies. To test state guardian certification, GAO used fictitious identities to apply for certification in four states. GAO's results cannot be projected to the overall population of guardians or state certification programs.

View GAO-10-1046 or key components.
For more information, contact Gregory D. Kutz at (202) 512-6722 or kutzg@gao.gov.

What GAO Found

GAO could not determine whether allegations of abuse by guardians are widespread; however, GAO identified hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010. In 20 selected closed cases, GAO found that guardians stole or otherwise improperly obtained $5.4 million in assets from 158 incapacitated victims, many of whom were seniors. In some instances, guardians also physically neglected and abused their victims. The guardians in these cases came from diverse professional backgrounds and were overseen by local courts in 15 states and the District of Columbia. GAO found several common themes. In 6 of 20 cases, the courts failed to adequately screen potential guardians, appointing individuals with criminal convictions or significant financial problems to manage high-dollar estates. In 12 of 20 cases, the courts failed to oversee guardians once they were appointed, allowing the abuse of vulnerable seniors and their assets to continue. Lastly, in 11 of 20 cases, courts and federal agencies did not communicate effectively or at all with each other about abusive guardians, allowing the guardian to continue the abuse of the victim and/or others. The table below provides examples of guardianship abuse cases.

Examples of Cases of Abuse by Guardians

Victim	Guardian/ state	Case details
87 year old man with Alzheimer's disease	Former taxi cab driver / Missouri	• Guardian embezzled more than $640,000, which included the purchase of a Hummer and checks written to exotic dancers. • County workers found the victim living in the guardian's filthy basement wearing an old knit shirt and a diaper. • Guardian was sentenced to 8 years in prison and ordered to pay $640,000 in restitution.
At least 78 victims	Private agency / Alaska	• Agency management stole at least $454,000 over 4 years. • Executive director used wards' funds to pay for his credit card bills, medical expenses, mortgage payments, and camp for his children. • Victims received partial repayment, but no criminal charges were filed.
20 victims of various ages with mental incapacities	Licensed social worker, registered nurse / Kansas	• Guardian and his wife sexually and physically abused residents of their unlicensed group home and billed Medicare for this "therapy." • Residents lived in a house described by the prosecutor as "dirty and bug-infested" and were videotaped engaged in forced sexual activities. • Guardian sentenced to 30 years in prison; wife sentenced to 15 years.

Source: GAO summary of closed cases of abuse, neglect and financial exploitation by guardians.

Using two fictitious identities—one with bad credit and one with the Social Security number of a deceased person—GAO obtained guardianship certification or met certification requirements in the four states where we applied: Illinois, Nevada, New York, and North Carolina. Though certification is intended to provide assurance that guardians are qualified to fulfill their role, none of the courts or certification organizations utilized by these states checked the credit history or validated the Social Security number of the fictitious applicants. An individual who is financially overextended is at a higher risk of engaging in illegal acts to generate funds. In addition, people with criminal convictions could easily conceal their pasts by stealing a deceased person's identity. The tests raise questions about the effectiveness of these four state certification programs.

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Accountability * Integrity * Reliability

United States Government Accountability Office
Washington, DC 20548

September 30, 2010

The Honorable Herb Kohl
Chairman
Special Committee on Aging
United States Senate

Dear Mr. Chairman:

According to the U.S. Census Bureau, by the year 2025, the number of Americans aged 65 and older will increase by 60 percent.[1] As citizens age, they may become physically or mentally incapable of making or communicating important decisions for themselves, such as those required to handle finances or secure their possessions. Compared to the general population, adults over the age of 65 are more likely to live alone than those of younger ages.[2] Given these statistics, it is important to ensure that systems designed to protect seniors[3] from abuse and neglect function properly.

Courts may appoint a family member, a professional guardian, a nonprofit social service agency, or a local or state agency[4], to care for an incapacitated person.[5] While many guardians[6] serve the best interests of the incapacitated people they are appointed to protect, others have taken

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[1] In 2009, the U.S. Census Bureau projected that the population of adults 65 and older will increase from 40.3 million in 2010 to 64.3 million in 2025.

[2] According to U.S. Census, in 2008, 1 in 3 adults aged 65 and older lived alone compared to 1 in 10 adults between the ages of 15 and 64.

[3] We define "seniors" as adults aged 50 and older, the population served by AARP, formerly known as the American Association of Retired Persons.

[4] State and local agencies include a Public Guardian, which is a publicly-funded state or county office that may be appointed to serve as guardian, and state and local Offices of Aging, which provide a variety of services to seniors and may be appointed to serve as a guardian.

[5] Incapacitated persons may include both seniors and younger adults, but this report focuses on cases involving seniors.

[6] For convenience, we use the term "guardian," even though some states use other terms or differentiate between an individual or group that controls only the finances and one that controls the ward's personal affairs, including health decisions. Court-appointed guardians may be family members or professionals.

advantage of these vulnerable individuals, according to our previous reports.[7] Given our prior findings of guardianship abuse, you asked us to (1) verify whether allegations of abuse, neglect, or exploitation by guardians are widespread; (2) examine the facts and circumstances surrounding selected cases of abuse by guardians, including whether inadequate communication between courts and federal agencies placed these victims at further risk; and (3) proactively test selected state guardian certification processes.

To verify whether allegations of guardian abuse, neglect, or exploitation are widespread, we interviewed state investigators, attorneys, advocates for seniors, and family groups nationwide. We also reviewed federal and state court documents. The abuse alleged by these sources occurred in 45 states plus the District of Columbia; however, this should not be taken to mean that alleged abuse by guardians is limited to these states. Allegations should not be considered proof of abuse. To select our case studies, we searched for instances of guardianship abuse in which there was a criminal conviction or finding of civil or administrative liability in the last 15 years, although in some cases the abuse began much earlier. As part of the selection process, we focused on cases involving professional guardians, guardianship agencies caring for multiple incapacitated people or cases of abuse by family members or other individuals involving significant financial loss by the victim. In addition, we considered factors such as geographic location, number of victims affected and whether the financial abuse involved federal funds. Ultimately, we selected 20 cases from 15 different states and the District of Columbia for further review. To determine whether these guardians continued to receive federal benefits on behalf of their victims or others after the abuse was discovered, we analyzed databases and case files from the Social Security Administration (SSA), the Department of Veterans Affairs (VA), and the Office of Personnel Management (OPM).[8] We did not examine whether state laws and regulations have changed since the abuse in our closed case studies occurred. To test the guardianship certification process, we posed as prospective professional guardians and made calls to state agencies and nonprofits to determine certification requirements. From the 13 states with certification programs, we selected 4 states that did not require

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[7] GAO, *Collaboration Needed to Protect Incapacitated Elderly People*, GAO-04-655 (Washington, D.C.: July 13, 2004); and *Little Progress in Ensuring Protection for Incapacitated Elderly People*, GAO-06-1086T (Washington, D.C.: September 7, 2006).

[8] OPM manages retirement programs for federal employees.

fingerprint background checks or time-intensive training courses.[9] Investigators created two fictitious identities and completed certification requirements in these states. We later interviewed state officials and representatives of the nonprofits to gather additional information on the certification process. Case study findings and undercover test results cannot be projected to the overall population of guardians or controls over guardian certification programs. See appendix I for additional details on our scope and methodology. We conducted our investigation from August 2009 through September 2010 in accordance with standards prescribed by the Council of the Inspectors General for Integrity and Efficiency (CIGIE).

Background

When an adult is found to be incompetent, a court can appoint a guardian to oversee the individual's personal and financial well-being. [10] Depending on the incapacitated person's needs, the court may appoint the following: a "guardian of the estate," also called a conservator, who makes decisions regarding the incapacitated person's finances; a "guardian of the person," who makes nonfinancial decisions; or a guardian who performs both functions. The appointment of a guardian typically means that the incapacitated person loses basic rights, such as the ability to sign contracts, vote, marry or divorce, buy or sell real estate, or make decisions about medical procedures.

State requirements for guardians vary. Thirteen states offer guardianship certification, including 11 states that require certain professional guardians to undergo certification[11] before they can be appointed but generally exempt family members from such directives. In 2 other states, certification is optional for all guardians. Certification programs in 5 states[12] require applicants to complete guardianship training, while 9 others order them to pass a national guardianship exam, a state exam, or both. Three states require applicants to complete both guardianship training and pass a competency exam before they can obtain certification.

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[9] A fingerprint background check could potentially have identified our investigators

[10] The court can also appoint a guardian for incapacitated minors or adults less than 50 years of age, but we have limited our investigation to cases where at least one victim was 50 years or older at the time of the abuse.

[11] For convenience, we use the term "certification," even though some states require their guardians to register or become licensed prior to appointment.

[12] Two additional states require guardians to complete training after they are appointed by the court. However, these states do not require a guardian to obtain certification.

In addition, some states conduct background checks using fingerprints. Three of the 13 states offering certification also conduct credit checks on applicants. Once guardians become appointed, most states demand that they report on the well being of the incapacitated person and provide an accounting of their ward's finances; however, the reporting frequency is left up to the court. See appendix II for detailed information on state guardianship laws. The federal government does not regulate or directly support guardians.

Representative payees[13] are appointed by SSA, VA, and OPM to handle the federal benefit payments they remit to an incapacitated person. For beneficiaries older than 50 years of age, court appointed guardians also serve as federal representative payees in 1 percent of cases at SSA, 13 percent of cases at VA, and 34 percent of cases at OPM. The agencies all provide oversight of representative payees, but agencies differ in how they screen and monitor them. For example, according to SSA, it compares the names and Social Security numbers of prospective representative payees against lists of prisoners, fugitive felons and parole violators; VA and OPM do not. SSA, VA, and OPM are required to oversee how representative payees manage federal benefits on behalf of their wards; however, agencies differ in the kinds of information they collect from court appointed guardians. For example, SSA officials said they require most representative payees, including court appointed guardians, to submit a standard accounting form.[14] According to VA, they ask for a two page accounting report, but also ask payees that are court-appointed guardians to submit whatever accounting the guardian submitted to the local courts. According to OPM, it sends out a brief survey asking for similar information, but OPM leaves the local courts to monitor these payees and does not require them to complete the survey. While federal agencies and state courts often share responsibility for protecting many of the same incapacitated seniors, their collaboration is often limited, according to our prior report. With few exceptions, federal agencies and state courts neither notify other oversight entities when they declare an individual to be incapacitated, nor share information with each other in instances in which a guardian or a representative payee has abused a ward.

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[13] We defined “representative payees” to include VA fiduciaries, OPM representative payees, and SSA representative payees who receive federal benefits on behalf of incapacitated beneficiaries.

[14] SSA officials said that on-site state mental heath facilities that serve as representative payees are not required to file this form.

Allegations of Abuse, Neglect, and Financial Exploitation by Guardians

Although we could not determine whether allegations of physical abuse, neglect, and financial exploitation by guardians were widespread, we reviewed hundreds of allegations of abuse occurring nationwide between 1990 and 2010. In addition, eight individuals that we interviewed, including prosecutors, attorneys, investigators and others involved with six of the closed cases we examined, told us that they knew of other cases of guardianship abuse, or believed that the current system of guardian oversight needs to be strengthened in order to protect incapacitated persons. While the alleged abuse identified through our own research, and reported to us in interviews with investigators, attorneys and others, occurred in 45 states and the District of Columbia, this should not be interpreted as evidence that guardianship abuse is actually occurring on a widespread basis. Most of the allegations we identified involved financial exploitation and misappropriation of assets. Specifically, the allegations point to guardians taking advantage of wards by engaging in schemes that financially benefit the guardian but are financially detrimental to the ward under their care. Also, the allegations underscore that the victim's family members often lose their inheritance or are excluded by the guardian from decisions affecting their relative's care.

Although we continue to receive new allegations from family members and advocacy groups, we could not locate a single Web site, federal agency, state or local entity, or any other organization that compiles comprehensive information on this issue. We attempted to identify entities compiling this information by contacting state courts, federal agencies, advocacy groups, and a professional guardian association. We also searched the Internet. Our research did not identify any public, private, or non-governmental organization that systematically tracks the total number of guardianships or allegations of abuse, neglect, and exploitation by guardians. GAO previously found that many of the courts we surveyed did not track the number of guardianships that they were responsible for monitoring.[15] Our work also identified differences in the way courts track guardianships. For example, in some jurisdictions, records of guardianship appointments were available online, but in many areas they were not. Some federal agencies identify guardians who also serve as representative payees for federal beneficiaries, but they do not keep a list of all court appointed guardians. Some states maintain lists of certified guardians, but these lists understate the number of guardians because often family

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[15] See GAO-06-1086T and GAO-04-655.

members and certain other guardians are exempt from certification requirements.

We also discovered that information about complaints or disciplinary action taken against guardians may not be publicly available. In addition, we found that state and local enforcement may consist of measures not specific to guardians, such as discipline by a bar association for lawyers or by a regulatory board for Certified Public Accountants. Thus, the exact number of allegations about abuse, neglect or exploitation by guardians remains unknown.

Allegations should not be considered proof of actual abuse. However, the hundreds of allegations we discovered came from a number of sources, including our own research on closed criminal and civil cases,[16] advocacy groups, news reports, family members, concerned citizens, and legal professionals. Frequently, we identified multiple allegations from each of our sources. For example, an attorney who belongs to the National Guardianship Association provided us information on over 300 cases of alleged abuse, neglect, and exploitation by guardians between 1990 and 2009. Examples of potential abuse, neglect, and exploitation appear below:

- Public guardians appointed to care for an 88-year-old California woman with dementia allegedly sold the woman's properties below market value to buyers that included both a relative of the guardian and a city employee. One of the public guardians also moved the ward into various nursing homes without notifying family members, who had to call the police to help them find their relative. The woman developed bed sores during this time that became so serious her leg had to be amputated at the hip.
- In Nevada, a former case manager in the public guardian's office who started her own guardianship business is accused of using her position to take at least $200,000 from her wards' accounts, in part, to support her gambling habit.
- A New York lawyer serving as a court appointed guardian reportedly stole more than $4 million from 23 wards, including seniors suffering from mental and physical impairments as well as children suffering from cerebral palsy due to medical malpractice. Some of the stolen

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[16] Closed criminal and civil cases with a finding of liability would be considered proven instances of abuse by guardians; however, we did not examine the facts and circumstances surrounding all closed cases we identified. Those that we did not examine are included in this section.

funds were part of a court award intended to pay for the children's medical and developmental needs.

- In Arizona, court-appointed guardians allegedly siphoned off millions of dollars from their wards, including $1 million from a 77-year-old woman whose properties and personal belongings, such as her wedding album, were auctioned at a fraction of their cost.
- A Texas couple, ages 67 and 70, were declared mentally incompetent and placed in a nursing home after the husband broke his hip. Under the care of court-appointed guardians, their house went into foreclosure, their car was repossessed, their electricity was shut off, and their credit was allowed to deteriorate. The couple was allegedly given a $60 monthly allowance and permitted no personal belongings except a television.
- In 2001, a Texas probate judge was appointed a guardian for a 91-year-old woman who displayed signs of senility. She later changed her will for the first time in 40 years, bequeathing $250,000 to the probate judge, the court appointed guardian, the judge's personal accountant, and the court-appointed attorney associated with her case.
- A 93-year-old Florida woman died after her grandson became her temporary guardian by claiming she had terminal colon cancer. He then moved her to hospice care, where she died 12 days later from the effects of morphine. The woman's condition was later determined to be ulcerative colitis, and the guardian's claims that she had 6 months to live were false. In addition, the guardian is accused of stealing $250,000 from the woman's estate.
- In Michigan, two former public guardians allegedly embezzled $300,000 from at least 50 clients between 1999 and 2009. One of the reported embezzlers used the wards' funds to buy animal feed and other supplies for her farm.

Cases of Abuse, Neglect, and Financial Exploitation by Guardians

We examined 20 cases in which guardians stole or otherwise improperly obtained more than $5.4 million in assets from 158 incapacitated victims. In some of these cases, the guardians also physically neglected and abused the people they had been appointed to care for. We obtained our information from court documents, disciplinary records, and our own interviews and research. The guardians in these cases possessed diverse professional backgrounds and were located in 15 states and the District of Columbia, however, we observed several common themes: (1) state courts failed to adequately screen potential guardians, appointing individuals with criminal convictions and/or significant financial problems to manage estates worth hundreds of thousands or millions of dollars; (2) state courts failed to adequately oversee guardians after their appointment, allowing the abuse of vulnerable seniors and their assets to continue; and (3) state courts failed to communicate with federal agencies about abusive guardians once the court became aware of the abuse, which in some cases enabled the guardians to continue to receive and manage federal benefits.

State Courts Failed to Adequately Screen Potential Guardians. In 6 of our 20 case studies, state courts failed to adequately review the criminal and financial backgrounds of prospective guardians, leading to the appointment of individuals or organizations whose past should have raised questions about their suitability to care for vulnerable seniors. For example, in one case, a federal tax lien worth $25,783 had been filed against a prospective guardian, yet 5 years later, an Iowa court appointed him to serve as a guardian for an estate worth hundreds of thousands of dollars. In another case, a New York attorney had declared bankruptcy just 3 years prior to being appointed by a court to serve as guardian over a senior's estate. In yet another case, a guardian certified in the state of Washington passed a criminal background check, but had $87,000 in federal and state tax liens filed against her. The court did not conduct a credit check before appointing her to serve as a guardian over one senior's estate.

State Courts Failed to Adequately Oversee Guardians after Their Appointment. In 12 of our 20 case studies, state courts failed to oversee guardians after their appointment, allowing the abuse of vulnerable seniors and their assets to continue. Courts ignored criminal and/or financial problems of guardians who served multiple roles with conflicting fiduciary interests. They also failed to review irregularities in guardians' annual accountings or sanction delinquent guardians. In one case, a federal tax lien of $31,000 was filed against a Washington state guardian just one month after she was appointed to care for a senior. Yet, a Washington court allowed her to continue serving as the man's guardian. In another case, a Kansas social worker served as a guardian, conservator, federal representative payee, therapist, landlord, and service provider to at least one senior victim. This enabled him to make payments to himself from the senior's estate and avoid the oversight, checks, and balances that might have existed if all these roles were performed by different individuals. In a third case, a Colorado conservator failed to file any interim financial reports over the course of 3 years to inform the court of the fees he was charging to the ward's estate. Despite this repeated failure, the court examiners did not investigate the conservator or make any other inquiries about the missing reports, telling the victim's family members that they had neither the time nor the knowledge to deal with the case.

State Courts Failed to Communicate with Federal Agencies about Abusive Guardians. In 11 of our 20 case studies, state courts failed to communicate with federal agencies about ongoing abuse committed by guardians. For example, in one case, a District of Columbia guardian continued to serve as the victim's SSA representative payee for four years after the court was alerted to thefts by her secretary. In another case, an Arizona court appointed a senior's niece to manage her aunt's affairs as her guardian. The aunt was 90 years of age, and suffered from dementia. The guardian also served as a representative payee for her aunt's Social Security benefits, and the SSA continued sending the guardian federal benefits during the abuse. This permitted the guardian to gain access to over $18,000 of the victim's Social Security benefits in a single year. In the end, an Arizona court discovered that the guardian misappropriated more than $200,000 from her aunt's estate and used the money to give loans to and pay for unauthorized gifts for her children. Some of these funds might have included the victim's Social Security benefits. The SSA did terminate the niece as the aunt's representative payee, but the SSA told us that it did not terminate her for misusing the aunt's funds. The SSA determines that misuse occurs when a payee does not use or conserve the beneficiary's Social Security benefits in such a way that benefits the beneficiary's current and foreseeable needs. The SSA was apparently unaware of the extent of abuse that the court determined the guardian committed against the aunt's estate, and possibly her Social Security benefits. In a third case, the VA suspended a North Carolina guardian as a representative payee when he failed to file annual accountings 2 years in a row. However, once the guardian submitted the accountings, the VA reinstated him as the victim's representative payee and resumed sending him federal benefits. The VA did not notify the local court of problems with the guardian, who eventually misappropriated $332,730 from the victim over a 14-year period.

Table 1 below provides a summary of the 10 cases in which guardians abused, neglected or financially exploited their victims, followed by a more detailed narrative on each of the first five cases. Table 2 contains details on an additional 10 cases we reviewed.

Table 1: Summary of the 10 Cases in Which Guardians Abused, Neglected, or Financially Exploited Their Victims

Case	Victim(s)	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
1	Two seniors and 18 other victims with dementia and mental illnesses	November 2005	Licensed social worker and his wife, a registered nurse / Kansas	• The guardian and his wife sexually and physically abused their victims and billed Medicare for the cost of this "therapy." • Victims lived in an unlicensed group home described by the prosecutor as "dirty and bug-infested." They were kept in isolation and videotaped while engaging in forced sexual activities and nude farm work. • According to a federal court order, the guardian paid himself more than $102,000 from one senior's inheritance and used some of those funds for purported "therapy" that he provided to her. • The federal court found that guardian failed to file any required accountings with the court. It also found that the guardian wrote checks as payments off the victim's estate, which bore notations that did not sufficiently note their legitimacy. Further, the guardian never filed required accountings with the SSA. • A federal court sentenced the guardian to 30 years in prison and his wife to 15 years in prison for involuntary servitude and fraud. The federal court ordered the couple to pay six victims, Medicare, and the Mennonite Mutual Aid a total of $534,806 in restitution. The remaining restitution balance is $364,511.
2	87 year old man with Alzheimer's disease	March 2008	Taxi cab driver / Missouri	• Guardian was a felon convicted of armed robbery and other crimes, yet became the victim's legal representative, conservator, co-trustee, and beneficiary. • Guardian embezzled over $640,000 from the victim, which he used in part to purchase a Hummer and a Chrysler as well as gift payments to himself and others, including exotic dancers. • Victim was discovered in the guardian's basement wearing an old knit shirt and a diaper, extremely dehydrated and confused. • Guardian was sentenced to 8 years in federal prison without parole, and ordered to pay $640,820 in restitution No part of this amount had been paid by February 2010, according to the prosecutor.

Case	Victim(s)	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
3	At least 78 victims	November 2004	Professional guardian agency / Alaska	• Company officers mismanaged or stole an estimated $454,416 from their wards between about 1998 and 2002, according to the information provided to Alaska's U.S. Bankruptcy Court by a trustee. • Executive director used company checks to pay for his utility bills, mortgage payments, credit card bills, medical expenses, and church camp for his children. • One mentally ill veteran's inheritance was depleted from $90,000 to almost nothing over 3 years in the early to mid 1990s in part because the company purchased mental health services at rates 1,500 percent higher than necessary, made improper travel charges, and charged twice for the same services. • Victims received partial restitution through bankruptcy proceedings, but no criminal charges were filed.
4	20 senior and disabled victims	January 2006 / October 2008	Office of the Public Guardian / California	• Two staff in the office of the public guardian stole a combined total of $97,000 from senior and disabled public wards with no one else to care for them. • One woman admitted stealing $90,000 by cashing victims' pension and Social Security checks while working temporarily in the public guardian's office. She testified that a permanent staff member had taught her to steal and split the proceeds with her. • The permanent guardian used victims' funds to buy herself jewelry, clothing, and electronics and stole valuables from their homes. • The prosecutor and nursing home staff said that the permanent guardian placed clients in her friend's nursing facility, described by the investigator as "a complete hellhole" and was convicted of taking kickbacks from a worker she hired to clean victims' homes. • The temporary guardian was sentenced to 5 years, 4 months in prison and $93,000 in restitution, of which she had paid $70,000 as of July 2010. The permanent guardian was sentenced to 9 months in prison, 5 years probation and $9,880 in restitution, of which she had paid $2,420 as of July 2010.

Case	Victim(s)	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
5	71 year old with dementia, schizophrenia, and alcohol dependency; 83 year old with mental incapacitation	November 2005	Attorney / District of Columbia	• A guardian's negligence allowed her secretary to embezzle nearly $50,000 from two elderly victims. Also, the guardian neglected to collect $39,000 of rental income for over four years on behalf of one victim. • The court found that the guardian's secretary embezzled funds from two victims' accounts by writing checks to herself and to a high-end department store. • The guardian's failure to pay taxes for one victim led to her house being confiscated and sold by tax authorities, according to a probate court complaint. The victim was rendered homeless, but the guardian claimed in a letter to the court that the woman preferred to live in city shelters. • The guardian continued to be the victim's representative payee for 4 years after the scheme was uncovered, according to SSA data. • The secretary disappeared with the embezzled money. Neither the secretary nor the guardian faced criminal charges, although the guardian was suspended from legal practice. The probate court ordered $97,000 in restitution, which was paid by bond companies, except for $27,000 still owed to the one victim's estate, as of August 2010.
6	85 year old woman and 79 year old man	June 2005 / January 2006	Certified Public Accountant / Iowa	• A CPA with known financial problems was appointed as conservator of two seniors and used his position to misappropriate $167,325. • The court found that the guardian wrote himself 21 checks ranging from $2,000 to $25,000 from one victim's estate, while failing to pay for her rent and prescription drugs. • The guardian refused to bring clothes and other belongings to the victim's nursing home, according to her guardian ad litem.[a] He also disposed of the victim's personal belongings, leaving her without her wedding band, personal papers and family photos. • The court found that the guardian misappropriated $15,000 from another victim by writing checks to his business and fraudulently altering the payee to make the checks appear legitimate. • The guardian repaid the misappropriated amounts and $3,014 in fines, so the court did not order restitution. The guardian worked at a CPA firm as of September 2010, although he lost his CPA license and served 150 days in prison with 5 years probation.

Case	Victim(s)	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
7	82 year old with Alzheimer's disease	June 2008	Attorney / New York	• Under court appointed guardians' watch, the value of a retired judge's estate dropped from several million dollars to almost nothing in 6 years and accrued $1 million in taxes, interest, and penalties. • The guardian had declared bankruptcy just three years prior to her appointment, accumulated $119,500 in debt just two years prior to her appointment, and accumulated $4,917 in debt during the guardianship, yet the court repeatedly renewed her appointment six times in 3 years. • Court judgments and accountings show that the guardian misappropriated at least $327,000 to pay herself, family, and friends for purported caretaking and home improvement services. She personally misappropriated $200,000 and some of the misappropriated funds were used to pay her mortgage and other expenses. • The attorney spent $120,000 of the victim's money to renovate a property that he no longer owned. Title had been transferred to a new owner for almost a year, but the attorney was apparently unaware of the status of a property she had been appointed to protect. • The guardian never faced criminal charges but was suspended from legal practice by a New York court and was later ordered to pay the estate $403,149. The court decision was affirmed on appeal. As of June 2010, the guardian had paid nothing toward the judgment.
8	101 year old with Alzheimer's	July 2005	Certified Public Accountant / Colorado	• The guardian stole $2 million from the victim's estate, forcing her family to mortgage her house to pay her bills, according to her niece. • The guardian funneled $1 million of the victim's funds to his company, then purchased an athletic club specializing in handball, according to the investigator's report and interviews. • The guardian also made a series of improper and bogus loans to family and friends totaling almost $1 million. • The court apparently failed to communicate the guardian's removal, so he continued to be listed as payee for OPM benefits. Also, SSA did not monitor the guardian because the guardian avoided SSA oversight by never applying to be a representative payee. • Due to the thefts, the victim's niece said they had to mortgage the victim's house to meet monthly bills, including $6,000 in nursing home fees. • The CPA was sentenced to 12 years in prison and was ordered to pay restitution of over $2.5 million, of which he had paid $4,366 as of June 2010.

Case	Victim(s)	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
9	Four victims over 70 years of age with dementia or Alzheimer's disease	November 2005	Attorney / Connecticut	• The conservator stole more that $120,000 from the estates of four seniors. • According to a state inspector's affidavit, the conservator used $24,500 from two seniors' estates to pay a housekeeper to clean and garden her home in Connecticut. A state prosecutor described the house as "magnificent." According to a real estate Web site, the home has five bedrooms and three baths, and was on sale for $1.2 million as of December 2009. • The state prosecutor contended that the conservator manipulated one victim's tax forms by increasing her tax withholdings so that the victim would receive $87,000 in refunds. The prosecutor said that it was reasonable to infer that the conservator pocketed the money for her personal use. • According to SSA data, the conservator served as a representative payee for at least three of the four senior victims. • In February 2006, the conservator was sentenced to 15 months in prison based on a "calculated continued pattern of deception for a lengthy period of time." After this sentence, she was scheduled to serve 5 years of probation. She was ordered to pay more than $120,000 in restitution to four victims and agreed to resign from the Connecticut Bar. According to the court's probation office, as of June 2010, she still owed $48,557 in restitution to at least one senior's estate. • According to a police report and sentencing documents, in May 2009, while the conservator was on probation, she was arrested for stealing from a friend's purse and shoplifting purses worth thousands of dollars from a Connecticut department store. This occurred after she served 15 months in prison for her previous crimes. She pled guilty in November 2009 for the thefts, and was sentenced to a total of 20 months in jail. It wasn't until January 2010, that the SSA terminated her as representative payee for another individual.

Case	Victim(s)	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
10	81 year old man with dementia; 77 year old man with dementia and seizures	September 2004 / February 2008	Professional Guardian / Washington	• A certified professional guardian used one ward's estate to generate tens of thousands in unnecessary fees and failed to visit another ward for nearly 8 months, yet she continues to serve as a guardian. • The court appointed the guardian to oversee one victim, even though $87,000 in tax liens had been filed against her during the previous 6 years. Another federal tax lien of $31,000 was filed against her just 1 month later. • The guardian hid the man's will from the court and family members, and continued filing motions contrary to his written wishes in order to generate $20,000 in legal fees for herself. • In another case, a court appointed attorney found that the guardian failed to visit the ward for 8 months and was 9 months delinquent in filing a personal care plan and asset inventory for the ward. • The guardian received disciplinary letters for both cases, but continues to serve as guardian for 86 incapacitated adults. She is also a representative payee for 69 beneficiaries at SSA, 3 beneficiaries at VA, and 2 beneficiaries at OPM.

Source: GAO.

[a] A guardian ad litem is appointed by the court to represent the interests of the ward for a limited time or in a single court action. For example, a guardian ad litem may investigate wrongdoing by a court appointed guardian or may be appointed as a temporary guardian while a more suitable guardian is found.

Case 1: A Kansas husband and wife, who owned an unlicensed group home for mentally ill adults, abused and financially exploited a 50-year old woman in their care. The husband served as the victim's guardian and conservator, enabling the couple to convert the victim's funds for their own use, and amass nearly $250,000 from the woman. In addition, they forced her and other residents to perform sexual acts for almost two decades as part of the fraudulent therapy treatment that they billed to Medicare, a federal court and jury found. At least 20 chronically and severely mentally ill adults, including at least one with schizophrenia, resided at the home—described by federal prosecutors as "dirty, bug-infested, and run down." The husband, a licensed clinical social worker, and the wife, a licensed nurse, served the residents in multiple capacities: landlord, caregiver, representative payee and, in the case of the 50-year old woman, the husband served as guardian. Federal prosecutors successfully argued that this helped the couple conspire to control their victims, and to fraudulently gain access to their Social Security benefits and bill Medicare for $216,906 in purported therapy. The husband also videotaped the sexual activities, nudity, and farm work that he forced victims to do as part of their "therapy" for his own viewing. One resident testified that the husband established and enforced a code of silence and secrecy in order to control and exploit them, creating what he called "a secluded, small, cult-like organization."

The state court that appointed the guardian was either unaware of the multiple roles that he served in the victim's life or failed to question the conflicts between them. According to a federal court order, the guardian paid himself more than $100,000 from one senior's inheritance, using some of those funds for the purported "therapy," and converting the rest for his own personal use. The guardian accounted for a portion of the money he disbursed and provided no supporting documentation. The guardian, under state law, was required to file annual reports on the condition of the victim's estate and well being. The couple also forced the victim to work on their farm nude and participate in nude massages while the pair watched.

After the abuse was discovered by children on a school bus who saw the residents working in the nude on the couple's farm, the local authorities and the Health and Human Services Office of Inspector General launched an investigation. Subsequently, a Kansas court removed the husband as the woman's guardian and the Kansas State Board of Nursing suspended the wife's nursing license. In addition, SSA terminated the couple as representative payees for the six victims receiving Social Security benefits. In 2006, a federal court sentenced the husband to a prison term of 30 years for the crimes of involuntary servitude, forced labor and health care fraud. In 2009, the wife was sentenced by the same court to a prison term of 15 years for the same three crimes. At the husband's sentencing, the judge compared conditions at the house to those of a third world prison, and concluded at the wife's sentencing that "…but for the sighting by the children on the school bus, I am firmly convinced that [the group home] would be in business today."

The federal court ordered the couple to pay six victims, Medicare, and the Mennonite Mutual Aid a total of $534,806 in restitution, including $250,000 to be paid to the guardian's former ward. As of May 2010, the court had received a total of $170,246 from the couple's seized and forfeited group home and $51 that the wife had earned by making license plates while in prison. The husband, however, had not paid any restitution directly as of May 2010.

Case 2: A Missouri taxi cab driver who became the guardian of a retired, Kansas City antiques dealer with Alzheimer's disease embezzled more than $640,000 from his ward and kept him confined in what federal prosecutors described as a filthy basement wearing a diaper until shortly before his death. The cab driver became acquainted with the senior while regularly transporting him from his home to various destinations, including restaurants and a bank. In July 2003, the antiques dealer fell and hit his head, requiring a surgically implanted shunt to be put in his head to control fluid in his brain. Due to his medical condition, he was admitted to the skilled care section of a nursing home and later transferred to an independent-living apartment. The cab driver presented himself to nursing home management as the senior's caretaker. Federal and local law enforcement officials, however, depicted the relationship between the cab driver and antiques dealer as improbable based on the background, appearance, and values of the two men. They described the cab driver as a large, foul-mouthed felon convicted of armed robbery and other crimes. They portrayed the antiques dealer, meanwhile, as a small, fastidious dresser who hailed from a wealthy family, lived in an exclusive neighborhood, and kept well-to-do friends. Nevertheless, they said that with the help of lawyers, the cab driver over time became the legal representative, guardian, conservator, co-trustee (along with a bank), and beneficiary of the antiques dealer and his assets. He assumed this control through the power vested in the legal documents that the parties signed, although the federal prosecutor said he saw indications that many of the signatures did not appear to belong to the antiques dealer. Federal and local law enforcement officials said in an interview that a probate hearing did not occur because the victim was not a ward of the state and he appeared to consent to the changes.

The cab driver removed the antiques dealer from the nursing home to the cab driver's residence in 2004. About a year later, a Kansas City Police Department detective received a tip that the antiques dealer was being exploited. The detective said in her investigative report that she and other law enforcement officials visited the cab driver's residence to check on the antiques dealer. They found him wearing an old knit shirt and a diaper, confined to a basement isolated from the remainder of the house except by surveillance camera. He was bedridden, covered with a dirty blanket, and unable to leave the room. He had no access to a telephone or water. He was also extremely dehydrated and confused. He died of natural causes 12 days after being removed from the basement at the age of 87. A subsequent search of the cab driver's residence revealed new furniture in almost every room of the home, two large-screen television sets, new silverware, and new accessories. The detective noted that this area of the house was relatively clean. Figure 1 below is a photograph of the half bathroom the victim was forced to use.

Figure 1: Bathroom Used By Guardianship Abuse Victim

Source: United States Attorney's Office, Western District of Missouri.

An investigation by federal and local law enforcement officials determined that the cab driver had used his personal and legal guardianship relationship with the antiques dealer to enrich himself and others. For example, he purchased a $35,000 Chrysler 300 and a $52,000, burnt orange Hummer H2 with “Bad to the Bone” emblazoned across the windshield. He also secured checks to himself and others, some of whom were exotic dancers. The cab driver was indicted on 16 counts, including felony bank and mail fraud. In a plea agreement, he admitted to making material false representations, possessing and negotiating unauthorized forged checks and instigating improper money gift payments to himself and others. He also admitted to defrauding financial institutions by misrepresenting or forging either his authority to write checks or his authority to withdraw the elderly man’s trust account funds, and/or misrepresenting the use and purpose of those funds. He was sentenced in October 2008 to 8 years in federal prison without parole and ordered to pay restitution of $640,820—none of which has been paid, said the U.S. assistant attorney that prosecuted the case.

Case 3: A mentally ill veteran saw his $90,000 inheritance rapidly depleted in the early to mid 1990s while under the care of an Alaskan professional guardianship company that later declared bankruptcy amid allegations that it mismanaged, converted, stole or embezzled at least $454,416 from its wards. The veteran had served four years in the U.S. Navy before being honorably discharged in 1966. He developed schizophrenia after leaving the service, experiencing more than a dozen hospitalizations in Alaska and stays in a number of VA hospitals in Wisconsin and Illinois. From 1976 onward, however, he participated in various community health programs in Alaska. After he received his inheritance in 1992, the Alaska Superior Court appointed a private guardianship company as his conservator. By 1995, the inheritance was gone, but the veteran continued to receive Social Security benefits and a VA pension. After the veteran intentionally cut his left wrist, the private company was appointed to be his guardian in February 1996 as well. The state court held that he was unable to physically care for himself or manage his money and would always need supervision.

In December 1996, the Alaska Superior Court ordered a court visitor[17] to report on the company's handling of the veteran's assets. The court visitor found a "disturbing breakdown" of costs and called some of the fees charged "unheard of," concluding that the money had been managed in a "spend down" fashion rather than in a frugal and conscientious manner. For example, she noted that the company had purchased mental health support services for the veteran at a rate that was 1500 percent higher than necessary. She also found improper travel charges, "vague charges for 'case management services'," and multiple staff charging for the same service. The veteran's conservatorship and guardianship were transferred to a new private company formed by former employees of the first one, but after concerns arose about it as well, the Alaska Superior Court made the veteran a ward of the state's Office of Public Advocacy (OPA). In 1999, OPA filed a complaint in state court on behalf of the veteran to recover money from both private guardianship companies.

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[17] In Alaska, a court visitor is appointed when a petition for guardianship or conservatorship is filed to investigate involved persons and the situation and recommend to the court an appropriate resolution. Court visitors are also reappointed every 3 years to review and report to the court regarding existing guardianship and conservatorship cases. The state's Office of Public Advocacy is required by Alaska statute to provide court visitor services.

The private company that served as the veteran's first conservator and guardian filed for bankruptcy in May 2002. An attorney for the veteran negotiated a settlement with the bankruptcy trustee for a payment of $42,500, or less than half of his inheritance. The trustee, however, also determined that corporate officers and directors mismanaged, converted, stole, embezzled, over-billed and took through other means an estimated $454,416 from other wards between about 1998 and 2002. A wards claim fund was established for that amount to help restore the assets of the company's clients. The trustee noted at the time that critical records were suspiciously destroyed by a fire and a final accounting of the wards' losses might never be known. An investigation conducted by a company official found that the group's former executive director at the time and an employee stole from wards in number of ways: writing checks payable to the company that investigators labeled as "direct theft"; writing checks to themselves; withdrawing cash; paying corporate credit card bills; and charging for services not rendered, among other actions.

Case 4: Two women working as public guardians for a county government in California stole over $97,000 from 20 senior and disabled victims, and one further used her authority to collect kickbacks from a man she hired to clean out victims' homes. [18] The victims were placed by the court in the care of the county public guardian's office, which serves as the guardian of last resort for individuals who have no family members willing or able to take care of them. One of the guardians involved in the theft was a temporary employee of the office, while the other guardian had worked there for 22 years. The temporary guardian was responsible for removing checks from the mail for deposit into wards' accounts, but over a 2 year period, she stole $90,000 in checks from six clients. The temporary guardian testified that she stole the funds at the direction of the permanent guardian, and split the proceeds with her. Among the thefts were $58,470 in monthly pension checks from a retired public school teacher and $2,034 from a retired cook with Alzheimer's. Even after the temporary guardian transferred out of the office in June 2004, she continued to cash checks. Local prosecutors said they were not able to determine whether she obtained the checks with the assistance of her former co-worker or by returning to the office to steal from the mail pile, which was kept in an open area. In January 2006, the temporary guardian pled guilty to felony

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[18] Staff employed by the Public Guardian's Office are responsible for making medical and financial decisions for wards, serving as a representative payee for the wards' federal benefits, and taking care of the wards' personal needs.

theft from an elder, tax fraud, and embezzlement by a public officer and was sentenced to five years, four months in prison and ordered to pay $93,344 in restitution. As of July 2010, she had made $70,000 in restitution payments. The permanent guardian, whose name was not on the cashed checks and who denied involvement, was not charged with these crimes.

However, the investigation subsequently broadened to include other potential charges against the permanent guardian who was convicted in October 2008 of bribery, theft of public funds, receiving stolen property and theft from a dependent person. She was sentenced to 9 months in jail and ordered to pay $9,879 in restitution, but as of July 2010, she had repaid just $2,420. According to the local prosecutor's trial brief, the permanent guardian used clients' funds to buy herself jewelry, clothing, wigs, cosmetics, perfume, CDs, and electronic equipment worth $7,000. For example, using the funds of a wheelchair-bound woman living in a nursing home, the permanent guardian bought herself $600 of perfume in one month, depleting the account of a woman who had just $3,000 in assets. One month later, she was reimbursed for $225 she claimed to have spent on jewelry for the client, including three pairs of long, dangling pierced earrings. However, the elderly woman did not have pierced ears and the earrings were later found in the guardian's home. Searches of her home also revealed coins, stamps, televisions, and a DVD player that she had stolen from other clients, both living and deceased.

In addition to the thefts, the permanent guardian used her position to enrich herself in other ways. A jury found that the guardian had taken kickbacks from the man she hired to clean out the houses, in one case instructing him to bill for a fictitious employee so that she could collect an additional $1,500. According to the prosecutor and grand jury testimony, the permanent guardian also used her authority to place several clients in facilities owned and operated by her friends, even though the facilities were located almost an hour away and the guardian had previously been investigated but not charged for taking kickbacks from one of the friends. The investigator described one of the friend's nursing homes as "a complete hellhole" with a stench. When her clients moved into a nursing facility, the permanent guardian would throw away everything in their houses, according to the prosecutor, because it was easier than putting the client's property in storage. One woman returned from a stay in the hospital to find that the permanent guardian had disposed of all her belongings, including her photographs, according to the investigator's testimony.

The thefts and abuse of power in this case were allowed to continue in part because of poor court oversight of guardianship cases managed by the Public Guardian's Office. For example, the office was several years late in filing annual accountings for some guardianship cases, but a probate court official told the prosecutor that the court did not have enough staff to review accountings or even track all its cases. Given the lack of oversight, it is possible that the thefts extended beyond the 20 identified victims, but no audit was done to determine whether funds had been stolen from any of the hundreds of other Public Guardian clients.

Case 5: A District of Columbia guardian breached her fiduciary duty by delegating her responsibilities to her secretary, who embezzled nearly $50,000 from two elderly wards—one of whom lost her home because of the guardian's failure to pay property taxes. The oldest victim was an 83-year-old who worked for the Merchant Marine during World War II and spent the rest of her career as a civil servant at the District of Columbia Department of Human Services, according to federal employment records. After a probate court determined her to be mentally incapacitated, an attorney was appointed as both her guardian and conservator. Although the elderly woman received $1,170[19] monthly income from both her federal pension and Social Security benefits, the attorney never applied to become a representative payee, effectively shielding herself from federal oversight, SSA and OPM data show. Assisting with the conservatorship was a woman that the attorney hired as her secretary after representing her in court on theft charges. The attorney gave most of her conservator responsibilities to the secretary, including writing and receiving checks on estates, which a DC court found to be inappropriate. The secretary forged the attorney's signature on 34 checks drawn on the victim's estate account, totaling more than $42,000 over the course of a year. One of the checks was made out to a high-end department store; the rest were payable to the secretary herself.

The secretary embezzled from another victim under the attorney's care during the same period, a DC court also found. The 71-year-old-woman was suffering from alcohol dependency, mild dementia, and schizophrenia. The attorney served as the court-appointed conservator and the representative payee for her Social Security benefits. The secretary forged the attorney's signature on two checks drawn on the victim's estate

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[19] The $1,170 represents an averaged total of monthly federal pension and Social Security benefits for the elderly woman.

account totaling $5,150, according to a court judgment and a probate clerk's memo. One of the checks, in the amount of $3,000, was deposited into the Merchant Marine's account, the judgment and memo show, in an apparent attempt to hide her previous embezzlement. The secretary made the other check for $2,150 payable to herself. Also, according to a court judgment, the guardian neglected to collect $39,000 of rental income on behalf of the victim for over 4 years. In addition, the attorney failed to pay property taxes on the elderly woman's home, a probate court complaint stated, prompting local authorities to auction it and causing her ward to become homeless. The attorney wrote a letter to probate court officials prior to the move saying the woman preferred to reside in city shelters. The attorney also claimed to have hired a social worker to help find her ward housing, but an attorney for the successor guardian said there was no evidence that a social worker was ever hired. The guardian also failed to file the last two required reports with the probate court, and submitted each of the prior required reports late to the probate court, according to the successor guardian's attorney and to the DC probate court.

The secretary later vanished and the attorney said she never saw her again, according to a DC court judgment. The disappearance did not cause the attorney to suspect her secretary of any wrongdoing, nor did it lead her to examine the bank statements that the secretary had maintained. In the opinion of the court, had the attorney reviewed the bank statements, she likely would have noticed her secretary's misappropriations. Subsequent secretaries identified problems with the account, but the attorney said she thought they were all incompetent and fired them one after the other. In letters to the court and the bar, the attorney said the secretary had been a good, trusted employee and blamed the ward's bank for negligence. By the time the court discovered the embezzlement from the Merchant Marine, the victim had already died. Four years later, the attorney was finally replaced as representative payee for the other victim's Social Security benefits, SSA data show.

In November 2005, a DC court suspended the attorney for violating professional conduct standards and engaging in misconduct as a result of her repeated failures to cooperate with disciplinary investigations by Bar Counsel. The probate court ordered $97,000 in restitution for the two victims, which was paid by the bond companies that insured the attorney, except for $27,000 still owed to the latter victim's estate. The attorney was not criminally charged but was ordered to comply with Bar Counsel's information requests, to show rehabilitation as well as fitness to practice law, and to reimburse the estates before she could be reinstated to the DC Bar. Bar records show the attorney was still suspended as of June 2010, thus indicating her continued failure to meet the full conditions of reinstatement.

Undercover Tests Reveal That Four States Offering Certification Failed to Adequately Screen Potential Guardians

Many of the guardians in our case studies had a poor track record of managing finances or a criminal background, yet courts failed to identify these warning signs before appointing them to care for vulnerable seniors. Certification programs are intended to provide assurance that a guardian is qualified to fulfill their role or, according to one certifying organization, is “worthy of the responsibility entrusted to him or her.” Thirteen states have a guardian certification program. In 11 states, certification is mandatory for some professional guardians and in two states, certification is optional for professional guardians. However, our investigation found that an individual with a poor credit history or a criminal using a fake identity can easily gain certification in the four states we tested. Utilizing two fictitious identities, we obtained guardianship certification from New York and North Carolina and met guardianship certification requirements for Illinois and Nevada.[20]

One of our fictitious applicants had a credit report that showed $30,000 in outstanding debt, a repossessed car and a credit score of 528. None of the courts or certification organizations in our tests; however, checked the applicant’s credit history. Some states require a guardian to obtain a bond to protect against the misappropriation of a ward’s assets. According to one official, many bonding companies check the applicant’s credit history before the guardian can obtain the bond. However, as our case studies demonstrate, the courts do not always verify that the guardian is bonded. An individual who is financially overextended is at higher risk of engaging in illegal acts to generate funds. In addition, none of the certifying organizations verified our applicants’ fingerprints or discovered that the Social Security number used by one fictitious applicant belonged to a dead person. This creates the risk that people with criminal convictions could steal a Social Security number and conceal their pasts to become certified guardians.[21] The certification organizations we tested also did not verify the academic and professional credentials submitted by our fictitious

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[20] These certification programs were administered by the nonprofit Center for Guardianship Certification (Illinois, Nevada), the nonprofit North Carolina Guardianship Association, and the New York Office of Court Administration.

[21] Certification programs in 6 of the 13 states conduct fingerprint background checks to verify an applicant’s identity.

applicants. Our undercover tests call into question the ability of these state certification programs to effectively prevent criminals and individuals with bad credit from gaining control over the lives and assets of vulnerable seniors. Table 2 summarizes the results of our investigation.

Table 2: Results of Undercover Tests of State Certification Processes

State	Certification steps	Results of undercover tests
Illinois	In Illinois, only politically appointed guardians are required to obtain certification; however, any prospective guardian is eligible to be certified. To obtain certification, guardians must: • Register with the Center for Guardianship Certification • Pass National Certified Guardian Examination	• We applied for guardianship certification from a national association using fictitious names and background information. Certifying organization did not require Social Security numbers or other identifying information. • Certifying organization did not verify the educational or professional credentials we claimed and did not conduct background checks or credit checks on our fictitious applicants. • Our fictitious applicants passed the National Certified Guardian Examination in March 2010. Exam proctor asked to see photo identification, but did not identify our bogus driver's licenses. • Illinois court officials told us they do not generally conduct criminal background checks on guardians.
Nevada	In Nevada, only private professional guardians with 3 or more unrelated wards are required to obtain certification; however, any prospective guardian is eligible to be certified. To obtain certification, guardians must: • Register with the Center for Guardianship Certification • Pass National Certified Guardian Examination	• We applied for guardianship certification from a national association using fictitious names and background information. Certifying organization did not require Social Security numbers or other identifying information. • Certifying organization did not verify the educational or professional credentials we claimed and did not conduct background checks or credit checks on our fictitious applicants. • Our fictitious applicants passed the National Certified Guardian Examination in March 2010. Exam proctor asked to see photo identification, but did not identify our bogus driver's licenses. • Nevada court officials told us they do not generally conduct criminal background checks on guardians.
New York	In New York, all professional guardians must obtain certification prior to appointment. To obtain certification, guardians must: • Register for training • Attend a 1 day training course • Complete an application listing Social Security number, educational and professional background	• We registered for the training course using fictitious names. We were not asked to prove our identity before training began. • In April 2010, we successfully completed the training, which did not include any tests to assess our comprehension of the subject matter. • We submitted a four page form that included Social Security numbers and other identifying information for our fictitious applicants, but New York courts did not conduct background or credit checks on them. • Courts also did not verify fictitious educational and professional credentials of our fictitious applicants. • Both of our fictitious applicants became certified guardians in New York.

State	Certification steps	Results of undercover tests
North Carolina	North Carolina does not require guardians to obtain certification; however, the North Carolina Guardianship Association (NCGA) offers a state certification exam. To obtain certification from NCGA, guardians must: • Register with NCGA • Pass North Carolina Guardianship Competency Exam	• We registered to take the state exam using fake educational and professional backgrounds and North Carolina addresses. • Certifying organization did not require Social Security numbers or other identifying information and did not conduct background checks or credit checks on our fictitious applicants. • Certifying organization did not verify the educational or professional credentials we claimed. • Exam proctor verified the photo identification of one applicant, but did not ask to see photo identification for the other. • We passed the North Carolina state exam in May 2010 and our fictitious applicants received badges attesting to their status as certified guardians 2 weeks later. • Certifying organization officials told us they do not conduct criminal background checks on their guardians.

Source: GAO.

Illinois and Nevada. Illinois and Nevada require certain guardians[22] to obtain certification through the Center for Guardianship Certification (CGC), a private nonprofit that offers national guardian certification. We submitted applications to the organization using two fictitious identities with driver's licenses from Virginia. We also listed fake educational and professional backgrounds for our applicants, which the certifying organization did not verify. For example, one applicant claimed to have a law degree and almost 3 years experience as a guardian, while the other claimed 3 years of experience as a guardian at a nonexistent guardianship firm. Both applicants studied for and passed the National Certified Guardian Examination, which covers guardianship ethical principles and best practices. After the exam, a proctor asked to see the photo identifications of our fictitious applicants, but failed to recognize them as bogus driver's licenses. Once we passed the test, the names of our fictitious applicants were listed on the organization's website as nationally certified guardians. Passing the national exam is the sole requirement to be a certified guardian in Illinois and Nevada. Officials in both states told us that local courts do not conduct background or credit checks, indicating that each of the two fictitious guardians could have been appointed by a court in those states with no further screening.

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[22] Illinois requires politically appointed guardians to obtain certification. Each county in Illinois has a public guardian appointed by the governor to serve wards in that county if appointed by the court. With the exception of Cook County, public guardians are not state employees and may make their living as a guardian or in some other line of work. Nevada requires guardians with three or more unrelated wards to obtain certification.

New York. In New York, applicants for certification are required to attend a 7-hour training course. We registered for the training course using the same two fictitious identities we did for CGC, which the training provider did not verify by requiring participants to present picture identification. The training class covered topics such as legal duties and responsibilities, ethics, and mandatory visits, but did not include a test to determine whether students understood the material. At the end of the course, both of our fictitious applicants received a Certificate of Attendance, enabling them to register with the New York Office of Court Administration (OCA). We registered using fictitious names, addresses, and Social Security numbers of our fictitious applicants, but OCA did not use this information to conduct a criminal background or credit check. In addition, OCA did not verify the personal, educational, and professional backgrounds of our fictitious applicants before listing them on the New York Unified Court System's Web site as certified guardians eligible to be appointed in up to five counties. New York law prohibits an individual who has a prior felony conviction or has been convicted of a misdemeanor in the past 5 years from serving as a guardian. However, court officials told us that courts do not conduct a criminal background check on certified guardians before they are appointed and instead rely on the guardian to disclose their prior convictions.

North Carolina. North Carolina does not require guardians to be certified; however, the North Carolina Guardianship Association (NCGA) offers certification to North Carolina guardians. To obtain certification, applicants must pass the North Carolina state guardianship exam. We applied to NCGA using the same fake educational and professional backgrounds as in the other states and North Carolina addresses. NCGA did not conduct a criminal background or credit check, and did not verify our applicants' professional credentials. We studied for and passed the North Carolina Guardian Competency Exam, which covers guardianship laws and regulations in North Carolina, under the names of our fictitious applicants. Before the start of the exam, the proctor asked to see the photo identification for one of our fictitious applicants, but failed to recognize it as bogus Virginia driver's license. Additionally, the proctor failed to check the photo identification of our second fictitious applicant. Once we passed the test, the names of our fictitious applicants were listed on the NCGA's Web site as certified guardians. They also received identification badges attesting to their status. While North Carolina does not require guardians to be certified, according to NCGA officials, certification is held in high regard by the courts because it helps the guardian prepare for their role. However, NCGA officials told us that they do not perform criminal background checks or credit checks on applicants.

As agreed with your office, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days from the date of this letter. We will then send copies of this report to the Commissioner of Social Security, the Director of the Office of Personnel Management, and the Secretary of Veterans Affairs. In addition, the report is available at no charge on the GAO Web site at http://www.gao.gov.

Please contact me at (202) 512-6722 or kutzg@gao.gov if you have any questions concerning this report. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report.

Sincerely yours,

Gregory D. Kutz

Gregory D. Kutz
Managing Director
Forensic Audits and Special Investigations

Appendix I: Scope and Methodology

To verify whether allegations of guardian abuse, neglect, or exploitation are widespread, we interviewed state investigators, attorneys, advocates for senior citizens, and family groups; reviewed past cases of abuse disclosed publicly on databases such as WestLaw, Public Access to Court Electronic Records (PACER) and LexisNexis; reviewed federal and state court documents related to criminal and civil litigation; and sought leads from state investigators, attorneys, and senior citizen advocacy groups. Except for the case studies discussed below, we did not attempt to verify the facts related to the allegations we reviewed nor can we use information gathered from the case studies to project to or characterize all court appointed guardianships.

To select our case studies, we searched for instances of guardianship abuse in which there was a criminal conviction or finding of civil or administrative liability in the last 15 years, though in some cases the abuse began much earlier. As part of the selection process, we focused on cases involving professional guardians, guardianship agencies caring for multiple incapacitated people or egregious cases of abuse by family members or other individuals serving as guardians. In addition, we considered factors such as geographic location, number of victims affected and whether the financial abuse involved federal funds. Ultimately, we selected 20 cases from 15 different states and the District of Columbia for further review. To the extent possible, we conducted interviews with related parties, including state and local court officials, victims, family members of victims, advocacy groups, and professional guardian certification organizations. Further, where applicable, we reviewed police reports, court investigations, financial records, and professional guardian disciplinary files. We also conducted searches to determine whether the abusive guardians in our case studies had previous criminal histories or financial problems, and we contacted probate courts to determine whether they are still serving as guardians today. In our case studies, we identified vulnerabilities in court oversight of guardianships, but we did not examine whether state laws and regulations have changed since the abuse occurred. To determine whether these guardians continued to receive federal benefits on behalf of their victims or others, we analyzed databases and case files from the Social Security Administration (SSA), Department of Veterans Affairs (VA), and the Office Performance Management (OPM). Further, we conducted interviews with the SSA, VA and OPM officials responsible for oversight of representative payees to gather information about the agencies' policies and procedures for appointing, overseeing and disciplining representative payees.

To test the guardianship certification process, we identified states that have certification programs or require their guardians to obtain certification. Once we identified these states, we reviewed the current state statutes and legislation and the requirements necessary for obtaining certification. Using counterfeit documentation and fictitious educational and professional histories, GAO investigators created two fictitious identities. One identity used the Social Security number of a deceased individual and the other had a credit history showing thousands of dollars of debt and a very low credit score. Using these two identities, we applied to take the guardianship competency exams required for Illinois, Nevada, and North Carolina and guardianship training in New York in order to complete the certification requirements in these four states. We selected these four states based on potential vulnerabilities in the states' background checks and our ability to complete certification requirements within the timeframe of our investigation. For example, we selected states that did not conduct background checks with fingerprints, which provide more assurance of an applicant's identity than background checks without fingerprints. In addition, a fingerprint background check could potentially have identified our investigators. We did not test states in which applicants were required to spend multiple days attending training classes or states that had no scheduled examinations for guardians between December 2009 and May 2010. To meet the different states' requirements for certification, we took the National Certified Guardian Exam, a state-based certification exam, and completed a one-day guardianship training. We posed as family members and sent emails to court officials to determine what background or credit checks courts conduct on applicants for certification.

Appendix II: Summary of State Laws Related to Guardianships

The following list provides an overview of specific issues involving state laws in the 15 states and the District of Columbia, in which our case studies occurred.

Alabama

- Provides - “The court shall exercise [its’] authority … so as to encourage the development of maximum self-reliance and independence of the incapacitated person…” Ala. Code § 26-2A-105, (2009).
- Provides - guardian required to report the condition of the ward and the ward’s estate as ordered by the court on petition of any person interested in the ward’s welfare. Ala. Code § 26-2A-78(b) (5), (2009).

Alaska

- Provides - that a full guardian of an incapacitated person has the same powers and duties respecting the ward that a parent has respecting an unemancipated minor child. Alaska Stat. § 13.26.150(c), (2009).
- Provides - guardian is to file a report with the court 90 days after appointment and then annually. The report is to include the wards present mental and physical condition, changes in capacity, services being provided and any significant actions taken by the guardian as well as a financial accounting. Guardian is to file an additional report should the court order it, the guardian is removed or terminated or there is a significant change in the wards condition. Alaska Stat. §§ 13.26.117 & 13.26.118, (2009).
- Provides - incapacitated person retains all rights except those expressly limited by court order. Alaska Stat. §§ 13.26.090 & 13.26.150(c) (4), (2009).

Arizona

- Provides -“In exercising its appointment authority … the court shall encourage the development of maximum self-reliance of the incapacitated person.” Ariz. Rev. Stat. Ann. § 14-5304, (2009).
- Provides - the guardian is to submit a written report to the court annually that addresses any major changes in the wards physical or mental condition, a summary of the services provided by the guardian and the date the ward was last seen by a doctor or nurse practitioner. Ariz. Rev. Stat. Ann. § 14.5315, (2009).

California

- Provides - a distinction between guardians and conservatorships, generally limiting guardians to unmarried minors. As to conservatorships California provides “A limited conservatorship …shall be designed to encourage the development of maximum self-reliance and independence of the individual...” Cal. Civ. Prac. & Trust Proc. § 25:14, (2009) and Cal. Prob. Code § 1801(d), (2009).

	• Provides - court shall review six months after appointment of conservator and also one year after appointment, thereafter annually. Cal. Prob. Code. § 1850(a) (1) & (2), (2009). • Provides - conservator recommends for or against disqualification from voting. Cal. Welf. & Inst. Code § 5357(c) (2009).
Colorado	• Provides - “The court, whenever feasible, shall grant to a guardian only those powers necessitated by the ward’s limitations and demonstrated needs and make appointive and other orders that will encourage the development of the ward’s maximum self-reliance and independence.” Colo. Rev. Stat. Ann. § 15-14-311(b)(2), (2009). • Provides - within 60 days after appointment guardian is to report to the court in writing on the condition of the ward, guardian’s personal care plan for the ward, accounting of money and assets in guardian’s control. Thereafter guardian is to report annually. Colo. Rev. Stat. Ann. § 15-14-317, (2009).
Connecticut	• Provides - “The court may assign to a limited guardian the custody of the ward for the purpose of exercising any, but not all, of the following limited duties and powers, in order to assist the ward in achieving self-reliance: (1) To assure and consent to a place of abode outside the natural family home, (2) to consent to specifically designed educational, vocational or behavioral programs, (3) to consent to the release of clinical records and photographs, (4) to assure and consent to routine, elective and emergency medical and dental care, and (5) other specific limited powers to assure and consent to services necessary to develop or regain to the maximum extent possible the ward’s capacity to meet essential requirements.” Conn. Gen. Stat. Ann. § 45a-677(d), (2009). • Provides – such annual reports shall include significant changes in the capacity of the ward, services provided to the ward, significant actions taken by the guardian, significant problems encountered by the guardian and whether such guardianship should continue. Conn. Gen. Stat. Ann. § 45a-677(f)&(g), (2009). • Provides - no patient hospitalized or treated in a public or private facility for psychiatric disabilities shall be deprived the right to vote unless such patient has been declared incapable. Conn. Gen. Stat. Ann. § 17a-541, (2009). A guardian or conservator may file a petition to determine such individual’s competency to vote. Conn. Gen. Stat. Ann. § 45a-703, (2009).
District of Columbia	• Provides - “The court shall …encourage the development of maximum self –reliance and independence of the incapacitated individual.” D.C. Code Ann. § 21-2044, (2009).

	• Provides - guardian to report in writing to the court semi-annually on the condition of the ward and of the ward's estate. D.C. Code Ann. § 21.2047(a)(5), (2009).
Iowa	• The law is silent on how much self-reliance to place with the ward. • Provides - guardian to file initial report within 60 days of appointment thereafter annually. Report to include condition of the ward, activities, living arrangements, services, visits, etc. Iowa Code Ann. § 633.669, (2009). • Provides - if court appoints a guardian based on mental incapacity court shall make separate determination as to ward's competency to vote. Iowa Code Ann. § 633.556, (2009).
Kansas	• Provides - "A guardian shall exercise authority only as necessitated by the ward's limitations." Kan. Stat. Ann. § 59-3075, (2009). • Provides - guardian to file written report annually in such form as the court may require. Kan. Stat. Ann. § 59.3083, (2009).
Missouri	• Provides - The court "shall design the guardianship so as to encourage the development of maximum self-reliance and independence in the individual." Mo. Ann. Stat. § 475.080, (2009). • Provides - guardian to file report annually addressing number of contacts with the ward, date last seen by a doctor and the purpose, any major changes in the physical or mental condition of the ward and the need for continuation of guardianship. Mo. Ann. Stat. § 475.082, (2009). • Provides – no person who has a guardian of his estate or person by reason of mental incapacity shall be entitled to vote. Mo. Const. art.VIII, § 2.
New Hampshire	• Provides - "No person shall be deemed incompetent to manage his affairs, to contract, to hold professional, occupational, or motor vehicle driver's licenses, to marry or to obtain a divorce, to vote, to make a will or to exercise any other civil right solely by reason of that person's admission to the mental health services system." N.H. Rev. Stat. Ann. § 135-C:56, (2009). • Provides - guardian to file an annual report with the court within 90 days after the anniversary date of the guardian's appointment addressing medical condition, major hospitalizations, care and treatment, services, and living conditions of ward and need for continuation of guardianship. N.H. Rev. Stat. Ann. § 464-A:35, (2009). • Provides – no deprivations "except as provided by law," which includes the right to vote. N.H. Rev. Stat. Ann. §135-C:56, (2009).
New York	• Provides - "Any guardian appointed under this article shall be granted only those powers which are necessary to provide for personal needs and/or

	property management of the incapacitated person in such a manner as appropriate to the individual and which shall constitute the least restrictive form of intervention…" N.Y. Mental Hyg. Law § 81.02, ((2009). • Provides - guardian to file initial report within 90 days of appointment by the court, thereafter annually in the month of May. The report shall be in a form prescribed by the court and shall include any major changes in the physical or mental condition of the ward, statement by a physician, psychologist, nurse clinician, or social worker or other person who last examined the ward, resume of activities and need to continue. N.Y. Mental Hyg. Law §§ 81.30 & 81.31, (2009).
North Carolina	• Provides - "To the maximum extent of his capabilities, an incompetent person should be permitted to participate as fully as possible in all decisions that will affect him." N.C. Gen. Stat. 35A-1201. • Provides - "If the clerk determines that the nature and extent of the ward's capacity justifies ordering a limited guardianship, the clerk may do so." N.C. Gen. Stat. 35A-1212. • Provides that the guardian shall file an initial status report within 6 months after being appointed followed by a second status report within one year, thereafter annually. N.C. Gen. Stat. 35A-1242.
Oklahoma	• Provides - "[T]he court shall … encourage the development of maximum self-reliance and independence of the incapacitated or partially incapacitated person…".Okla. Stat. Ann. tit. 30, § 1-103, (2009). • Provides - guardian to file at least annually and address significant changes in the capacity of the ward, services provided, significant actions taken by guardian, problems encountered, and should appointment be continued. Okla. Stat. Ann. tit. 30, §§ 4-303, 4-305 & 4-306, (2009). • Provides – person adjudged incapacitated shall be ineligible to register to vote. Okla. Stat. Ann. tit. 26, § 4-101, (2009).
Texas	• Provides - "[T]he court shall design the guardianship to encourage the development or maintenance of maximum self-reliance and independence in the incapacitated person." Tex. Prob. Code Ann. § 602, (2009). • Provides - guardian to file written report annually that addresses living arrangements, guardian visits, physical and mental health, unmet needs of the ward. Texas Prob. Code Ann. § 743, (2009).
Washington	• Provides - "The legislature recognizes that people with incapacities have unique abilities and needs, and that some people with incapacities cannot exercise their rights or provide for their basic needs without the help of a guardian. However, their liberty and autonomy should be restricted

through the guardianship process only to the minimum extent necessary to adequately provide for their own health or safety, or to adequately manage their financial affairs." Wash. Rev. Code Ann. § 11.88.005, (2009).

- Provides - guardian to file report with court annually that addresses ward's medical and mental status, activities, changes in functional abilities, and identifies professionals who have assisted. Wash. Rev. Code Ann. § 11.92.043, (2009).
- Provides - assignment of guardianship for incapacitated person does not result in loss of voting rights unless court determines person incompetent for purposes of voting. Wash. Rev. Code Ann. 11.88.010(5), (2009).

Appendix III: Additional Cases of Abuse, Neglect, and Financial Exploitation by Guardians

Table 3 provides a summary of ten additional case studies in which guardians abused, neglected or financially exploited their victims.

Table 3: Additional Cases of Abuse, Neglect and Financial Exploitation by Guardians

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
11	80 year old man	February 1998	Attorney / Oklahoma	• An attorney took $37,000 from the victim's account, using some of the funds to buy into a get-rich-quick scheme with a bank in Nigeria. • According to the Oklahoma Supreme Court ruling, the attorney shared a law practice with his father, who had become incapacitated. • The attorney had borrowed money to pay his debts. When he heard about a bank in Nigeria promising $28 million for assistance setting up a corporation, he believed it was the solution to his financial problems. • When the Nigerian scammers asked him to send money, the attorney took his incapacitated father to the bank and had him withdraw money from the account of one of his wards. The attorney sent the funds to Nigeria. • The attorney resigned from the Oklahoma Bar in 1998 after it was discovered that he taken funds from a guardianship account for his own use. • In 2007, he applied for reinstatement to the Bar, claiming to have been rehabilitated through an organization he founded to help lawyers with character problems. He was readmitted and is now free to practice law and accept guardianship cases in Oklahoma.

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
12	71 year old woman with Alzheimer's	August 1996	Attorney / Oklahoma	• An attorney converted $175,000 from an elderly woman's estate, but later testified that he had caused her no harm. • According to relatives, the victim had no children and lived frugally all her life. She asked a partner in a local law firm to be her conservator because she did not trust her brother, who had a gambling problem, to protect her assets. • An audit found that the attorney converted $44,600 for his income taxes, $39,000 in checks payable to himself and $1,600 for his international phone bills. • The audit also showed monthly payments of between $225 and $630 to the victim's brother and his wife for 7 years. Relatives said the attorney allowed the brother to move into the victim's house and paid his bills out of the victim's estate, even though the victim had sought a conservator to protect her estate from her brother. • Court records show that the attorney did not file a single annual accounting with the courts in ten years as conservator, and his final accounting omitted numerous unauthorized payments to himself. He admitted to the woman's relatives that he had paid himself whatever he felt he deserved in conservator's fees. • In 1996, the attorney received a 5 year deferred sentence for embezzlement by a trustee, an unusually light sentence for such a large loss, according to the prosecutor. • The attorney only paid $7,000 in restitution himself; his father, and later his fiancée, paid a total of $78,000 on his behalf. The remaining $90,000 identified by the audit had not been repaid by 2007, when he applied for reinstatement to the Bar. • The guardian's petition for reinstatement to the Bar was denied in October 2007. The court disagreed with his contention that the victim never suffered because "she always was provided for," finding that the attorney had violated her trust "when it mattered most."

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
13	84 year old WWII veteran	April 2004	Attorney / North Carolina	• A federal indictment accused the guardian of embezzling $332,730 over a 14 year period, during which he was allowed to continue serving as a guardian despite clear indicators of fraud. • The victim had been a ward of the court since his discharge from the military in 1946, according to the indictment. The guardian was the former president of the county bar association • The guardian wrote checks to himself from the victim's estate and cashed a CD worth $163,000 for his personal benefit, according to the indictment. He also filed false accountings with the court and the VA to cover up his misappropriations. For example, he certified that the victim's bank balance was $356,142, when in fact the account had been depleted to $21,792. • The guardian also deposited the victim's funds into guardianship accounts for other wards to disguise his misappropriations from these individuals, according to the federal indictment. • Despite two suspensions of VA benefits for failure to file accountings, he was allowed to continue serving as the victim's guardian and representative payee. • After pleading guilty, the guardian served a 51 month prison sentence with 3 years parole according to his federal sentencing. As of June 2010, he had paid $3,112 of the $467,000 in court ordered restitution.

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
14	81 year old man, mentally incapacitated	May 2008	Court appointed guardian / Texas	• The guardian, who was the victim's son, admitted to misappropriating some of his father's veterans' benefits for his own benefit, which a federal prosecutor contended was more than $300,000. • For example, according to the federal prosecutor, within a two-year period, the guardian used his father's estate to write himself $32,130 in "business loans" and $201,483 in promissory notes. He used the proceeds of these supposed loans for his own personal benefit. • In 2006, the local county court that appointed the guardian filed a court motion seeking to remove the guardian for failing to reimburse the funds that he took from the victim's estate. The motion was later transferred to a local district court, which ultimately dismissed this motion in 2008 for lack of prosecution. As of June 2010, neither the county nor district courts have formally terminated the guardian. • In 2008, a federal court sentenced the guardian to 2 years and 6 months in federal prison, 3 years supervision upon his release, and ordered him to pay more than $272,800 in restitution. As of June 2010, the guardian had only paid back $17,689 in restitution, according to a federal court, and still owes $255,112 in restitution.

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
15	90 year old woman with dementia	February 2000	Licensed healthcare practitioner / Arizona	• A niece misappropriated $235,561 from her aunt's estate, according to an Arizona court. Although a plea agreement prohibited her from managing the victim's finances as a guardian in Arizona, the agreement stated that she would be allowed to continue to manage the victim's well-being as a guardian in California. • An Arizona court found that within a three-year period, the niece took hundreds of thousands of dollars from aunt's estate to give loans and pay for unauthorized gifts to her children. • The niece's attorney documented these transactions in two annual accountings that were submitted to the court, but the attorney never attempted to stop her or notify the court about her improprieties. • One annual accounting filed with the Arizona court documents that she managed $18,000 of the victim's SSA benefits in just one year. According to SSA data, the guardian was terminated as the victim's payee, but not for misuse, indicating that the abuse was not communicated to the SSA. • The niece was given 3 years probation and ordered to make full restitution. However, she only repaid $45,561 and her insurance company paid the remaining $190,000. • A state prosecutor stated that the victim moved to California, where she had no other relatives to care for her. Because of this, the niece's plea agreement stated that she would be permitted to serve as the victim's guardian in California, provided she had no authority over the victim's finances there.

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
16	74 year old mentally incapacitated man	October 2007	Victim's son / New Hampshire	• The victim's son misappropriated $137,206 from his father, fled to American Samoa and escaped punishment for his actions. • Despite criminal charges of marijuana possession and disobeying a police officer, he was allowed to continue as guardian. • After the guardian quit his job and divorced his wife, he sought court permission to relocate his father to American Samoa and borrow $90,000 from the estate to finance a new business and marry his Samoan girlfriend, according to a court judgment and interviews. The court denied both requests. • The court removed him as guardian and ordered him to file a final accounting. Instead, the guardian fled the country with thousands from his father's estate. The bond company repaid the estate and obtained a default judgment against the guardian totaling $203,510. • According to the bond company's attorney, the guardian never faced criminal charges. Investigators hired by the company said they tracked the guardian to Pago Pago, American Samoa where he draws Social Security disability due to an injury sustained from falling out of a banana tree. In July 2009, a Samoan court ordered the guardian to pay back the bond company in $300 monthly payments. As of June 2010, the guardian has paid $3,300.
17	89 year old incapacitated woman	July 1995	Court appointed guardian / Alabama	• An Alabama court found that a guardian's negligence enabled her attorney to embezzle almost $53,000 from the ward's estate. • The guardian testified that her attorney directed her to use a cashier's check to withdraw all the funds in the victim's account, approximately $53,000, and endorse the check over to him. He claimed that he would deposit the sum into an account with a higher interest rate. • After the attorney's death, the guardian said that she discovered that he had taken the funds for his own personal use. • In July 1995, the Alabama court held the guardian liable for the attorney's actions because she never demanded to see the attorney's bank statements, but instead believed that the attorney was taking care of all the guardianship duties for which she was responsible. • As a result of the guardian's negligence, the guardian's surety paid $61,472 in restitution, and the guardian paid nothing.

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
18	80 year old woman with dementia	September 2008	Victim's niece / Arizona	• A niece misappropriated more than $150,000 from her elderly aunt's estate. • The niece was appointed as guardian less than 5 years after filing for Chapter 13 bankruptcy twice and being arrested numerous times for and pleading guilty to issuing numerous bad checks. Further, the court appointed her despite the victim's attorney's objection due to his belief that the guardian was not close to her aunt. • Further, the guardian received court permission to sell the victim's ranch to pay for her medical bills, provided that she would obtain a bond to protect the victim's estate. The guardian, however, was unable to obtain the required bond due to poor credit and a prior bankruptcy, information she had disclosed to the bonding company before. • After the sale, the guardian misappropriated $150,000 from the victim's estate, according to an Arizona court, leaving the victim in danger of losing her housing and medicine, according to her court-appointed attorney. • SSA data shows that the niece served as the aunt's representative payee, giving her access to the victim's Social Security benefits. In 2005, an Arizona court held the niece's insurance company liable for her actions. • The court ordered $198,721 in restitution against the guardian, for which the surety was held liable and paid. In addition, the court ordered that "treble damages" be awarded because the guardian breached her fiduciary duties to the victim, thereby increasing the total restitution amount to $596,165, amounting to three times the amount for which the surety was held liable. As of May 2010, the guardian has failed to pay the remaining $397,443 in restitution that is due.

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
19	92 year old victim, with significant memory loss and limited judgment	May 2009	Attorney / New York	• A New York attorney manipulated his elderly and mentally incapacitated client into revoking her trust in order to generate nearly $74,000 in excessive fees for himself. • The New York Supreme Court found that the guardian convinced the victim to appoint him as her trustee, power of attorney and health care proxy. Just two months later, her doctor found that she had limited judgment due to memory loss and was vulnerable to financial exploitation. • The attorney had the victim to revoke her trust, generating $74,000 in excessive commissions and fees for himself, and convinced the court that the victim had revoked the trust voluntarily, despite the doctor's diagnosis that she had impaired judgment. • The court recommended that it could either appoint the attorney to serve as the victim's guardian, or allow the attorney to continue to serve as the victim's trustee instead. However, in the end, it allowed both to occur, appointing the attorney to serve as the victim's guardian, and permitting the revocable trust to continue. • Then, the attorney had the victim to revoke her trust, generating $74,000 in excessive commissions and fees for himself, and convinced the court that the victim had revoked the trust voluntarily, despite the doctor's diagnosis that she had impaired judgment. • He later sought to terminate the guardianship, requesting more than $27,000 in additional guardianship commissions and legal fees, which the court denied as excessive. In May 2009, the court denied these fees because he had already "collected nearly every conceivable fee" from the woman's estate. • According to the guardian's final accounting, the SSA, unlike the court that appointed the guardian, was not made aware of the victim's death before it had already paid hundreds of dollars in Social Security benefits to the guardian, months after the victim died.

Case	Victim	Date of conviction, settlement, plea agreement, or finding of liability	Guardian / state	Case details
20	15 elderly victims	December 2001	Professional guardian agency / Washington	• A professional guardianship agency responsible for 59 incapacitated wards was found to have committed “persistent and repeated” guardianship reporting violations. • A court appointed guardian ad litem found that the professional guardian agency failed to notify the court that 7 of its wards had passed away, and in one of these cases the court was not notified until 2 years after the ward’s death. • In addition, the agency had no system in place to remind them when mandatory annual accountings were due and instead waited for an overdue notice from the court to submit reports. • The agency was found to be non-compliant in 15 cases. The guardian ad litem recommended the agency to continue to limit the number of wards under its care and regain compliance within 30 days. • The agency came into compliance and Certified Professional Guardian Board records indicate that the guardian agency continues to operate today with 42 wards. • The agency currently acts as representative payee for 28 wards.

Source: GAO.

Appendix IV: Summary of State Certification Requirements

Table 4 below provides a summary of the state certification requirements.

Table 4: Summary of State Certification Requirements

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
Alaska	• License • Private Professional Guardian / Conservator	• Yes • No	• National exam[a] • No	Professional Guardians / Conservators must: • Be 21 years of age • Have two or more years of professional client casework experience or a least an associate degree in human services, social work, psychology, sociology, gerontology, special education; or has six months' employment experience in a position involving financial management, or has at least an associate's degree in accounting • Must be certified by the Center for Guardianship Certification

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
Arizona	• License • Fiduciaries (Guardians and Conservators)	• Yes • Yes	• State exam • Must attend and complete a session on the roles and responsibilities of the certified professional fiduciary	Fiduciaries must: • Be 21 years of age • Be US citizens • Not be a convicted felon • Not have been civilly liable in an action that involved fraud, misrepresentation, material omission, misappropriation, theft or conversion; • Must possess one of the following: a high school degree or GED equivalent and 3 years experience as a guardian, conservator or personal representative; a bachelor degree and 1 yr of experience as a guardian, conservator, or personal representative, a high school degree or GED equivalent and a certificate of completion from a paralegal program and 2 years experience as a guardian, conservator, or personal representative; a high school degree or GED equivalent and a certificate of completion from an accredited educational program designed to qualify a person as a fiduciary and 2 years work experience as a guardian, conservator, or personal representative; a juris doctorate degree and currently admitted to practice law, active and in good standing; a high school degree or GED equivalent with evidence of an appointment as a foreign fiduciary and 3 years experience as a guardian, conservator, or personal representative; a high school degree or GED equivalent and certified as a registered master guardian by the National Guardianship Association

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
California	• License • Fiduciaries (Guardians and Conservators)	• Yes • Yes	• State exam • Must complete 30 hours of prelicensing education courses provided by an educational program.	To become licensed, fiduciaries must: • Be at least 21 years of age • Be a US citizen, or legally admitted to the US • Not have been convicted of a crime substantially related the qualifications, functions, or duties of a fiduciary • Not have engage in fraud or deceit in applying for license • Not have engaged in dishonesty, fraud, or gross negligence in performing the functions or duties of a professional fiduciary • Have not been removed as a professional fiduciary by a court for breach of trust • Agree to adhere to the Professional Fiduciaries Code of Ethics and to all statutes and regulations • Must possess at least one of the following; a baccalaureate degree from a college or university accredited by a nationally recognized accrediting body or a higher level of education; an associate's degree from a college or university accredited by a nationally recognized accrediting body or a higher level of education and at least three years experience working as a professional fiduciary or working with substantive fiduciary responsibilities; or at least 5 years of experience working as a professional fiduciary or working with substantive fiduciary responsibilities

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
Florida	• Registration • Professional Guardianship	• Yes • Yes	• State exam • Must obtain 40 hours of instruction and training within 1 year of appointment	To become licensed, professional guardians must: • Be competent • Be a resident of Florida • Not have been convicted of a felony, judicially determined to have committed abuse, abandonment, or neglect against a child. • Must pass a Florida Professional Guardian competency exam • Must obtain 40 hours of instruction and training within 1 year of appointment • Must register with Statewide Public Guardianship Office within 30 days of bond anniversary date • Must show proof of a $50,000 blanket bond
Illinois	• Certification • Politically Appointed Guardians	• No • No	• National exam • No	Must be appointed by the Governor
Nevada	• Certification • Professional Guardians	• No • No	• National exam • No	A professional guardian must: • Be competent • Must be a resident of Nevada • Have not been convicted of a felony, unless the court determines that such conviction should not disqualify the person from serving as the guardian of the ward • Have not been judicially determined to have committed abuse, neglect or exploitation of a child, spouse, parent or other adult • Have not been suspended for misconduct or disbarred from the practice or law; the practice of accounting, or any other professional which involves the management or sale of money, investments, securities or real property and requires licensure from the state • Must have three or more unrelated wards

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
New Hampshire	• Certification • Professional Guardians	• No[b] • No	• National exam • No	A professional guardian must: • Be a national certified guardian or national master guardian with the Center for Guardianship Certification (CGC) and maintain this status • Be a resident of New Hampshire or have a resident agent • Adhere to the Standards of Practice published by the National Guardianship Association (NGA) • Adhere to the Model Code of Ethics published by NGA • Provide a bond that is acceptable to the court • Carry malpractice insurance and provide proof of insurance on an annual basis to the administrative judge of the probate court • Comply with all requirements of applicable statutes, regulations, and court rules and orders • Disclose to the court any conflicts of interest upon discovery of such conflict • Provide necessary and appropriate quality guardianship services as dictated by ward's needs • Certify that the guardian will maintain generally accepted standards of accounting on all funds of all wards in their custody or their control • Adhere to billing and annual report requirements • Consult with a national certified guardian or national master guardian that has been approved by Probate Court Administrative Judge for a least the first two cases • Be approved by Probate Court Administrative Judge • Be subject to removal from the list of approved guardians for non-compliance

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
New York	• Certification • Professional and Nonprofessional Guardians	• No • No	• No exam • Must complete a one-day 6 hour training course.	To apply the guardian must: • Be 18 years of age • Not have a prior felony conviction, or have been convicted of a misdemeanor within the last 5 years • Not be a an active or former judge of the Unified Court System of the State of new York, or a spouse, sibling, parent or child of such judge within two years from the date that the judge left judicial office • Not be an employee of Unified Court System of the State of New York or a spouse, sibling, parent, or child of an employee who hold a position of salary grade JG24 or equivalent • Not be a person who has served as a campaign chair, coordinator, manager, treasurer or finance chair for a candidate for judicial office, or the spouse, sibling, parent or child of that person, or anyone associated with the law firm of that person for a period of two years following the judicial election • Not be an attorney currently disbarred or suspended from the practice of law
North Carolina	• Certification • N/A[c]	• No • No	• State exam • No	To apply the guardian must: • Disclose misdemeanor or felony convictions • Disclose actions of fraud, misrepresentation, material omission, misappropriation, theft, or conversion where the guardian has been found civilly or criminally liable • Must have at least 5 years of guardianship services experience

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
Oregon	• Certification • N/A[d]	• No • No	• National and State exam • Must complete 32 hours of education/training with at least 3 hours in the areas of legal, ethics, health/medical, social and financial services.	A professional guardian / conservator must: • Be 21 years of age • Have a Bachelor's degree from an accredited educational institution with a minimum of 1 year experience as a fiduciary or court-appointed trustee with 2 or more clients that are unrelated to you or be the person primarily responsible for fiduciary duties under the direction of an Oregon Certified Professional Fiduciary or have an Associate's degree from an accredited educational institution with 3 years relevant experience in the field of legal, health, social, or financial services with 1 year experience as a fiduciary or court-appointed trustee with 2 or more clients that are unrelated to you or be the person primarily responsible for fiduciary duties under the direction of an Oregon Certified Professional Fiduciary • Must not have been convicted, plead guilty, or no contest to a felony • Must not have been found civilly or criminally liable for an action of fraud, moral turpitude, misrepresentation, material omission, misappropriation, theft, or conversion • Must not have been relieved of responsibilities as a guardian or conservator • Must not have been found liable of subrogation action by an insurance or bonding agent • Must be bonded in accordance with state statutes and local practice • Must review and understand the Oregon Revised statutes (ORS), the GCA of Oregon Standards of Practice, The NGA Standards of Practice, and NGA Code of Ethics

State	Type of program offered / requirements apply to	Fingerprint background check / credit checks	Exam / training requirements	Other requirements
Texas	• Certification • Professional guardians and public guardians	• Yes • No	• State exam • No[e]	A guardian must: • Be 21 years of age • Must have a high school diploma or GED equivalent • Must have two years of relevant experience related to guardianship or have at least a four-year degree in a field related to guardianship.
Utah	• Certification • Specialized Care Professional	• No • No	• National exam • No	A specialized care professional must: • Be certified or designated as a provider of guardianship services by a nationally recognized guardianship accrediting organization • Licensed by or registered with the Division of Occupational and Professional Licensing as a health care provider including, but not limited to, a registered nurse, a social service worker, certified social worker, or clinical social worker, a marriage and family therapist, a physician, or a psychologist, or has been approved by the court as one with specialized training and experience in the care of incapacitated persons
Washington	• Certification • Professional Guardians	• Yes • No	• No exam • Must complete a 6 month program that includes 56 hours of classroom sessions and 34 hours of online distance learning	A professional guardian must: • Be 18 years of age • Have an Associate's degree from an accredited institution and have 4 years experience working in a position relevant to guardianship services or have a Bachelor's degree from an accredited institution and two years experience working in a position relevant to guardianship services. • Be competent • Have not been convicted of a felony or misdemeanor involving moral turpitude • A resident of Washington

Source: GAO.

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[a] Center for Guardianship Certification requires applicants to be at least 21 years of age, possess a high school degree or GED equivalent; have one year of relevant work experience related to guardianship or the following educational requirements: (1) a degree in a field related to guardianship, or (2) completion of a course curriculum or specifically related to guardianship approved by the CGC; not been convicted on a felony; not been civilly liable in an action that involved fraud, misrepresentation, material omission, misappropriation, moral turpitude, theft, or conversion; not been relieved of responsibilities as a guardian by a court, employer, or client for actions involving fraud, misrepresentation, material omission, misappropriation, theft, or conversion; must be bonded in accordance with state statutes and local practice; and not found liable in a subrogation action by an insurance or bonding agent.

[b] New Hampshire conducts a criminal background check on professional guardians, but does not include fingerprints.

[c] The North Carolina Guardianship Association offers guardianship certification; however, certification is optional and is not required by law.

[d] The Oregon Guardian / Conservator Association, through the Center for Guardianship Certification, offers guardianship certification; however, certification is optional and is not required by law.

[e] Certified guardians must complete 12 hours of continuing education during the two-year certification period. Provisionally certified guardians are bound by the same continuing education rules as certified guardians

(192329)

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Report to the Chairman, Special Committee on Aging, U.S. Senate

July 2004

GUARDIANSHIPS

Collaboration Needed to Protect Incapacitated Elderly People

Correction made on 7/22/04 to p. 4, line 13, revised to read "Few courts provide a basis for estimating how many incapacitated elderly people have guardians".

G A O

Accountability ★ Integrity ★ Reliability

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Accountability•Integrity•Reliability
Highlights

Highlights of GAO-04-655, a report to the Chairman, Special Committee on Aging, U.S. Senate

July 2004

GUARDIANSHIPS

Collaboration Needed to Protect Incapacitated Elderly People

Why GAO Did This Study

As people age, some become incapable of managing their personal and financial affairs. To protect these people, state laws provide for court appointment of guardians to act on their behalf. In many cases federal programs provide these incapacitated people financial benefits. GAO was asked to examine: (1) what state courts do to ensure that guardians fulfill their responsibilities, (2) what guardianship programs recognized as exemplary do to ensure that guardians fulfill their responsibilities, and (3) how state courts and federal agencies work together to protect incapacitated elderly people.

What GAO Recommends

GAO recommends that (1) the Social Security Administration lead an interagency/state court group to study options for prompt and systematic information sharing for the protection of incapacitated elderly people and that (2) the Department of Health and Human Services provide support to states and national organizations involved in guardianship programs in efforts to compile national data on the incidence of abuse with and without the assignment of a guardian or representative payee and to review state policies for interstate transfer and recognition of guardianship appointments. HHS, Office of Personnel Management (OPM), and VA agreed with the recommendations. SSA disagreed, citing privacy issues.

www.gao.gov/cgi-bin/getrpt?GAO-04-655.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Barbara Bovbjerg at (202) 512-7215 or bovbjergb@gao.gov.

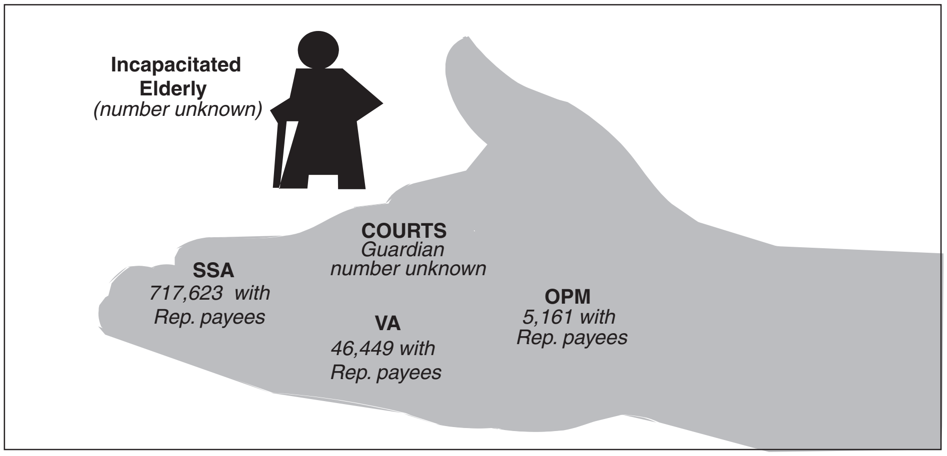
What GAO Found

All states have laws requiring courts to oversee guardianships, but court implementation varies. Most require guardians to submit periodic reports, but do not specify court review of these reports. Interstate jurisdictional issues sometimes arise when states do not recognize guardianships originating in other states. Most courts responding to our survey did not track the number of active guardianships, and few indicated the number of incapacitated elderly people under guardianship.

Four courts recognized by members of the National Guardianship Network as having exemplary guardianship programs devote staff to strong programs for guardianship training and oversight. Three of these courts offer training to guardians even though state law does not require it. Three also have programs in which volunteers or social work student interns visit people under guardianship and report on their condition.

Although state courts and federal agencies are responsible for protecting many of the same incapacitated elderly people, they generally work together only on a case-by-case basis. Some courts send notices of guardianship to the Department of Veterans Affairs and the Social Security Administration, but generally coordination among federal agencies and courts is not systematic. Federal agencies and courts do not systematically notify other agencies or courts when they identify someone as incapacitated, or when they discover that a guardian or a representative payee is abusing the incapacitated person. This lack of coordination may leave incapacitated people without the protection of responsible guardians and representative payees.

Courts and Federal Agencies Have Responsibilities for Protecting Incapacitated Elderly People



Source: SSA, VA, and OPM data and GAO analysis.

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Abbreviations

HHS	Department of Health and Human Services
OPM	Office of Personnel Management
SSA	Social Security Administration
VA	Department of Veterans Affairs

GAO
Accountability * Integrity * Reliability

United States General Accounting Office
Washington, DC 20548

July 13, 2004

The Honorable Larry E. Craig
Chairman
Special Committee on Aging
United States Senate

Dear Mr. Chairman:

As people age, some of them become incapable of caring for themselves and must rely on a guardian—a person or entity appointed to make decisions for them. In the United States, the number of people requiring a guardian is expected to increase considerably in the years ahead. The number of elderly people (those aged 65 and older) is expected to increase substantially over the next several decades, and the number of people aged 85 and older is expected to triple by 2040 to 15 million. The Census Bureau estimates that about one-quarter of the people in this older age group has Alzheimer's disease, which may lead to dementia that is severe enough that people become incapable of caring for themselves.[1] Generally, adults are identified as incapacitated when they become physically or mentally incapable of making or communicating important decisions, such as those required in handling finances or securing possessions. In many cases, incapacitated adults are elderly, but in many other cases they are not, and generally the same laws and procedures apply to all incapacitated adults. Often, family members can provide assistance, but sometimes a state or local court needs to appoint a guardian to act on behalf of the incapacitated person.[2] The guardian becomes responsible for making decisions to protect the incapacitated person from financial and physical abuse or neglect, and the incapacitated person loses decision-making rights.

Although guardianship is a state responsibility, there are many incapacitated elderly people who receive federal benefits, and this group

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[1] Alzheimer's disease is only one of the health conditions leading to dementia or other incapacity.

[2] For convenience, we use the term "guardian" though some states use other terms. California, for example, uses the term "conservator" when the incapacitated person is an adult.

of people may need federal agencies to identify a representative payee—a person or organization designated to handle those benefits on their behalf. State and local courts are responsible for oversight of guardianship appointments, and federal agencies are responsible for oversight of representative payees. Courts and federal agencies have identified instances in which guardians or representative payees have taken advantage of incapacitated elderly people by, for example, stealing from them or billing for services not provided. Such cases of abuse and neglect of elders by guardians and representative payees have prompted questions about the oversight of these programs.

As part of your committee's focus on aging issues, you asked us to study guardianships for the elderly and the representative payee programs of federal agencies such as the Social Security Administration (SSA), the Department of Veterans Affairs (VA), and the Office of Personnel Management (OPM), which manages retirement programs for federal employees. In response to your request, we examined: (1) what state courts do to ensure that guardians fulfill their responsibilities, (2) what exemplary guardianship programs do to ensure that guardians fulfill their responsibilities, and (3) how state courts and federal agencies work together to protect incapacitated elderly people. To study these topics, we reviewed state statutes and conducted surveys of courts responsible for guardianships in the three states with the largest elderly populations—California, Florida, and New York. Forty-two of 58 courts in California, 55 of 67 courts in Florida, and 9 of 12 judicial districts in New York responded to our surveys. We also visited courts in eight states and interviewed officials responsible for representative payee programs at SSA, VA, and OPM and officials at the Department of Health and Human Service's Administration on Aging. In addition, we visited 4 courts identified by members of the National Guardianship Network (a joint council representing eight national organizations involved in guardianship issues) as having exemplary guardianship programs. We conducted our work between March 2003 and May 2004 in accordance with generally accepted government auditing standards. (For details concerning our scope and methodology, see app. I.)

Results in Brief

All states have laws requiring courts to oversee guardianships, but court implementation of these laws varies. At a minimum, most states' laws require guardians of the person to submit a periodic report to the court regarding the well being of the incapacitated person and guardians of the estate to provide an accounting of the incapacitated person's finances. Many states' statutes also authorize measures that courts can use to enforce guardianship responsibilities, such as termination of the guardianship appointment or imposition of fines for failure to fulfill guardianship responsibilities. Often states do not recognize guardianships originating in other states, which can raise jurisdictional issues. In addition to variations among states' laws, courts we studied have quite varied procedures for implementing guardianship requirements in state law. For example, most California and Florida courts responding to our survey require guardians to submit time and expense records to support petitions for compensation, but both states also have courts that do not require these reports. Some courts also take steps beyond what is required by state statutes. For example, some courts require that guardians receive more training than the minimum required by law. Although information, such as the number of people with guardians, is needed for effective oversight of guardianships, it is neither required, nor generally available from the courts. One-third or fewer of the responding courts tracked the number of active guardianships for incapacitated adults and only a few in each state provided the number of those who were elderly.

Judges for four courts widely recognized as having exemplary guardianship programs devote staff to the management of guardianships, allowing the courts to specialize and develop programs for guardianship training and oversight. For example, the court we visited in Florida provided comprehensive reference materials for guardians to supplement training. The other three courts offered training to guardians even though state law does not require it. Three of the exemplary courts have programs in which volunteers or student interns visit people under guardianship and report on their condition to the court. For example, the court in New Hampshire recruits volunteers, primarily retired senior citizens, to visit incapacitated people, their guardians, and care providers at least annually, and submit a report of their findings to court officials. Exemplary courts in Florida and California also have permanent staff to investigate allegations of fraud, abuse, or exploitation or cases in which guardians have failed to submit required reports.

Although state courts and federal agencies are responsible for protecting many of the same incapacitated elderly people, they generally work together only on a case-by-case basis. For example, some courts may send notice of guardianship appointments to SSA, allowing the federal agency to determine whether the court-appointed guardian could also act as a representative payee. Federal agencies may also provide information about incapacitated beneficiaries to courts to help assess the incapacitated person's income and whether the guardian needs to coordinate with a payee. However, coordination between federal agencies and state and local courts does not take place systematically, nor do federal agencies systematically share information with one another. For example, if VA does not notify SSA when it identifies someone as incapacitated, SSA may not learn that one of its beneficiaries may need a representative payee. Similarly, courts identifying a guardian who has abused or neglected an incapacitated person do not automatically notify the federal agency that assigned the guardian as a representative payee. Thus, an incapacitated person may remain at risk of having an identified abuser in charge of his or her benefit payments. The extent to which this is a problem is unknown, because current efforts to compile statistical data by Adult Protective Service agencies and the Justice Department's Bureau of Justice Statistics do not identify cases of elder abuse involving guardians or representative payees. Few courts provide a basis for estimating how many incapacitated elderly people have guardians. Without such data, the extent to which improvements in guardian and representative payee oversight are needed remains unknown.

We are making recommendations to the Social Security Administration, Office of Personnel Management, the Department of Health and Human Services (HHS), and the Department of Veterans Affairs concerning interagency and state and federal collaboration in efforts to plan and implement cost-effective measures to systematically compile and share information needed to enhance the protection of incapacitated elderly people. We provided a draft of this report to each of these agencies and received written comments on the draft from all four. See appendixes IV, V, VI, and VII for their comments. VA, OPM, and HHS agreed with our conclusions and indicated their willingness to participate in the study group and other efforts we are recommending. SSA disagreed with our recommendations concerning an interagency study group, citing differences in federal agency and state court policies regarding protection of the incapacitated, the difficulties that would be involved, and requirements of the Privacy Act that it believes would preclude the kind of information sharing we recommend that SSA and the other agencies study.

Background

The number of people age 65 and older will nearly double by the year 2030 to 71 million. An estimated 6 percent of people aged 65 or older have Alzheimer's disease, a degenerative condition that may lead to dementia.[3]

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[3] Other causes of dementia include strokes, brain tumors, and a variety of endocrine, metabolic, and nutritional disorders.

Over time, some elderly adults may become physically or mentally incapable of making or communicating important decisions, such as those required to handle finances or secure their possessions. In addition, while some incapacitated adults may have family members who can assume responsibility for their decision-making, many elderly incapacitated people do not. The Census Bureau predicts that in the future the elderly population will be more likely to live alone and less likely to have family caregivers. In situations such as these, additional measures may be necessary to ensure that incapacitated people are protected from abuse and neglect.

Several arrangements can be made to protect the elderly or others who may become incapacitated. A person may prepare a living will, write advance health care directives, and appoint someone to assume durable power of attorney, or establish a trust. However, such arrangements may not provide sufficient protection. Some federal agencies do not recognize durable powers of attorney for managing federal benefits. SSA, for example, will assign a representative payee for an incapacitated person if it concludes that the interest of the incapacitated beneficiary would be served, whether or not the person has granted someone else power of attorney.[4] In addition, many states have surrogacy healthcare decision-making laws, but these alternatives do not cover all cases. Additional measures may be needed to designate legal authority for someone to make decisions on the incapacitated person's behalf.

To provide further protection for both elderly and non-elderly incapacitated adults, state and local courts appoint guardians to oversee their personal welfare, their financial well being, or both.[5] The appointment of a guardian typically means that the person loses basic rights, such as the right to vote, sign contracts, buy or sell real estate, marry or divorce, or make decisions about medical procedures. If an incapacitated person becomes capable again, by recovering from a stroke,

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[4] For convenience, we use the term "incapacitated," recognizing that federal agencies and states use a variety of terms and somewhat different definitions to assess whether someone is in need of a guardian or representative payee. SSA, for example, assigns representative payees to people it has determined are incapable of managing or directing the management of benefit payments. OPM and VA use the term "incompetent" but have somewhat different definitions. Most states use the term "incapacitated," but others use "incompetent," "mental incompetent," "disabled," or "mentally disabled."

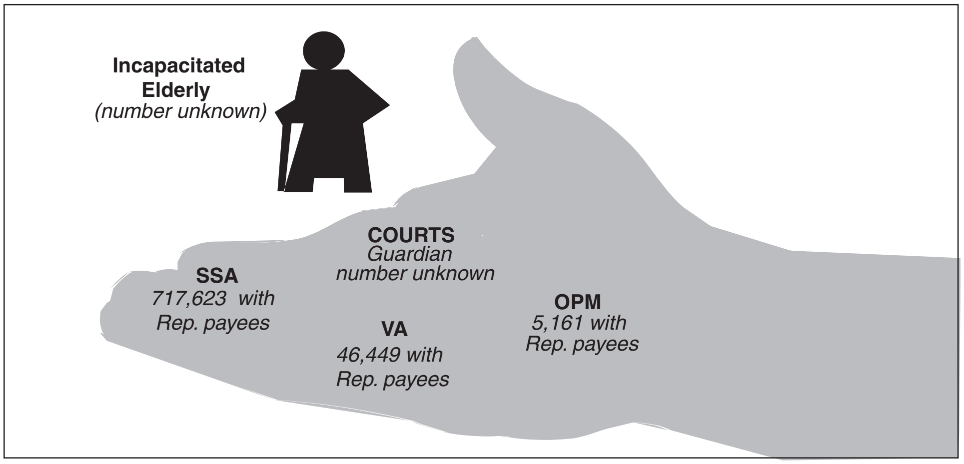
[5] Generally states also have separate provisions for guardianship of minor children, including those who are incapacitated and those who are not.

for example, he or she cannot dismiss the guardian but, rather, must go back to court and petition to have the guardianship terminated.

The federal government does not regulate or provide any direct support for guardianships, but courts may decide that the appointment of a guardian is not necessary if a representative payee has already been assigned to an incapacitated person by a federal agency. Representative payees are entirely independent of court supervision unless they also serve their beneficiary as a court-appointed guardian. Guardians are supervised by state and local courts and may be removed for failing to fulfill their responsibilities. Representative payees are supervised by federal agencies, although each federal agency with representative payees has different forms and procedures for monitoring them.

Each state provides a process for initiating and evaluating petitions for guardianship appointment. Generally, state laws require that a petition be filed with the court and notice be provided to the alleged incapacitated person and other people with a connection to the person. In nearly all states, the alleged incapacitated person is granted the right to be present at the hearing, and the right to counsel. Most states require clear and convincing evidence of a person's incapacity before a guardian can be appointed. The court may appoint a family member, friend, attorney, a paid private professional, a nonprofit social service agency, or a local public agency to serve as the guardian.

Figure 1: Courts and Federal Agencies Have Responsibilities for Protecting Incapacitated Elderly People



Source: SSA, VA, OPM data, and GAO analysis.

In many cases, both courts and federal agencies have responsibilities for protecting incapacitated elderly people, as shown in figure 1. For federal agencies, a state court determination that someone is incapacitated or reports from physicians often provide evidence of a beneficiary's incapacity, but agency procedures also allow statements from lay people to serve as a sufficient basis for determining that a beneficiary needs someone to handle benefit payments on their behalf—a representative payee. SSA, OPM, and VA ask whether the alleged incapacitated person has been appointed a guardian and often appoint that person or organization as the representative payee. In some cases, however, the agencies choose to select someone other than the court-appointed guardian. Social Security officials sometimes designate the nursing home where the incapacitated person resides as the representative payee because it provides for direct payment to the nursing home, ensuring continuity of care for the incapacitated person.[6]

Table 1: Characteristics of Selected Federal Representative Payee Programs

Characteristics	SSA	OPM	VA
Benefit programs with representative payees	Old Age and Survivors, Disability Insurance, and Supplemental Security Income	Civil Service Retirement System, Federal Employee Retirement System	VA Compensation, VA Pension, and other VA programs providing cash benefits
Beneficiaries age 65 and older with representative payee	717,623[a]	5,161[b]	46,449[c]
Beneficiaries of all ages with representative payee	6,863,785[a]	11,157[b]	100,239[c]
Estimated benefits paid in fiscal year 2003 to all beneficiaries with representative payees	$43 billion[d]	$115 million	$1 billion

Source: SSA, OPM, and VA data.

[a] As of December 2003.

[b] As of November 2002.

[c] As of September 30, 2003.

[d] Annualized estimate based on data for December 2002.

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[6] In cases where a Medicaid-eligible nursing home resident has insufficient SSA benefits to cover the entire cost of the nursing care; however, the law provides that the resident shall nonetheless be provided a personal needs allowance of at least $30 each month.

In many cases, guardians are appointed with a full range of responsibilities for making decisions about the incapacitated person's health and well-being as well as their finances, but several states' laws require the court to limit the powers granted to the guardian, if possible. The court may appoint a "guardian of the estate" to make decisions regarding the incapacitated person's finances or a "guardian of the person" to make nonfinancial decisions. An incapacitated person with little income other than benefits from SSA for example, might not need a "guardian of the estate" if he or she already has a representative payee designated by SSA to act on their behalf in managing benefit payments. Sometimes the guardian is paid for their services from the assets or income of the incapacitated person, or from public sources if the incapacitated person is unable to pay. In some cases, the representative payee is paid from the incapacitated person's benefit payments.

Guardians and representative payees may have conflicts of interest that pose risks to incapacitated people. While many people appointed as guardians or representative payees serve compassionately, often without any compensation, some will act in their own interest rather than in the interest of the incapacitated person. Oversight of both guardians and representative payees is intended to prevent abuse by the people designated to protect the incapacitated people.

While the incidence of elder abuse involving persons assigned a guardian or representative payee is unknown, certain cases have received widespread attention. The following are examples of abuse by guardians and representative payees provided by courts and federal agencies:

- A guardian and an employee of the guardian's law firm brought a nursing home resident in New York a cake and flowers on her birthday and billed her $850 for the visit using hourly rates for legal services.
- Rather than using electronic direct deposit, a guardian in New York City appointed to protect an incapacitated person regularly traveled to their branch bank in another borough to deposit her monthly $50 Social Security check, charging her $300 per deposit.
- A company in Michigan acting as guardian for more than 600 incapacitated people committed felonies against them, including selling one individual's home to a relative of a company employee for $500.
- A woman in the position of Public Fiduciary at the Gila County Public Fiduciary's Office in Arizona served as guardian of incapacitated

people and in that capacity embezzled and misused a total of at least $1.2 million of public funds. The county's investigation concluded that "the Court's lack of oversight contributed to the enormous loss of public monies."

- A woman in Washington State established a nonprofit service organization that SSA designated as the representative payee for about 200 beneficiaries. One of her clients was a homeless man entitled to retroactive payment of benefits totaling about $15,000. She received the payment on his behalf, but used the money as her own, along with SSA benefits for others. She embezzled a total of approximately $107,000 of SSA benefits.

- A guardian and representative payee for veterans pled guilty to four counts of misappropriation after a joint VA and SSA Office of Inspector General investigation substantiated allegations that he had embezzled over $400,000 from the veterans' estates.

- The head of a foundation in West Virginia serving as a representative payee for 140 people (including veterans and elderly people) embezzled over $300,000 from them over a 4-year period, consisting mostly of Social Security benefits.

State Laws Provide for Court Oversight of Guardianships, but Court Procedures Vary

All 50 states and the District of Columbia have statutes providing for state or local court oversight of guardianship appointments, but court procedures for implementing these laws vary considerably. Generally, guardians submit periodic reports to the court, but courts' procedures for reviewing reports vary, as do procedures for monitoring guardianships and the penalties courts impose when guardians do not perform their duties. Jurisdictional issues, such as courts in 2 states being asked to appoint a guardian for the same incapacitated person, sometimes complicate guardianship appointments. In addition, most state courts surveyed do not maintain information needed for effective monitoring and oversight of guardianships.

State Laws Require Courts to Oversee Guardianships, but Jurisdictional Issues Complicate Oversight

State laws provide for court appointment and oversight of guardianships. Nearly all states require two kinds of reports: one regarding the personal status and well being of the incapacitated person and another regarding the accounting of the person's finances. The personal status reports usually include information regarding the condition of the incapacitated person, although many states require more specific information regarding various aspects of the incapacitated person's status. In many states, the laws require the report to include documentation of the need for continued guardianship. Many statutory requirements are very detailed and require a physician's statement, a determination of the mental status of the incapacitated person, or in some instances, reports of any change in the condition of the incapacitated person. Other basic report elements may include living conditions, place of residence, and the number of guardian visits. Some states may allow courts to waive certain reporting requirements.

Most states require that guardians submit a financial accounting and record of expenditures for the care of the incapacitated person on an annual basis. This document may list the assets and income of the incapacitated person, including bank balances, real property holdings, and detailed expenses associated with the care and housing of the incapacitated person. State statutes usually require court approval for the sale of real estate by a guardian.

How often guardians are required to submit reports varies. Most states require guardians to submit personal status reports at least annually. Only the District of Columbia's law requires submission at least semiannually. Statutory requirements for filing financial accountings range from annually to at least once every 3 years. (See fig. 2.) In states where accounting frequency requirements are left to the discretion of the courts, the minimum requirement is that an accounting be made upon resignation or removal of the guardian. In many states, there is an explicit requirement that court personnel take action when reports are not filed on time. In Texas, if a guardian of the person fails to file a report or a guardian of the estate fails to file an annual accounting, the guardianship appointment expires.

Figure 2: How Often Guardians' Accounting Reports Must Be Submitted Varies by State

Source: American Bar Association Commission on Law and Aging.

Some state statutes require an independent party or court personnel to determine the accuracy and validity of personal status and accounting reports. However, fewer than half of the states require courts to review the reports guardians have submitted to them. Other states leave it to the court to determine who reviews the reports. For example, Texas specifies that a statutory probate[7] court must review filings as part of the annual determination of the continued need for a guardianship, but provides that courts of general jurisdiction may use any appropriate method determined by the court according to the court's caseload and resources available" in order to assess the continued need for a guardianship.

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[7] Typically, probate courts are those that handle cases involving trusts, wills, estates, and guardianships.

Apart from requirements for review of the submitted reports, some states' statutes require a periodic review of the guardianships to ensure that guardians are adequately fulfilling their responsibilities and there is a continuing need for the guardianship. In some states, an investigator will visit the incapacitated person to determine whether there is a continuing need for a guardianship or if the current guardian should be terminated and a new one appointed. For example, Alaska requires courts to evaluate incapacitated persons every 3 years. Some states hold a hearing to assess the continuing need for a guardianship. For example, Connecticut law requires a hearing every 3 years to determine if any changes need to be made to the guardianship appointment.

Many states' laws authorize penalties that courts can impose to enforce guardianship responsibilities. These most frequently include termination of the guardianship appointment or imposition of fines for failure to fulfill responsibilities. Some states have statutes providing for the denial of guardianship fees while others authorize penalties against negligent or ineffective guardians, including charging the guardian with contempt of court, imprisonment, restitution for mismanagement of property, recovery of assets and surcharges, or loss of bond. Many other state statutes allow hearings at the court's discretion or in response to a petition.

Some states are reluctant to recognize guardianships originating in other states, leading to jurisdictional complications. The 1998 Uniform Guardianship and Protective Procedures Act has been adopted into many states' statutes. This act gives courts the power to exercise jurisdiction when an incapacitated person is moved or travels from one state to another. However, these provisions may not sufficiently address all complications that arise in guardianships for the elderly such as when more than one jurisdiction is asked to appoint a guardian for the same incapacitated person. For example, a guardian appointed in one state that attempts to sell an incapacitated person's real property located in another state may need to travel to that state and petition a court there in order to establish authority to act on behalf of the incapacitated person. Interstate jurisdictional issues also arise when the guardian or the incapacitated person needs to move to another state. Issues may also occur in cases involving the physical removal of an incapacitated person from one jurisdiction to another in an effort to gain control over the incapacitated person.

Courts' Procedures for Implementing State Laws Vary

While some state statutes specify minimal requirements for overseeing guardians, individual courts may set their own, sometimes more stringent, requirements and standards. The courts in the 3 states we surveyed (California, Florida, and New York) implemented their state laws through reporting and oversight procedures. (See app. III for a state-by-state compilation of survey results.)

Within the 3 states, court procedures varied for the submission and review of reports guardians are required to submit. Most courts responding to our survey require an initial inventory of assets, income, and liabilities, and courts in Florida and New York typically require annual financial statements or accountings. Most courts in Florida and New York require some or all guardians to submit a financial plan detailing how the guardian will manage the financial affairs of the incapacitated person. Most of the responding courts in California and Florida and all of the responding judicial districts in New York indicated they require some or all guardians to petition or inform the court if plans for the incapacitated person's care change. Nearly all of the courts responding to our survey in each state indicated that judges, court personnel, or court examiners review guardians' reports, and a few courts use volunteers.

In each state surveyed, when guardians receive pay for services, the pay varies. We asked courts about compensation approved in the last 12 months before responding to our survey. Most courts indicated that some guardian compensation was based on an hourly rate. In New York, rates typically ranged from $25 to $400 per hour, in California they ranged from $7 to $250 per hour, and in Florida they ranged from $8 to $85 per hour.[8] In other cases, guardians' compensation was based on the value of an elderly incapacitated person's estate but, while most judicial districts in New York had allowed this, few courts in Florida and about one-quarter of the courts in California had. In each state, most courts responding to our survey required all guardians to submit time and expense records to support petitions for compensation, but other courts in each state only require these reports for some guardians.

In all 3 states, responding courts reported a variety of measures for guardianship oversight. Most California courts indicated that court

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[8] The New York State Unified Court System's Commission on Fiduciary Appointments and a Special Inspector General have raised concerns about the selection and compensation of guardians and other fiduciaries in New York, and the court has established the Office of Guardian and Fiduciary Services to help administer a new appointment system.

personnel visit all or almost all the incapacitated people, and several responding Florida courts and two New York judicial districts indicated they had court personnel visit some or most of the incapacitated people. Most responding courts reported that they ask questions raised by guardians' reports, send follow-up letters to conservators, or send notices or orders to appear in court when reports are late, incomplete, or inaccurate.

Most responding courts in each state indicated they had imposed some kinds of penalties when guardians failed to fulfill their responsibilities. The most commonly used measures included withholding or reducing guardianship compensation, terminating guardianship appointments, and contempt of court citations. Several courts indicated they had done one or more of these things more than 10 times during the past 3 years. A 1999 California State law established a statewide registry of private professional guardians and requires courts to notify the registry when a complaint against a guardian is valid. Only one court indicated it had yet notified the registry of a guardian's resignation or removal for cause.[9] Eleven responding courts in California and 9 in Florida indicated they had convicted guardians of a crime against the incapacitated person. In New York, 2 judicial districts had notified the state registry of a guardian's resignation or removal for cause and 1 had convicted a guardian of a crime against an incapacitated person.

Most Courts Surveyed Do Not Track the Number of Active Guardianships

In each state surveyed, some information needed for effective oversight of guardianships, such as the number of people with guardians, was generally not available. In each of the 3 states, one-third or fewer of the responding courts tracked the number of all guardianships for adults that they were responsible for monitoring, and only a couple of courts in each state provided us with the number of these guardianships that were for incapacitated people aged 65 and older. (See table 2.) California courts report the number of probate and guardianship filings they handle each year, including guardianships, probate of decedents' estates, and trusts—for a total of 50,786 filings in fiscal years 2001-2002. The state court administration does not, however, require a separate count of guardianship filings for adults or the elderly.

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[9] Staff in the California Attorney General's office responsible for the registry indicated that as of April 2003 the registry consisted of 463 guardians, and in only one instance since the registry's establishment has a court-submitted notice of a complaint.

Table 2: Few Surveyed Courts Tracked the Number of Elderly People with Guardians the Courts Oversee

	Number of courts[a]		Number of judicial districts in New York
	California	Florida	
Provided number of people aged 65 and older with guardians[b]	2	2	2
Provided the number of people with guardians, but not number of those aged 65 and older	8	9	1
Provided neither	32	44	6
Did not respond to survey	16	12	3
Total number of courts and New York State judicial districts	**58**	**67**	**12**

Source: GAO surveys of courts in California, Florida, and judicial districts in New York.

[a] GAO sent surveys to California superior courts in each California county and to Florida circuit courts in each Florida county. GAO sent similar surveys to each New York State judicial district. The population of people 65 years of age or older was about 3.7 million in California, 2.8 million in Florida, and 2.4 million in New York as of July 2001.

[b] Includes one California court that indicated it had no elderly people with a guardian, but did not provide the number of all people (elderly and non-elderly) with guardians.

In 1999, amendments to California law established a statewide registry of private professional guardians, providing courts information about prospective guardians' experience and a record of complaints and cases in which they have had a guardianship appointment terminated for cause. (The names of people on the registry are available to the public.) Florida also maintains a statewide registry of most professional guardians, but registration is not required of nonprofessional guardians.[10] New York also maintains a list of private professional fiduciaries, including guardians. However, most of the courts responding to our survey in each state indicated that less than half of the guardians they appointed were on the state registry. Many of the guardians appointed are family members or friends of the incapacitated elderly person.

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[10] Professional guardians in Florida are those who receive compensation for serving more than two incapacitated people who are not family members. Nonprofessional guardians and guardians who are trust companies, state or national banks, federal savings and loans associations, neither state, nor independent colleges or universities are required to register.

Most courts surveyed said they did not have sufficient funds for guardianship oversight.[11] Often the courts handling guardianship matters handle several kinds of cases. In each state, one-fifth or fewer of the judges who hear guardianship cases in the responding courts spend a majority of their time on them. Judges who spend little of their time on guardianship cases tend to focus on each case as it comes up on their calendar and find it difficult to devote the time and resources needed to develop an effective guardianship program, according to some officials at courts recognized as exemplary, but others disagreed saying that general jurisdiction courts can also provide good oversight of guardians. In Florida, about one-fifth of the judges in courts responding to our survey spend the majority of their time on guardianship cases. While in California and New York 17 percent and 12 percent of judges, respectively, spend a majority of their time on these cases.

Courts Recognized as Exemplary Focus on Training and Monitoring

Each of the four courts recognized as exemplary went well beyond minimum state requirements for guardianship training and oversight. Each court provides training of guardians, even though training is only required in one of the state's statutes. (See table 3.) The courts also actively utilize computerized case management, court visitor programs, in-depth review of annual reports, or investigations by court employees to oversee guardianship cases. Two court officials told us that specialization allows courts to focus on issues specific to guardianships and try new strategies to improve the court's oversight of guardians.

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[11] In a December 2003 opinion, the Florida Supreme Court called for additional state judges, including 6 in Broward County, citing in part the growing number of guardianship and probate cases due to Florida's growing elderly population.

Table 3: Characteristics of Courts Recognized as Exemplary

	Broward County, Fla.	Rockingham County, N.H.	San Francisco County, Calif.	Tarrant County, Tex. Probate Court #2
Type of court	Probate court	Probate court	Probate Department of the Superior Court	Probate court
Number of people under guardianship	5,000 to 6,000[a]	679[b]	1,350[c]	978[d]
People under guardianship who are elderly	About half	More than half	About three-quarters	299[e]

Source: Court officials and documents.

[a] The court does not keep count of the number of individuals under guardianship as this is done by the Clerk of Court in Florida as an independent constitutional officer. Court officials estimate, based upon the Clerk of Court reports, that there are between 5,000 and 6,000 open guardianship cases for adults and children.

[b] As of December 31, 2003. Number includes adult cases only (minor guardianships tracked separately).

[c] Includes adult cases only (minor cases are called guardianships and are tracked separately).

[d] As of June 2004, including guardianships of adults and children.

[e] As of June 2004.

Courts Recognized as Exemplary Provide Training and Sources of Information Resources for Guardians

The courts recognized as exemplary provide training and/or information resources for guardians. (See table 4.) Of the 4 states in which the courts recognized as exemplary are located, only Florida requires guardians to receive training, but Broward County provides training beyond what is required in state law for nonprofessional guardians and provides supplemental reference materials, such as a software program for preparing guardianship reports.[12] The courts in San Francisco and Tarrant County, Texas, also provide independently developed training for guardians. For example, as of January 2004, the San Francisco court required professional and nonprofessional guardians alike to complete formal classroom training.[13] Working in partnership with a group of

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[12] Parents who are appointed guardians of the property of their minor children are subject to different requirements. Each person appointed by the court to be the guardian of the property of his or her minor child must receive a minimum of 4 hours of instruction and training that covers the guardian's duties, preparation of reports, and use of guardianship assets

[13] In California a private professional guardian (conservator) is generally "a person or entity appointed as conservator of the person or estate, or both, of two or more conservatees at the same time who are not related to the conservator by blood or marriage, except a bank or other entity authorized to conduct the business of a trust company, or any public officer or public agency including the public guardian, public conservator, or other agency of the State of California."

professional guardians, the court developed a required half-day training course that nonprofessional guardians must complete within 6 months of their appointment.

Table 4: Training and Information Resources for Guardians in the Four Courts

	Training requirements in state law	Court procedures exceeding state law
Broward County, Fla.	• Nonprofessional: 8 hours (4 hours parent of minor child.) • Professional: 40 hours, plus 16 continuing education hours every 2 years. • Courses must be certified by state.	• Requires 12-hour course for nonprofessional guardians and a 48-hour course for professional guardians. • Handbook, required forms, required software for preparing guardianship reports, court procedures, and answers to frequently asked questions available on Web site.[a]
Rockingham County, N.H.	• None specified	• Provides information packet and checklist. • Offers informal information sessions with judge. • Provides video explaining guardianship. • Forms, information packet, and checklist available on Web site.
San Francisco County, Calif.	• Required to provide handbook and resource supplement book for local resources.	• Nonprofessionals: must complete up to 6 hours of court-supervised training. Those appointed guardian of person must complete a 3-hour course and those appointed guardian of estate must complete another 3-hour course. • Professionals: complete certificate program at university or demonstrate equivalent experience. • Guardians are required to watch video.
Tarrant County, Tex.	• None specified.	• Court staff provides 20-30 minute training and handbook. • Training also available at local organization offering guardianship services.

Source: Court officials and documents.

[a] The court requires that guardians use this software to prepare initial inventories, initial plans, annual plans, annual accountings, and simplified accounting reports.

Courts Recognized as Exemplary Actively Oversee Guardianships

Each of the exemplary courts uses at least one means to actively oversee guardianships, and while each will penalize guardians who fail to fulfill their responsibilities, two courts dedicate extra resources to enforcement activities. These two, Rockingham County and Tarrant County, oversee guardianship cases through computerized case management systems. The system in Rockingham County automatically notifies court staff when reports are due for each guardianship case. For example, when a guardianship of the estate is established, the system prints a notice to the guardian that an inventory of the incapacitated person's assets must be submitted to the court within 90 days. If the court has not received the inventory, the system notifies court staff that an inventory default notice is needed. This system also tracks the number of new guardianship cases and the total number of active cases. Similarly, Tarrant County enters information about each new guardianship case into a database. Each month the court generates a list of annual reports that are due and mails the guardians the required report form. The court also enters the date the report is received into the database.

Two of the courts have developed procedures for in-depth review of guardians' reports. In Florida, the state statute requires that the clerk of the court review each guardianship report to ensure that it contains the appropriate information. Broward County has implemented a three-tiered sampling system for reviewing the reports from the substantial caseload of approximately 5,000 guardianships. All reports are subject to the first level of review, which is conducted by the Audit Division of the Clerk of the Court's office. A further sample of reports is selected, and the Audit Division conducts a more intensive second level review. At the third level of review, a further sample of reports is selected, and the audit division conducts detailed in-house and field audits of supporting documentation to verify the information in the reports. If these reviews indicate any irregularities, the Audit Division sends a memorandum to the judge to review the report and the auditor's findings. Tarrant County also employs an auditor who is responsible for monitoring guardianships of the estate. The auditor uses a database to track when guardians' reports are due. Twice a month, the auditor checks this database to ensure that no reports are overdue or overlooked.

As shown in table 5, each court recognized as exemplary uses a visitor program to support guardianship oversight. Tarrant County is required by state law to have court visitors monitor the status of people under guardianship, so the court provides visitation internships to social work students who work as court visitors.[14] A licensed Master Social Worker on the court staff acts as program manager and trains and supervises the interns. The students receive course credit, and the program is of little cost to the court. There are typically 4 or 5 interns making an average of 60-70 visits each month. The visitors submit a report of the visit to the program manager for review, and the judge reviews these reports to guide his or her decision on whether to continue the guardianship for an additional year.

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[14] Volunteers also conduct some court visits. The county has a volunteer coordinator who assists in finding volunteers who are interested in doing court visits. The court asks volunteers to make a 1-year commitment. Volunteers attend the 4-hour orientation and training.

Rockingham County recruits volunteers from AARP to serve as either visitors or researchers. Researchers prepare files for the court with contact information, case background, and the last annual guardian's report. The visitors then contact the guardian and arrange to visit the incapacitated person. They assess the ward's living situation, finances, health, and social activities, and recommend follow-up actions to the court. A court employee serves as the volunteer coordinator. According to the volunteer coordinator in Rockingham County, costs are minimal because volunteers use court telephones, and the state provides supplies. According to the court, the detailed, first-hand information provided about the incapacitated person's environment and condition helps the court make better decisions when the case is reviewed.

Table 5: Oversight Procedures in the Four Courts

	Requirements in state law	Court procedures exceeding state laws
Broward County, Fla.	**Monitoring:** • Court may require background investigation of nonprofessionals. • Court must require initial background investigation of professionals and reinvestigate every 2 years. • Clerk's office is required to audit guardian reports. • Registration of professional guardians. • Bond required for all. **Enforcement:** • Court may employ court monitors. • Show cause hearing, etc., for delinquent reports.	• Background investigations of all guardians required. • Background investigations required annually. • 3-tiered report review system. • Electronic reporting software. • The Office of the Public Guardian—a publicly funded agency that serves as a guardian, which is one of only a handful in the state. • Full-time court monitor on staff and part-time contractors to investigate abuse.
Rockingham County, N.H.	**Monitoring:** • Bond required for all guardians. • Criminal background check required for guardians of the person. **Enforcement:** • Court may issue show cause order, fine guardian, arrest guardian, or terminate guardianship for failure to file reports.	• Volunteer Court Visitor program. • Follow-up on court visitor recommendations.
San Francisco County, Calif.	**Monitoring:** • Court investigators visit incapacitated people 1st year then every other year. • Status reports required for guardians of estate who are also guardians of person. • Statewide registration system for professionals. • Full bond on all liquid assets required for all guardians. **Enforcement:** • Punish or remove guardian, suspend powers, appoint legal counsel, or granting a 60-day extension.	• General Plan required for all guardianships. • Status report required for all guardianships of person after first year then every other year even if no guardianship of estate exists. • Examiners review accountings. • Yearlong study on guardianship data. • More frequent investigations on troubled cases. • Investigations on all petitions for termination of guardianship.
Tarrant County, Tex.	**Monitoring:** • Court visitor program. • Annual renewal of guardianship letters. • Judge considers and approves annual accounts. • Criminal background check for professionals required. • Bond required for all guardians. **Enforcement:** • Show cause hearing, fine, or removal if necessary. • Court investigator investigates complaints. • Authority to sentence guardians to jail for misconduct.	• Court visitors are social work students. • Database system to track open cases. • Auditor reviews annual accounts. • Program Manager follows up on concerns in guardian and court visitor reports before judge's review. • Criminal background checks for nonprofessional guardians in court-initiated guardianship.

Source: Court officials and documents.

When guardians fail to fulfill their responsibilities, the courts have legal authority to penalize guardians, and two of the courts recognized as exemplary have staff dedicated to investigating these types of cases. Broward County employs court monitors to investigate abuse allegations involving guardians, or problems discovered due to annual background checks, report review, or other tips. A study of statewide guardianship monitoring practices found that Broward County conducts about 400 field investigations a year, some of which have resulted in referrals to the state attorney for prosecution.

State Courts and Federal Representative Payee Programs Serve Many of the Same Incapacitated Elderly People, but Collaborate Little in Oversight Efforts

Federal agencies and state courts' representative payee programs collaborate little to protect incapacitated people and prevent misuse of federal benefits. Although overlap is known to occur among the incapacitated populations they serve, the extent of this overlap is not known. Some state courts and federal agencies share certain information on a case-by-case basis. However, the absence of a systematic means for compiling and exchanging pertinent information may leave many incapacitated people at risk and result in the misuse of benefits and increased federal expense. State courts and federal agencies lack consistent and sustained compilations of data needed to assess options for improving oversight of guardians and representative payees.

Beneficiary Populations Overlap, but Coordination Is on a Case-by-Case Basis

The incapacitated populations served by state courts and federal agencies overlap to some extent. Because we focused on incapacitated elderly people, we did not assess overlaps between agencies' general beneficiary populations. (See table 6.) An estimated 95 percent of all people 65 and older are SSA recipients, and elderly recipients of OPM or VA benefits often also receive SSA payments. An estimated 96 percent of VA beneficiaries aged 65 and older are also SSA recipients and about 9 percent are OPM beneficiaries. Also, an estimated 82 percent of OPM elderly beneficiaries are also SSA beneficiaries. While there are no data on the number of beneficiaries who are incapacitated in each category, it is likely that a number of incapacitated people are beneficiaries from more than one federal agency, and a number could also have court-appointed guardians.

Table 6: Many Elderly People Receive Benefits from More than One Federal Agency

Agencies providing benefits[a]	Estimated number of beneficiaries aged 65 or older[a]
SSA and VA	1,164,000[b]
SSA and OPM	1,191,000
VA and OPM	109,000
SSA, VA, and OPM	100,000

Source: Census Bureau analysis of Survey of Income and Program Participation (SIPP) Data, 2001, Wave 6 survey results.

[a] Each estimate includes beneficiaries listed in other rows. For example, about 100,000 of the estimated 1,164,000 people aged 65 or older who were beneficiaries of both SSA and VA were also OPM beneficiaries.

[b] The 90 percent confidence interval for this estimate is from 1.0 to 1.3 million elderly people.

Like many courts that oversee guardianship programs, federal agencies collect certain information from representative payees.[15] SSA annually sends each representative payee (whether a court-appointed guardian or not) a two-page report form asking for certain information—for example, whether the representative payee was convicted of a felony, whether the beneficiary continued to live in the same circumstances, how much of the benefit payments were spent on the beneficiary's behalf, how much was saved, and in what kind of account the funds are held.[16] Similarly, OPM biennially sends its representative payees a brief survey asking for similar information, though those who are court-appointed guardians are not required to complete the survey. OPM leaves it to the courts to monitor these payees. VA also requires its representative payees to submit a two-page accounting report, but asks payees who are court-appointed guardians to submit the same accountings that they submit to the court. Each agency sends follow-up mailings, and SSA and VA visit payees as needed in cases where payees fail to submit a report. In addition, VA sends field examiners to visit each incapacitated beneficiary. Agency officials indicated that these efforts often help identify cases in which beneficiaries or representative payees have moved or cases where a payee may need to be replaced for a variety of reasons. For example, they may no longer be living close enough to the beneficiary or they themselves have become

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[15] Each of the three agencies has its own criteria and process for identifying beneficiaries in need of a representative payee and though the three agencies use terms such as "incompetence," we use the term "incapacitated."

[16] State mental hospitals that are representative payees are subject to different accounting requirements and are subject to on-site reviews by SSA staff.

unable to handle the benefit payments. Typically, however, cases of abuse come to the agencies' attention by way of tips from individuals who know of the beneficiary rather than from report and survey follow-up efforts.

Some state courts and federal agencies share certain information about some beneficiaries on a case-by-case basis. Some state court officials that we spoke with indicated that they have established a rapport with staff in local offices of federal agencies, such as SSA and VA, and are able to obtain information concerning incapacitated beneficiaries or their representative payees. (See table 7.) For example, upon request, federal agencies will sometimes provide them with information to allow the court to determine all sources of the incapacitated person's income and whether the guardian needs to coordinate with a payee. State courts may also offer information to federal agencies. For example, some courts send occasional notices of guardianship appointment to SSA, allowing SSA staff to identify which of their beneficiaries is incapacitated and determine if the guardian can be designated as a representative payee.

While coordination is often case-by-case, some takes place more systematically and is based on previously established agreements. For example, about one-third of the states have adopted the Uniform Veterans' Guardianship Act that requires state courts to notify VA when they appoint a guardian for a veteran. According to this act, VA must receive copies of court orders and accountings related to the veteran's case. The act also gives VA the right to appear in court during guardianship proceedings involving a veteran.

Federal agencies may also establish agreements with one another to exchange information. For example, SSA allows a limited number of VA service representatives nationwide to electronically access some SSA information about veterans' SSA benefits. This SSA data system includes the amount of SSA benefits veterans receive, whether SSA has identified them as incapacitated, and the identity of a representative payee, if one has been designated. VA officials regularly look at SSA's information before conducting a field examination to help determine incapacity and choose a fiduciary, according to a VA official responsible for managing the agency's fiduciary program. VA is not, however, notified when SSA changes a beneficiary's representative payee. Many VA representative payee program staff that do not currently have access to the database see it as a useful tool and have expressed a desire to be able to use it in order to more efficiently assess beneficiaries' needs.[17]

Lack of Systematic Coordination Weakens Oversight of Incapacitated People

The lack of systematic coordination weakens the oversight of both elderly and non-elderly incapacitated people and may leave incapacitated people at risk of not being assigned a representative payee or guardian despite having been identified either by a state or federal entity as a person who needs one. For example, if a federal agency has identified one of its beneficiaries as incapacitated and assigns a representative payee, the agency does not systematically notify the courts or other agencies. (See table 7.) The other agencies making payments to the same person may not learn that they may need to assign a representative payee to handle their benefit payments to the person. Such notification could also be useful to state courts in assessing the need for a guardian. This lack of coordination could leave the incapacitated person who needs a representative payee or guardian without one.

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[17] Without the information on SSA benefits being provided to veterans, VA staff would have to find benefit and income information through other means, and they would have no way to verify the information. There is a potential for fraud, since a beneficiary could claim to not receive Social Security benefits, when in fact the person does receive a benefit and this may affect their eligibility for VA benefits. In addition, without information from SSA that may help indicate a veteran's total income, VA may recommend an inappropriately low spending allowance for the incapacitated person.

Table 7: Representative Payee Programs' Gathering and Exchange of Information

Information gathered or exchanged	SSA	OPM	VA
Ask whether incapacitated beneficiary has a court-appointed guardian?	Yes	Yes	Yes
Compile names of guardians not designated as agency's payee?	No	Not applicable[a]	No
Give other agencies/courts access to database with name of representative payee?	Yes, VA access only	No	No
Systematically notify other agencies/courts of assignment of a representative payee?	No	No	Not other agencies, courts in some cases[b]
Systematically notify other agencies/courts of the replacement of a representative payee?	No	No	Not other agencies, courts in some cases[b]

Source: GAO interviews with SSA, OPM, and VA officials.

[a] OPM's policy is to designate the guardian as the representative payee.

[b] A VA official indicated that VA typically informs the court by letter if it selects a new or successor representative payee other than one who was previously appointed by the court.

Insufficient interagency coordination may also leave incapacitated elderly people more vulnerable to abuse or neglect. For example, when an agency identifies a representative payee who is abusing or neglecting an incapacitated person, it does not automatically notify the state court or other federal agencies that have assigned a guardian or representative payee. Without such a notification, the court or other federal agency may be unaware of the need to replace an abusive or negligent guardian or representative payee.

If agencies and courts do not communicate with each other concerning incapacitated beneficiaries, they may unknowingly assign different people as representative payees or guardians with overlapping responsibilities. However, in some cases, agencies and courts intentionally select different people or organizations as representative payee or guardian. Although most Old Age, Survivor, and Disability Insurance beneficiaries with both a guardian and SSA-designated representative payee, have the same person serving in both roles, for an estimated 19 percent of these beneficiaries the guardian is not their representative payee.[18] Some guardians choose not to

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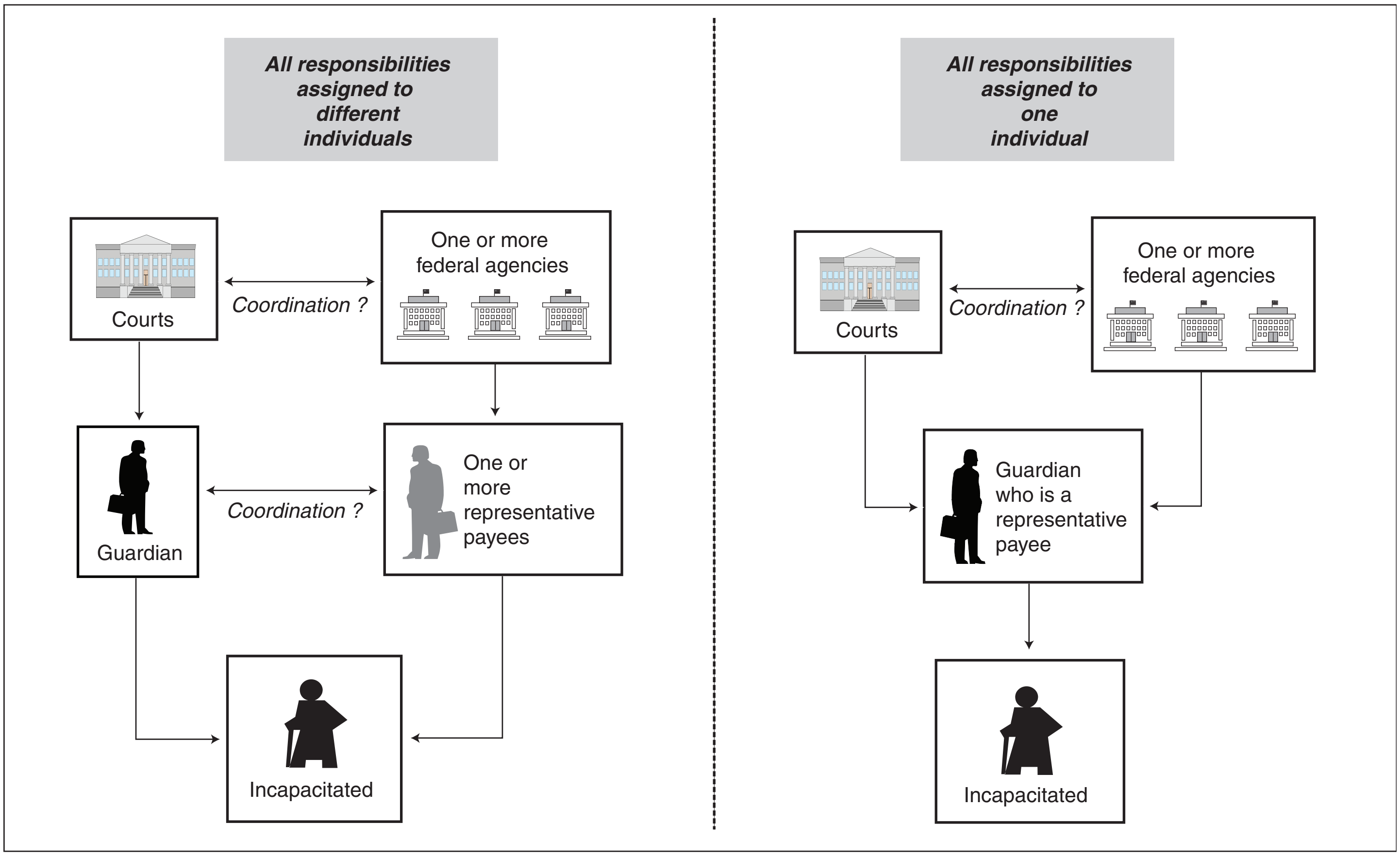
[18] SSA estimated that as of December 2002, 250,000 Old Age, Survivor, and Disability Insurance beneficiaries had both an SSA-designated representative payee and a court-appointed guardian. For about 48,000 of these beneficiaries the guardian was not the designated representative payee.

be the representative payee, so SSA designates someone else. (See fig. 3.) Sometimes VA designates a nursing home as a representative payee, even though a court has appointed a family member or other person to be the incapacitated resident's guardian. The guardian and the nursing home may get into conflict over the use of the incapacitated person's benefit payments. Additional coordination among federal agencies and courts and cooperation among guardians and representative payees may be necessary to avoid conflicts and better protect the incapacitated person.

Figure 3: Federal Agencies and the Courts May or May Not Assign Representative Payee and Guardianship Responsibilities to the Same Individual



Source: Interviews with court officials and federal officials responsible for for SSA, VA, and OPM representative payee programs.

Federal officials have recognized the need for better exchange of information regarding incapacitated beneficiaries. In response to provisions in the Omnibus Budget Reconciliation Act of 1990, SSA and VA studied the feasibility of collaborating in serving veterans who were also SSA beneficiaries.[19] In 1993, several agencies participated in a discussion group on representative payee programs. Two of the agencies—SSA and VA—signed an agreement calling for each agency to notify the other when it had information that could be helpful to the other agency's oversight of its representative payee.[20] However, according to VA and SSA officials, efforts to implement the agreement failed due to changes in management personnel, concerns about costs, and issues concerning nondisclosure of confidential information.

Not only is it likely that the lack of coordination limits the protection of incapacitated people and their federal benefits, it may also result in increased federal expenditures. The recently enacted Social Security Protection Act of 2004 requires SSA to repay the benefits in certain cases of misuse.[21] For example, if a representative payee that is an organization, or an individual serving 15 or more beneficiaries misuses the benefit payments, SSA will have to reissue the misused benefits to the beneficiaries or to an alternate representative payee, resulting in increased federal expenditures. Before the passage of this act, SSA was only required to replace benefits if SSA was negligent in its oversight of a representative payee. Annually, SSA has found fewer than 1,000 cases of misuse, and only in a small percentage of those cases was SSA found to be negligent. However, according to an SSA official, the new provisions may mean that more benefits will have to be reissued.

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[19] These and other federal agencies currently collaborate in the exchange of data on beneficiaries for other purposes. For example, through SSA's Death Master File federal and state agencies, including SSA, OPM, and VA, periodically match their beneficiary lists with lists of people who have died. This cooperative effort helps agencies ensure that they do not continue to send payments to people who are no longer eligible.

[20] Memorandum of Understanding between the Social Security Administration and the Department of Veterans Affairs, signed by Acting Commissioner, SSA, and Undersecretary for Benefits, October 13, 1993.

[21] Pub. L. No. 108-203 §101, March 2, 2004.

Statistical Data to Analyze Options for Improving Oversight Not Available

Certain data, such as the number of active guardianships and incidence of abuse, could help courts and agencies determine the effectiveness of efforts to protect incapacitated people but are not currently available. The courts we surveyed generally do not compile aggregate data such as the number of incapacitated people, or elderly incapacitated people, with guardians. Often the only records concerning guardianship appointments aside from a calendar of upcoming hearings and due dates for required reports are in individual paper files. Some states, however, are making efforts to compile statewide data on guardianships. In Vermont, for example, the Supreme Court compiles reports from each court on the number of open guardianship cases, but without any information on the age of the incapacitated people. In New York, the state court's Guardian and Fiduciary Services is working on the development of a statewide database on guardians, fiduciaries, and the people they were appointed to serve.

The federal agencies that we examined, SSA, VA, and OPM, do more to compile data on representative payees than most courts responding to our 3-state survey do for incapacitated people with guardians. All three of the federal agencies that we examined have databases that keep count of the different types of representative payees for incapacitated people. Neither SSA nor VA, however, consistently compiles information showing how many beneficiaries with representative payees have a court-appointed guardian who is not the representative payee.[22]

To keep these databases current, all three agencies require most of their representative payees to submit periodic reports. SSA, VA, and OPM compile and maintain basic information, such as contact information, about the representative payees they designate. They also ask whether an incapacitated beneficiary has a court-appointed guardian before designating a representative payee. They do not, however, compile and maintain more detailed information that could contribute to more effective oversight of representative payees. For example, none of these agencies consistently records information about a beneficiary's court-appointed guardian in its computerized records system or updates the information unless the agency also designates the court-appointed guardian as its beneficiary's representative payee. Although SSA compiles some information about the reasons it replaces representative payees, such as the assignment of a more suitable payee, misuse of benefits, or fraud, for

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[22] OPM's policy is to designate the guardian as the representative payee.

example—OPM and VA do not. This information might be useful in making future assignments.

Sufficient data are not available to determine the incidence of abuse of incapacitated people by guardians or representative payees, nor the extent to which guardians and representative payees are protecting incapacitated people from abuse. Current efforts to compile aggregate national data on elder abuse do not identify cases when a guardian or representative payee has been assigned to the victim of abuse, or whether a guardian or representative payee commits the abuse. States compile statistics on incidence of abuse and neglect, including information on the age of victims.[23] National associations collect these statistics from Adult Protective Service agencies and Area Agencies on Aging. Generally, states track types of abuse and some of the relationships between perpetrators and victims, but they do not track instances where the victim had been assigned a guardian or representative payee or had granted a power of attorney to someone. As a result, federal agencies lack national data concerning the incidence of elder abuse by guardians and representative payees or the incidence of abuse with and without the assignment of a guardian or representative payee. Similarly, national crime statistics, such as crime victimization surveys, identify various relationships between victims and perpetrators, and the age of victims, but fail to identify cases involving guardians or representative payees. SSA tracks the number of cases in which representative payees are found to have misused benefits—fewer than a 1,000 cases each year for beneficiaries of all ages. SSA officials agreed, however, that since SSA largely relies on tips from third parties to discover cases of misuse, their records of misuse might be incomplete.

Conclusions

Although state and local courts have primary responsibility for protecting incapacitated people, including the elderly, by appointing and overseeing guardians, federal agencies also have responsibilities to help protect many of the same incapacitated people through representative payee programs. Yet, courts and federal agencies collaborate little in the protection of incapacitated elderly people and the protection of federal benefit payments from misuse. Court and agency efforts to improve protection of the incapacitated is limited by their failure to systematically compile and exchange data—by, for example, promptly notifying each other when an

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[23] 42 U.S.C. §3058i.

incapacitated person is identified or a representative payee or guardian is appointed or needs to be replaced, due to their failure to fulfill their responsibilities, or for other reasons. However, the extent to which the courts and agencies leave elderly incapacitated people at risk is unknown. Neither the states nor the federal government compile data concerning the incidence of abuse of people assigned a guardian or representative payee or even the number of elderly people with guardians. Without better statistical data concerning the size of the incapacitated population or how effectively it is being served, it will be difficult to determine precisely what kinds of efforts may be appropriate to better protect incapacitated elderly people from exploitation, abuse, and neglect.

Improvements in oversight of guardians and representative payees depend in part on additional efforts by states, state and local courts, federal agencies, state area agencies on aging, and HHS. Although the focus of our review was elderly incapacitated people, state guardianship and federal representative payee programs also serve other incapacitated adults. Improvements could be of benefit to all incapacitated adults, particularly if they are designed with both the elderly and non-elderly in mind. However, certain actions that would improve oversight are not currently being undertaken. For example, the various entities responsible for oversight do not collaborate to compile, on a continuing basis, consistent national data concerning guardianships and representative payees. Without such statistical data, the extent of preventable abuse and neglect of incapacitated elderly people is unknown. Finally, the states have done little to collaborate on interstate recognition and transfer of guardianship appointments. Few states have adopted procedures for accepting transfer of guardianship from another state or recognizing some or all of the powers of a guardian appointed in another state. This can be a problem when an incapacitated elderly person needs to move to another state or the guardian needs to conduct business in another state on his or her behalf. The need to establish a new guardianship in another state because of these gaps in states' law can make it difficult for guardians and the courts that supervise them to ensure that they fulfill their responsibilities.

The prospect of increasing numbers of incapacitated elderly people in the year's ahead signals the need to reassess the way in which state and local courts and federal agencies work together in efforts to protect incapacitated elderly people.

Recommendations

To increase the ability of representative payee programs to protect federal benefit payments from misuse, SSA should convene an interagency study group that includes representatives from HHS, federal agencies with representative payee programs, including VA and OPM, and state courts that wish to participate in order to study the costs and benefits of options for improving interagency cooperation and federal-state cooperation in the protection of incapacitated elderly and non-elderly people. Options may include:

- prompt and systematic sharing among federal agencies' representative payee programs of information such as the identity of individuals who are incapacitated, the identity of those individuals' designated guardians and representative payees, the identity of guardians and representative payees who fail to fulfill their duties, and the assignment of successor guardians and successor representative payees; and

- prompt and systematic sharing of similar information among federal agencies and courts responsible for guardianships that choose to participate.

Information-sharing initiatives must be designed in a manner that is cost-effective, respectful of privacy rights, and consistent with federal nondisclosure requirements concerning confidential information.

To facilitate state efforts to improve oversight of guardianships and to aid guardians in the fulfillment of their responsibilities, the Department of Health and Human Services should work with national organizations involved in guardianship programs, such as the those represented on the National Guardianship Network, to provide support and leadership to the states for cost-effective pilot and demonstration projects to:

- develop cost-effective approaches for compiling, on a continuing basis, consistent national data concerning guardianships to aid in the management of programs for protecting incapacitated adults, such as the age of the incapacitated person, the type of guardian appointed, etc;

- study options for compiling data from federal agencies and state agencies, such as Adult Protective Services agencies, concerning the incidence of elder abuse in cases in which the victim had granted someone the durable power of attorney or had been assigned a fiduciary, such as a guardian or representative payee, and in cases in which the victim did not have a fiduciary; and

- review state policies and procedures concerning interstate transfer and recognition of guardianship appointments to facilitate efficient and cost-effective solutions for interstate jurisdictional issues.

Agency Comments

We provided a draft of this report to SSA, OPM, VA, and HHS and received written comments on the draft from all four. See appendixes IV, V, VI, and VII for their responses.

SSA disagreed with our recommendation concerning an interagency study group. It views the study we recommend as something beyond its purview. Although SSA shares concern about incapacitated people's general welfare, it stated that its responsibility focuses on ensuring that any SSA benefits incapacitated people receive are used for their maintenance and welfare. SSA stated that systematic sharing of information among federal agencies and state courts would be extremely difficult and a study group focusing on such sharing would not be within SSA's purview. SSA also commented that efforts to coordinate with state courts must meet Privacy Act requirements, and in that regard they noted that there is currently no statement of routine use allowing SSA to share representative payee information with state courts. Because state courts, SSA, and other federal agencies have such different policies regarding representative payees and guardians, SSA believes that it is constrained by the Privacy Act in releasing information.

We believe that the systematic exchange of data could help SSA better ensure that SSA benefits are used for incapacitated people's maintenance and welfare. The interagency study group should be able to develop policies allowing for the sharing of information consistent with the Privacy Act and other applicable nondisclosure requirements. We believe that an interagency study group could identify carefully specified kinds of information that under specified circumstances could be shared among limited numbers of federal and state court officials with jurisdiction over guardianships in a manner that is consistent with the Privacy Act and other applicable nondisclosure requirements. SSA and the other federal agencies involved have the authority to develop statements of routine use to provide for such exchange of information. They currently have such agreements in place to share data with other federal agencies, such as SSA's sharing of information concerning its representative payees with a limited number of VA staff. Although exchange of data among federal agencies with representative payee programs may be easier to establish than exchange between federal agencies and state courts, further study is warranted to assess the feasibility of such exchange and the extent to which it could enable courts and federal agencies to better protect incapacitated elderly people.

VA and OPM agreed with our conclusions pertaining to their agencies, indicating that they look forward to participating in the study group we are recommending. VA noted wide variations in state guardianship laws and procedures, the need for federal agencies and state courts to share information on cases of common interest, and the current lack of systematic information sharing among federal agencies state agencies, and state courts relating to the protection of elderly beneficiaries. OPM suggested that we assert that it would be to the federal government's benefit, either in terms of efficiency or savings, to create systems for sharing information on guardians or representative payees. OPM also urged that we add to the report statistics demonstrating the efficiency of coordination with state courts. Although adding these would strengthen the report, data necessary to do so are not currently available. Our findings strongly suggest that savings and greater efficiency would result from collaboration, but the extent to which this is the case will not be known until agencies and state courts start collaborating in efforts to assess overlaps in the populations of incapacitated people they serve, incidence of abuse, and the costs and benefits of data exchange.

HHS agreed that guardians should be adequately trained and monitored, and that governmental agencies and courts should coordinate their efforts and share information concerning guardians and representative payees. HHS plans to carry out our recommendation to study options for compiling data from federal agencies and state agencies concerning the incidence of elder abuse in cases in which the victim had granted someone the durable power of attorney or had been assigned a fiduciary, such as a guardian or representative payee. This year the National Center on Elder Abuse will survey all state adult protective services agencies to determine the incidence of elder abuse reports and the characteristics of victims and perpetrators. The center plans to ask states to cite the number or percentage of perpetrators of elder abuse who served as the victims' powers of attorney, guardians, or representative payees. HHS also plans to explore cost-effective pilot and demonstration projects to develop approaches for compiling guardianship data and to facilitate solutions for interstate jurisdictional issues. It also agreed to serve on an interagency study group to develop options for improving interagency cooperation and federal-state cooperation in the protection of incapacitated elderly and non-elderly people.

As agreed with your office, unless you publicly announce its contents or authorize its release sooner, we will not distribute it until 30 days from the date of issuance. At that time, we will send copies of this report to the Commissioner of Social Security, the Director of the Office of Personnel

Management, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs. We will also make copies available to others on request. In addition, the report will be available at no charge on GAO's Web site at http://www.gao.gov/.

If you have any questions concerning this report, please contact Barbara Bovbjerg or Alicia Puente Cackley at (202) 512-7215. See appendix VIII for other contacts and staff acknowledgments.

Sincerely yours,

Barbara D Bovbjerg

Barbara D. Bovbjerg
Director, Education, Workforce,
and Income Security Issues

Appendix I: Scope and Methodology

Our review included a review of state laws on guardianship, the development and administration of surveys of state courts in 3 states, visits to 15 courts in 8 states, and interviews with federal officials at the Social Security Administration (SSA), Department of Veterans Affairs (VA), Office of Personnel Management (OPM), and the Department of Health and Human Services (HHS). In addition, one member of the team completed a 2-day training program for professional guardians in Washington State and two attended a conference of the National Guardianship Association. We conducted our review between March 2003 and May 2004 in accord with generally accepted government auditing standards.

To determine what state courts do to ensure that guardians fulfill their responsibilities, we studied both states' laws concerning guardianship and court practices, particularly those concerning court oversight of guardians. Our review of states' laws relied in part on the compilations prepared by the American Bar Association Commission on Law and Aging. To review court practices we limited our scope to courts with jurisdiction over guardianships for the elderly in the three states with the largest elderly populations (residents aged 65 and older)—California, New York, and Florida. Together these three states account for about one-quarter of the nation's elderly population. We administered similar survey instruments tailored to the courts in each of these states. We refined the survey instruments based on pretest visits to court officials at three counties in California, three counties in Florida, and two counties in New York. We sent finalized survey instruments to California Superior Courts in each of California's 58 counties, to circuit courts in each of Florida's 67 counties, and to each of New York's 12 judicial districts. We received usable survey responses from 42 California courts, 55 Florida courts, and 9 of New York's judicial districts for response rates of 72 percent, 82 percent, and 75 percent, respectively. Several courts provided responses to some items, but no responses to other items in the survey instrument. For details on the numbers of responses to each item and a compilation of responses by state, see appendix III. We reviewed courts' survey responses for consistency, but did not independently review the accuracy of the court officials' responses.

To determine what guardianship programs recognized as exemplary do to ensure that guardians fulfill their responsibilities we visited 4 courts to study their procedures. We selected the four courts by contacting members of the National Guardianship Network and asking them which courts throughout the nation they regard as having exemplary practices.[1] The four courts we selected were each identified as exemplary by two or more members of the network. We visited each of the courts and interviewed judges, probate directors, monitoring staff, volunteers, legal staff, and others. In two of the courts, we attended guardianship hearings. We reviewed each of the court's documents concerning probate procedures including state laws, rules of court, training materials, forms, and written and Web site documents. We also examined examples of guardianship case files.

To determine to what extent do state courts and federal agencies coordinate their efforts to protect incapacitated elderly people, we interviewed court officials in each of the four courts recognized as exemplary and in several additional courts. We attended the National Guardianship Association's conference including sessions concerning guardianships and VA and guardianships and the Healthcare Insurance Portability and Privacy Act of 1996.[2] We met with a group of conference attendees, including judges, probate lawyers, and guardians, to discuss federal agencies' interactions with guardians and courts. We also reviewed documents provided by court officials concerning specific cases in which federal agencies were involved in guardianship cases. We also interviewed officials at SSA, VA, OPM, and HHS and reviewed applicable regulations and policy manuals and handbooks.

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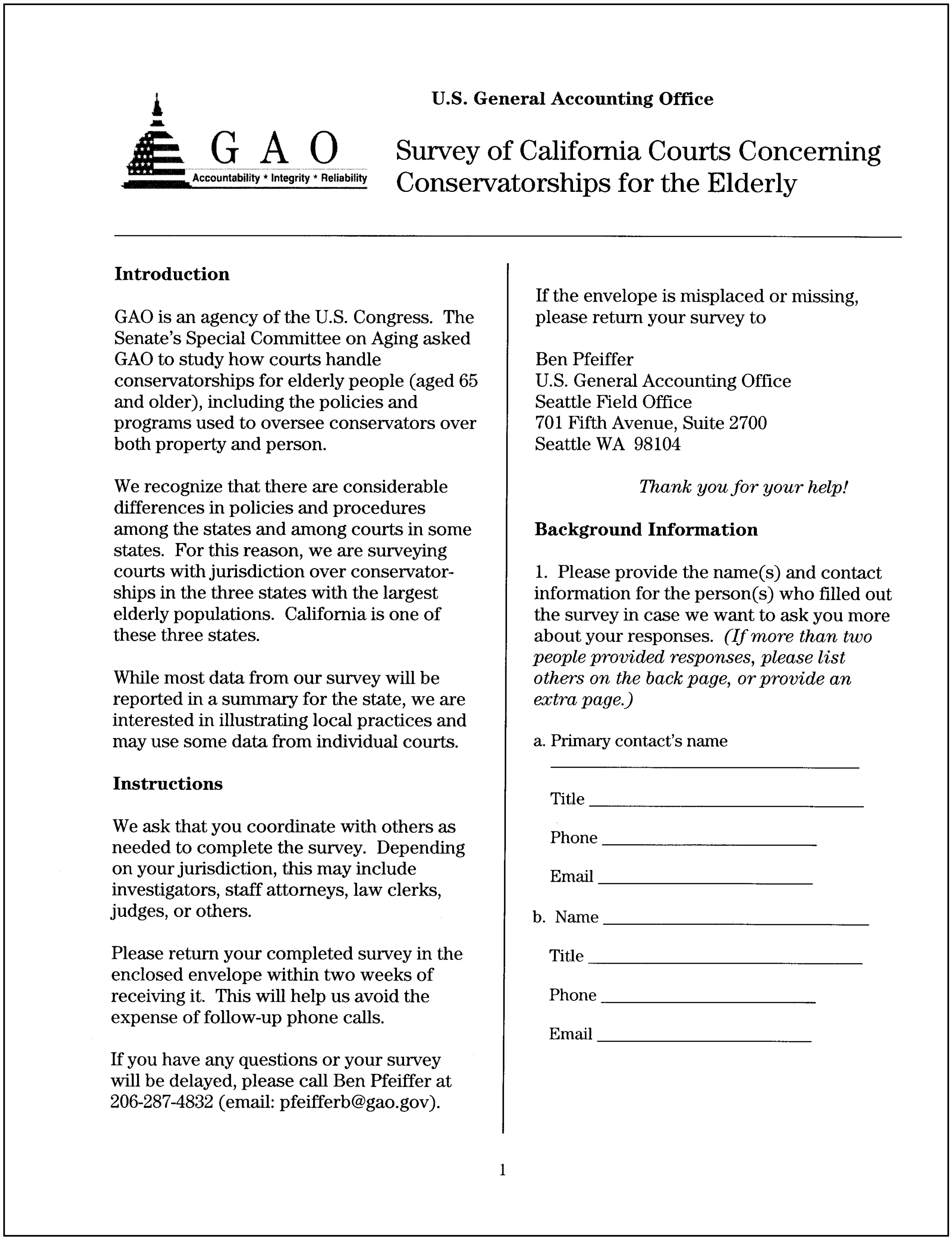
[1] The National Guardianship Network is a joint council representing the National College of Probate Judges, National guardianship Association, American Bar Association—Commission on Law and Aging, National Center for State Courts, National Academy of Elder Law Attorneys, National Guardianship Foundation, American Bar Association—Real Property Probate and Trust Section, and American College of Trust and Estate Counsel.

[2] Pub. L. 104-191, August 21, 1996.

Appendix II: GAO Surveys of Courts in California, Florida, and New York

The following are surveys GAO mailed to the California Superior Court in each of the 58 counties in California, the Florida Circuit Courts in each of the 67 counties in Florida, and the 12 Judicial Districts in New York. For summary results of the survey, see appendix III.



GAO
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U.S. General Accounting Office

Survey of California Courts Concerning Conservatorships for the Elderly

Introduction

GAO is an agency of the U.S. Congress. The Senate's Special Committee on Aging asked GAO to study how courts handle conservatorships for elderly people (aged 65 and older), including the policies and programs used to oversee conservators over both property and person.

We recognize that there are considerable differences in policies and procedures among the states and among courts in some states. For this reason, we are surveying courts with jurisdiction over conservatorships in the three states with the largest elderly populations. California is one of these three states.

While most data from our survey will be reported in a summary for the state, we are interested in illustrating local practices and may use some data from individual courts.

Instructions

We ask that you coordinate with others as needed to complete the survey. Depending on your jurisdiction, this may include investigators, staff attorneys, law clerks, judges, or others.

Please return your completed survey in the enclosed envelope within two weeks of receiving it. This will help us avoid the expense of follow-up phone calls.

If you have any questions or your survey will be delayed, please call Ben Pfeiffer at 206-287-4832 (email: pfeifferb@gao.gov).

If the envelope is misplaced or missing, please return your survey to

Ben Pfeiffer
U.S. General Accounting Office
Seattle Field Office
701 Fifth Avenue, Suite 2700
Seattle WA 98104

Thank you for your help!

Background Information

1. Please provide the name(s) and contact information for the person(s) who filled out the survey in case we want to ask you more about your responses. *(If more than two people provided responses, please list others on the back page, or provide an extra page.)*

a. Primary contact's name

____

Title ______________________________

Phone ________________________

Email ________________________

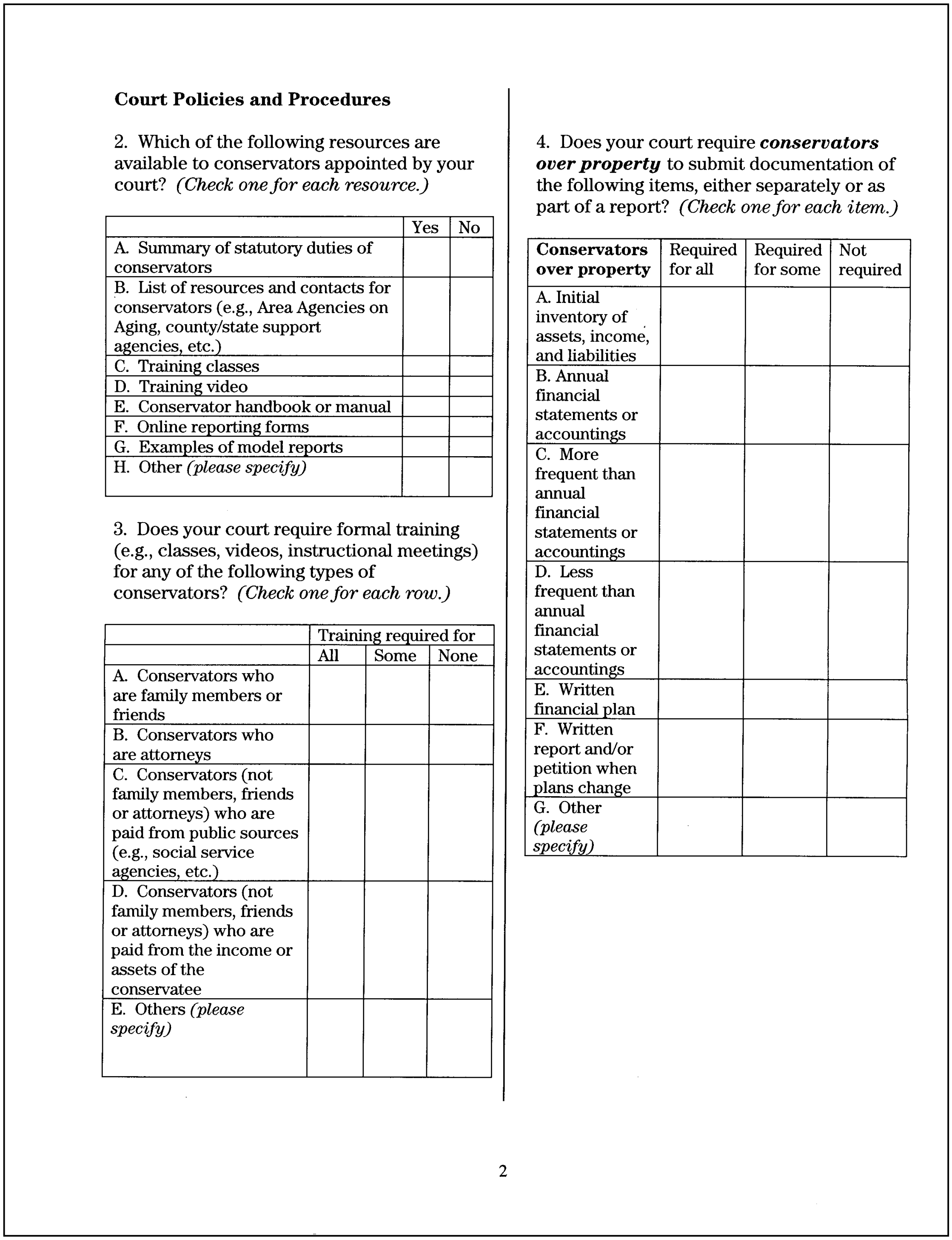
b. Name ______________________________

Title ______________________________

Phone ________________________

Email ________________________

1



Court Policies and Procedures

2. Which of the following resources are available to conservators appointed by your court? *(Check one for each resource.)*

	Yes	No
A. Summary of statutory duties of conservators		
B. List of resources and contacts for conservators (e.g., Area Agencies on Aging, county/state support agencies, etc.)		
C. Training classes		
D. Training video		
E. Conservator handbook or manual		
F. Online reporting forms		
G. Examples of model reports		
H. Other *(please specify)*		

3. Does your court require formal training (e.g., classes, videos, instructional meetings) for any of the following types of conservators? *(Check one for each row.)*

	Training required for		
	All	Some	None
A. Conservators who are family members or friends			
B. Conservators who are attorneys			
C. Conservators (not family members, friends or attorneys) who are paid from public sources (e.g., social service agencies, etc.)			
D. Conservators (not family members, friends or attorneys) who are paid from the income or assets of the conservatee			
E. Others *(please specify)*			

4. Does your court require ***conservators over property*** to submit documentation of the following items, either separately or as part of a report? *(Check one for each item.)*

Conservators over property	Required for all	Required for some	Not required
A. Initial inventory of assets, income, and liabilities			
B. Annual financial statements or accountings			
C. More frequent than annual financial statements or accountings			
D. Less frequent than annual financial statements or accountings			
E. Written financial plan			
F. Written report and/or petition when plans change			
G. Other *(please specify)*			

5. Does your court require ***conservators over persons*** to submit documentation of the following items, either separately or as part of a report? *(Check one for each item.)*

Conservators over persons	Required for all	Required for some	Not required
A. Initial description of personal status			
B. Annual personal status reports			
C. More frequent than annual personal status reports			
D. Less frequent than annual personal status reports			
E. Written plan for personal care			
F. Written report and/or petition when plans change			
G. Other *(please specify)*			

Monitoring Conservatorships

6. How sufficient is your court's funding for monitoring conservatorships? *(Check one.)*

A. Much more than sufficient
B. More than sufficient
C. Sufficient
D. Less than sufficient
E. Much less than sufficient
F. No funds available for this purpose

7. Do courts in your county require that ***conservators over property*** be bonded? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
Which conservators must be bonded?
____
____

C. Not required for conservators over property

8. Do courts in your county require background checks on ***conservators over property***? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
For which conservators are background checks required?
____
____

C. Not required for conservators over property

9. Do courts in your county require background checks on ***conservators over persons***? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
For which conservators are background checks required?
____
____

C. Not required for conservators over persons

10. Other than relying on reports by conservators, which, if any, of the following strategies does your court use *after the initial hearing* to assess the personal status of people who have conservators appointed by the court? *(Check one for each strategy.)*

Court strategy	All/almost all the cases	Most cases	About half the cases	Some cases	No cases
A. Personal visits by court official					
B. Personal visits by persons outside the court, other than the appointed conservator					
C. Periodic hearings on the continued need for conservatorship					
D. Other *(please specify)*					

11. Who reviews financial and personal status reports submitted by conservators appointed by your court? *(Check one for each type of reviewer.)*

	All or almost all reports	Most reports	About half the reports	Some reports	No reports
A. A judge					
B. Court personnel other than judges					
C. Volunteers					
D. Government agencies other than the court					
E. Other *(please specify)*					

12. What steps, if any, are taken to verify information in financial and personal status reports? *(Check one for each step.)*

	All or almost all reports	Most reports	About half the reports	Some reports	No reports
A. Information in personal status reports is verified.					
B. Information in financial reports is verified.					
C. Supporting documentation for financial information must be submitted (e.g., bank/brokerage statements).					
D. Other *(please specify)*					

13. Is your court required to document approval of financial and personal status reports? *(Check one.)*

A. Only required to document approval of financial reports
B. Only required to document approval of personal status reports
C. Required to document approval of both financial and personal status reports
D. No requirements for court to document approval of reports

14. Does your court use a computer(s) to track when financial and/or personal status reports are due and when they are filed? *(Check one.)*

A. Yes, for financial reports only
B. Yes, for personal status reports only
C. Yes, for both financial and personal status reports
D. No

15. About how many of the required conservatorship reports for the elderly are filed on time? *(Check one.)*

A. All or almost all
B. Most
C. About half
D. Less than half
E. Few, if any
F. Do not know

Conservator Compensation

16. In the last 12 months, has your court approved any conservator compensation that was based on a percentage of the value of an elderly conservatee's *estate*? *(Check one.)*

A. Yes→ What is the range of percentages typically approved? _______ % to _______%

B. No

17. In the last 12 months, has your court approved any conservator compensation that was based on a percentage of an elderly conservatee's *income*? *(Check one.)*

A. Yes→ What is the range of percentages typically approved? _____ % to _______%

B. No

18. In the last 12 months, has your court approved any conservator compensation based on an hourly rate? *(Check one.)*

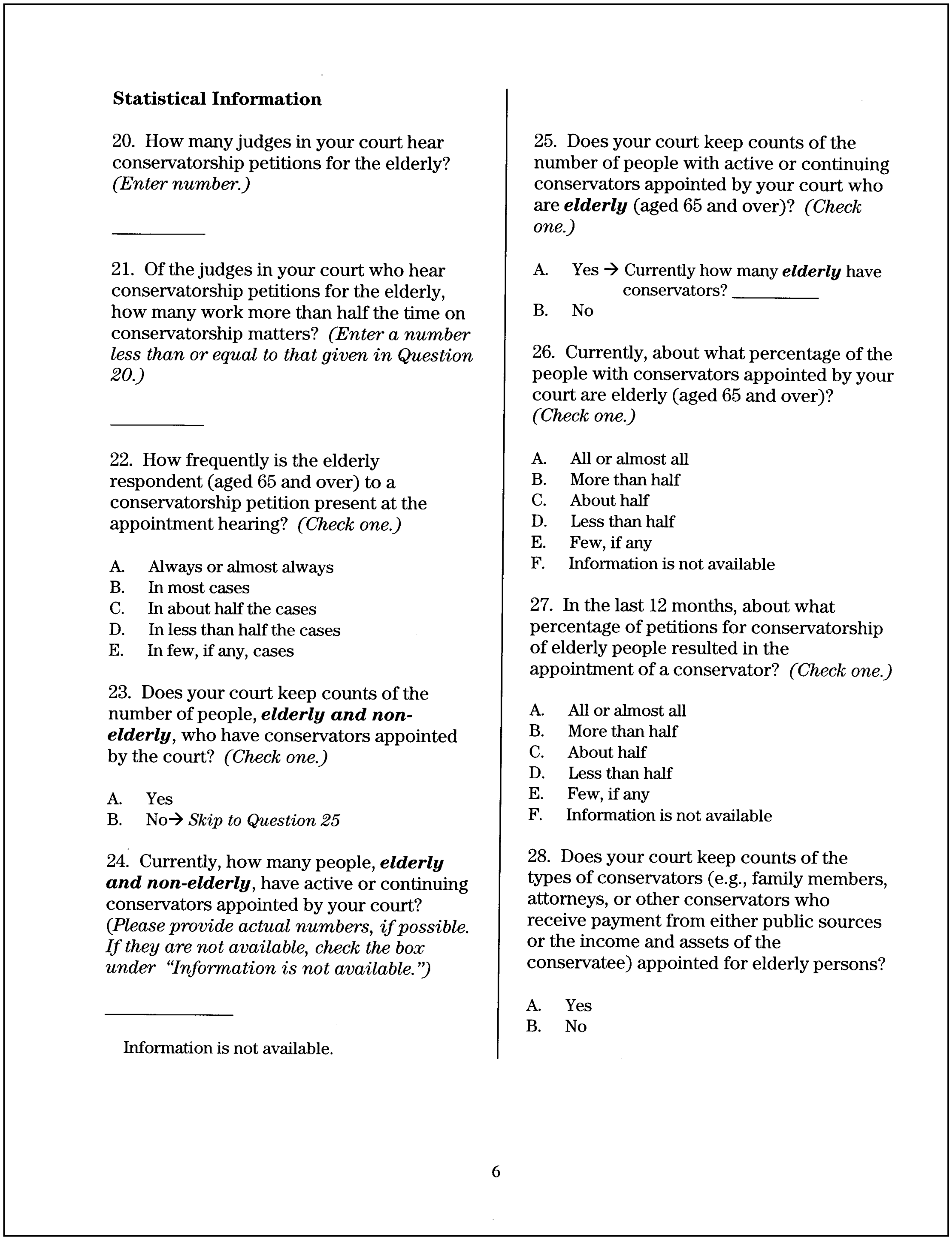
A. Yes→ What is the range of hourly rates typically approved? $_______ to $_______

B. No

19. How does your court handle petitions from conservators for compensation? *(Check one for each row.)*

	All	Some	None
A. Court personnel review petitions.			
B. Judges review petitions.			
C. Conservators are required to submit time and expense records to support their compensation petitions.			
D. Petitions are approved by court personnel or judge unless a problem surfaces.			
E. Final approval is required by circuit or state office.			
F. Other *(please specify)*			

5



Statistical Information

20. How many judges in your court hear conservatorship petitions for the elderly? *(Enter number.)*

____

21. Of the judges in your court who hear conservatorship petitions for the elderly, how many work more than half the time on conservatorship matters? *(Enter a number less than or equal to that given in Question 20.)*

____

22. How frequently is the elderly respondent (aged 65 and over) to a conservatorship petition present at the appointment hearing? *(Check one.)*

A. Always or almost always
B. In most cases
C. In about half the cases
D. In less than half the cases
E. In few, if any, cases

23. Does your court keep counts of the number of people, ***elderly and non-elderly***, who have conservators appointed by the court? *(Check one.)*

A. Yes
B. No→ *Skip to Question 25*

24. Currently, how many people, ***elderly and non-elderly***, have active or continuing conservators appointed by your court? *(Please provide actual numbers, if possible. If they are not available, check the box under "Information is not available.")*

____

Information is not available.

25. Does your court keep counts of the number of people with active or continuing conservators appointed by your court who are ***elderly*** (aged 65 and over)? *(Check one.)*

A. Yes → Currently how many ***elderly*** have conservators? __________
B. No

26. Currently, about what percentage of the people with conservators appointed by your court are elderly (aged 65 and over)? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

27. In the last 12 months, about what percentage of petitions for conservatorship of elderly people resulted in the appointment of a conservator? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

28. Does your court keep counts of the types of conservators (e.g., family members, attorneys, or other conservators who receive payment from either public sources or the income and assets of the conservatee) appointed for elderly persons?

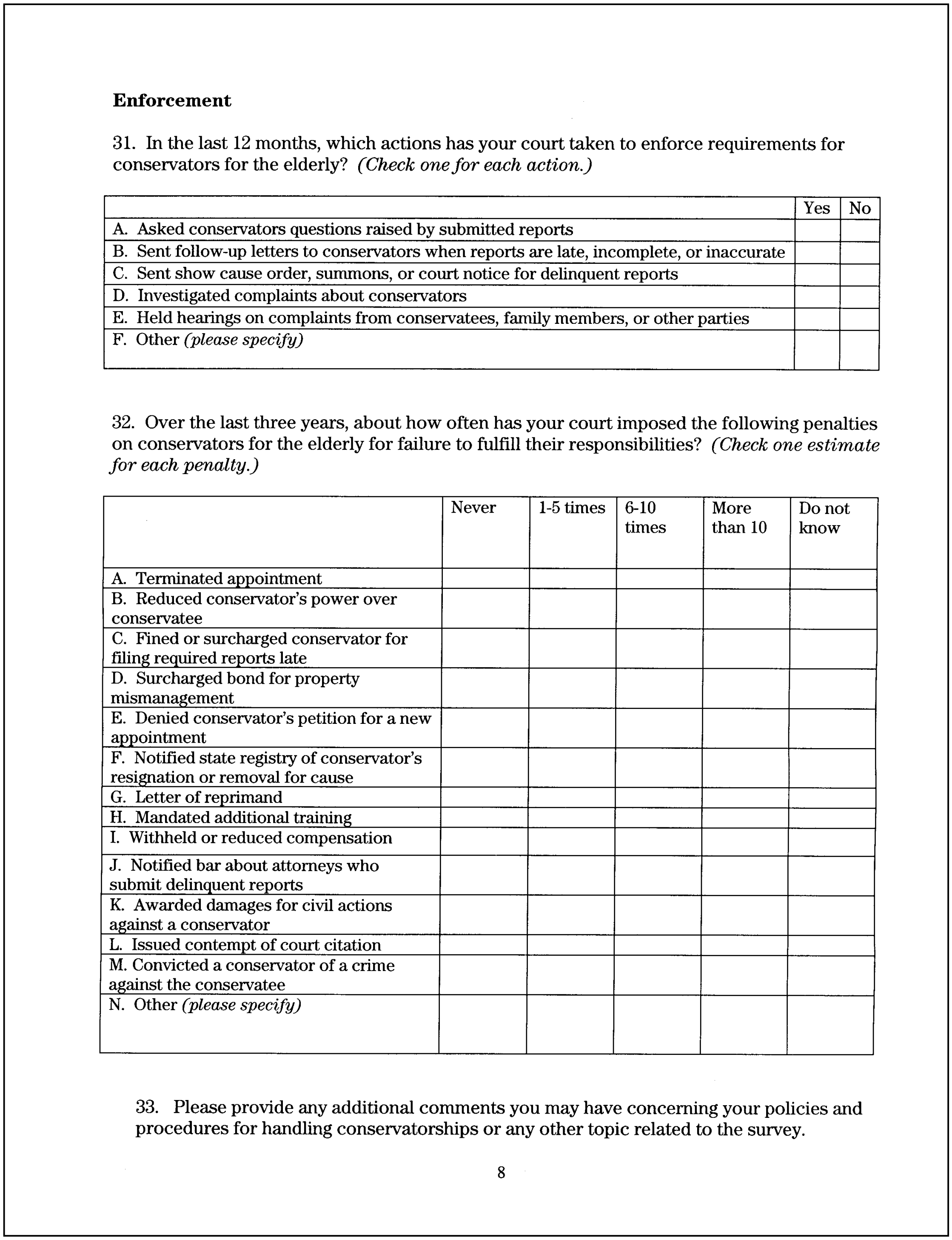
A. Yes
B. No

29. How frequently does your court appoint each of the following types of conservators for elderly persons? *(Check one for each type.)*

	Few, if any, cases	Less than half the cases	About half the cases	Most cases	All or almost all the cases
A. Conservators who are family members or friends					
B. Conservators who are attorneys					
C. Conservators, other than family members, friends, or attorneys, who receive payment for services from public sources (e.g., social service agencies, etc.)					
D. Conservators, other than family members, friends, or attorneys, who receive payment for services from the income or assets of the conservatee					
E. Other *(please specify)*					

30. About what percentage of the conservators appointed by your court are on the state registry? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available



Enforcement

31. In the last 12 months, which actions has your court taken to enforce requirements for conservators for the elderly? *(Check one for each action.)*

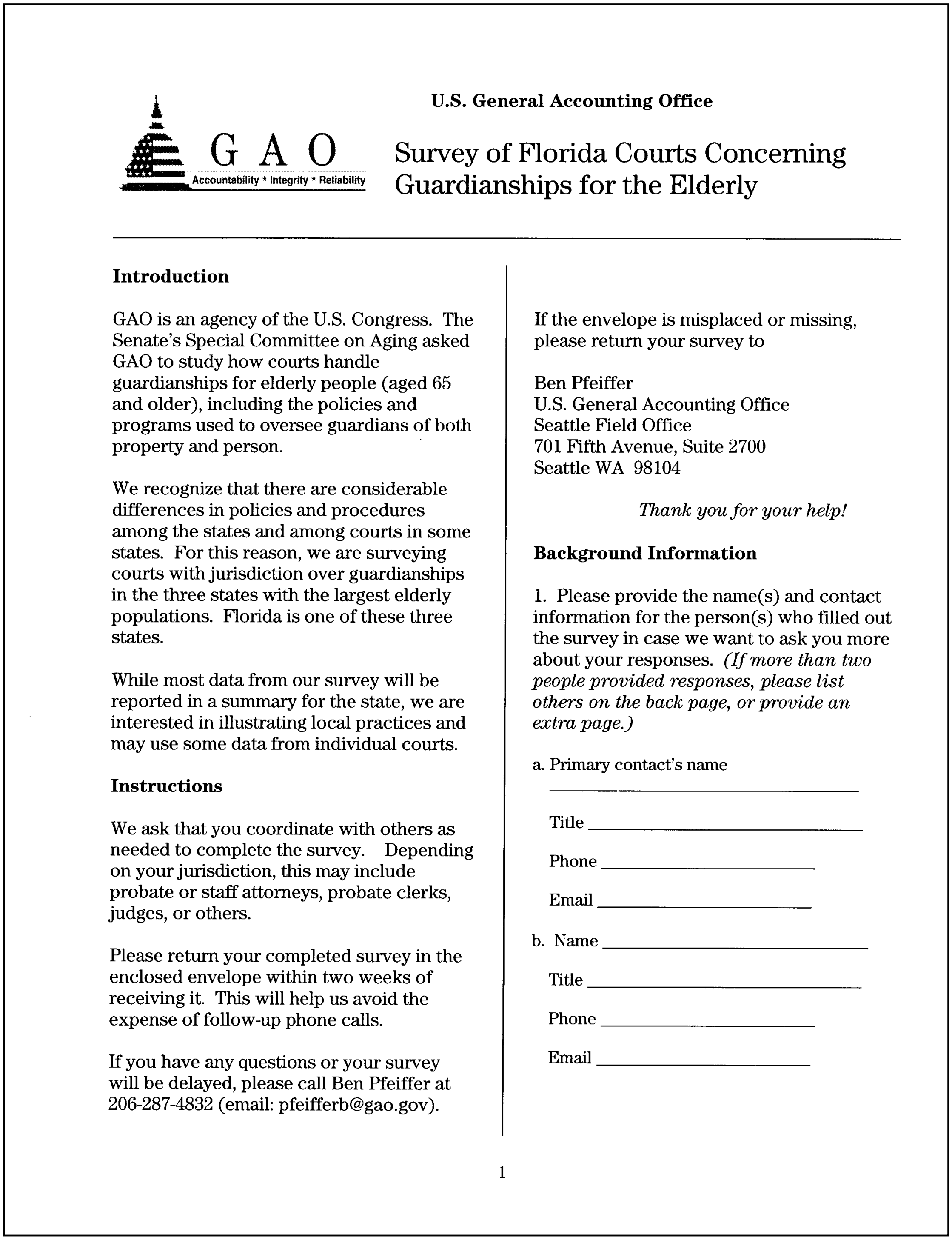
	Yes	No
A. Asked conservators questions raised by submitted reports		
B. Sent follow-up letters to conservators when reports are late, incomplete, or inaccurate		
C. Sent show cause order, summons, or court notice for delinquent reports		
D. Investigated complaints about conservators		
E. Held hearings on complaints from conservatees, family members, or other parties		
F. Other *(please specify)*		

32. Over the last three years, about how often has your court imposed the following penalties on conservators for the elderly for failure to fulfill their responsibilities? *(Check one estimate for each penalty.)*

	Never	1-5 times	6-10 times	More than 10	Do not know
A. Terminated appointment					
B. Reduced conservator's power over conservatee					
C. Fined or surcharged conservator for filing required reports late					
D. Surcharged bond for property mismanagement					
E. Denied conservator's petition for a new appointment					
F. Notified state registry of conservator's resignation or removal for cause					
G. Letter of reprimand					
H. Mandated additional training					
I. Withheld or reduced compensation					
J. Notified bar about attorneys who submit delinquent reports					
K. Awarded damages for civil actions against a conservator					
L. Issued contempt of court citation					
M. Convicted a conservator of a crime against the conservatee					
N. Other *(please specify)*					

33. Please provide any additional comments you may have concerning your policies and procedures for handling conservatorships or any other topic related to the survey.

8



U.S. General Accounting Office

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Survey of Florida Courts Concerning Guardianships for the Elderly

Introduction

GAO is an agency of the U.S. Congress. The Senate's Special Committee on Aging asked GAO to study how courts handle guardianships for elderly people (aged 65 and older), including the policies and programs used to oversee guardians of both property and person.

We recognize that there are considerable differences in policies and procedures among the states and among courts in some states. For this reason, we are surveying courts with jurisdiction over guardianships in the three states with the largest elderly populations. Florida is one of these three states.

While most data from our survey will be reported in a summary for the state, we are interested in illustrating local practices and may use some data from individual courts.

Instructions

We ask that you coordinate with others as needed to complete the survey. Depending on your jurisdiction, this may include probate or staff attorneys, probate clerks, judges, or others.

Please return your completed survey in the enclosed envelope within two weeks of receiving it. This will help us avoid the expense of follow-up phone calls.

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U.S. General Accounting Office
Seattle Field Office
701 Fifth Avenue, Suite 2700
Seattle WA 98104

Thank you for your help!

Background Information

1. Please provide the name(s) and contact information for the person(s) who filled out the survey in case we want to ask you more about your responses. *(If more than two people provided responses, please list others on the back page, or provide an extra page.)*

a. Primary contact's name
____

Title ____________________________

Phone ______________________

Email ______________________

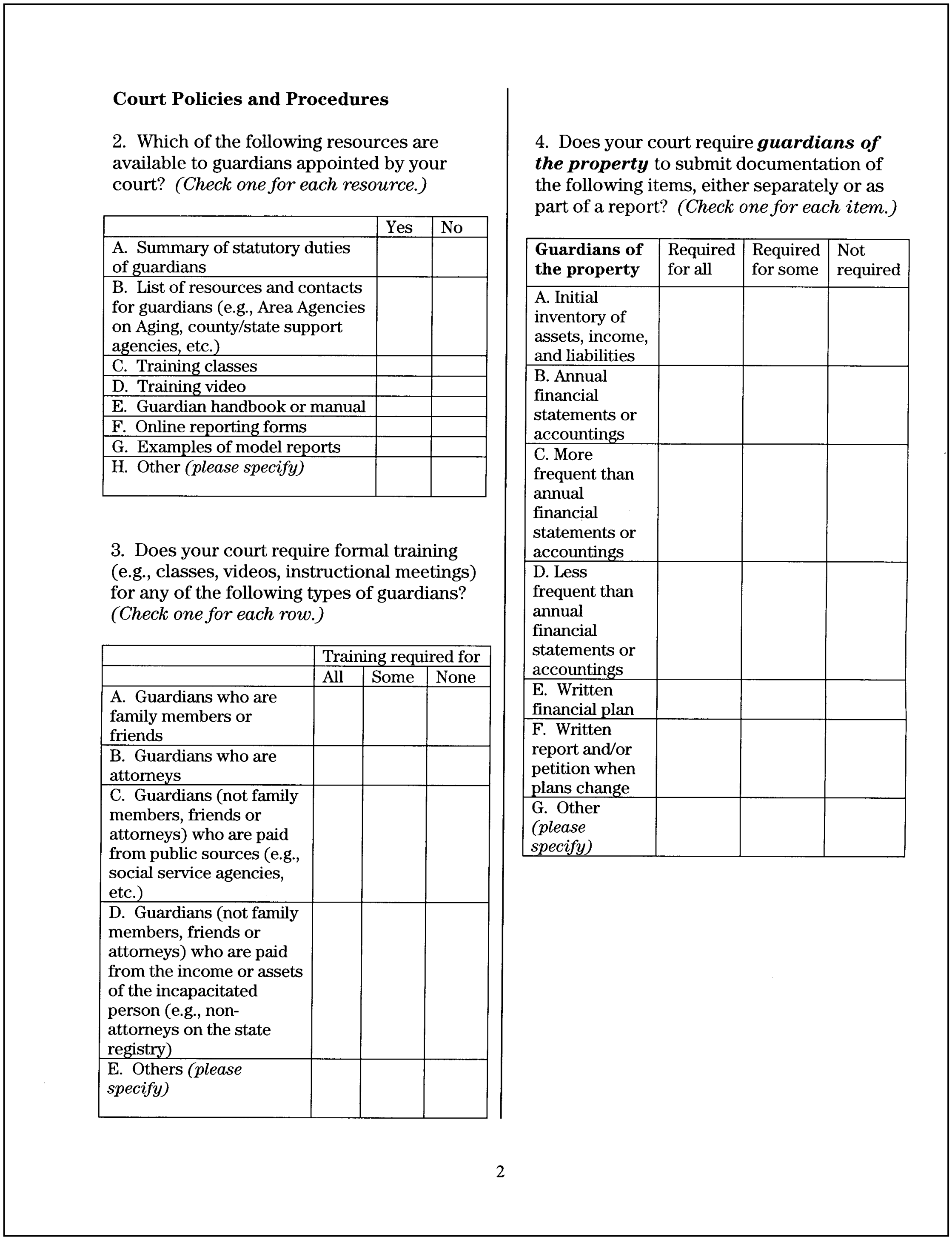
b. Name ___________________________

Title ____________________________

Phone ______________________

Email ______________________

1



Court Policies and Procedures

2. Which of the following resources are available to guardians appointed by your court? *(Check one for each resource.)*

	Yes	No
A. Summary of statutory duties of guardians		
B. List of resources and contacts for guardians (e.g., Area Agencies on Aging, county/state support agencies, etc.)		
C. Training classes		
D. Training video		
E. Guardian handbook or manual		
F. Online reporting forms		
G. Examples of model reports		
H. Other *(please specify)*		

3. Does your court require formal training (e.g., classes, videos, instructional meetings) for any of the following types of guardians? *(Check one for each row.)*

	Training required for		
	All	Some	None
A. Guardians who are family members or friends			
B. Guardians who are attorneys			
C. Guardians (not family members, friends or attorneys) who are paid from public sources (e.g., social service agencies, etc.)			
D. Guardians (not family members, friends or attorneys) who are paid from the income or assets of the incapacitated person (e.g., non-attorneys on the state registry)			
E. Others *(please specify)*			

4. Does your court require ***guardians of the property*** to submit documentation of the following items, either separately or as part of a report? *(Check one for each item.)*

Guardians of the property	Required for all	Required for some	Not required
A. Initial inventory of assets, income, and liabilities			
B. Annual financial statements or accountings			
C. More frequent than annual financial statements or accountings			
D. Less frequent than annual financial statements or accountings			
E. Written financial plan			
F. Written report and/or petition when plans change			
G. Other *(please specify)*			

2

5. Does your court require ***guardians of the person*** to submit documentation of the following items, either separately or as part of a report? *(Check one for each item.)*

Guardians of the person	Required for all	Required for some	Not required
A. Initial description of personal status			
B. Annual personal status reports			
C. More frequent than annual personal status reports			
D. Less frequent than annual personal status reports			
E. Written plan for personal care			
F. Written report and/or petition when plans change			
G. Other *(please specify)*			

Monitoring Guardianships

6. How sufficient is your court's funding for monitoring guardianships? *(Check one.)*

A. Much more than sufficient
B. More than sufficient
C. Sufficient
D. Less than sufficient
E. Much less than sufficient
F. No funds available for this purpose

7. Do courts in your county require that ***guardians of the property*** be bonded? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
Which guardians must be bonded?
____
____

C. Not required for guardians of the property

8. Do courts in your county require background checks on ***guardians of the property***? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
For which guardians are background checks required?
____
____

C. Not required for guardians of the property

9. Do courts in your county require background checks on ***guardians of the person***? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
For which guardians are background checks required?
____
____

C. Not required for guardians of the person

10. Other than relying on reports by guardians, which, if any, of the following strategies does your court use *after the initial hearing* to assess the personal status of people who have guardians appointed by the court? *(Check one for each strategy.)*

Court strategy	All/almost all the cases	Most cases	About half the cases	Some cases	No cases
A. Personal visits by court official					
B. Personal visits by persons outside the court, other than the appointed guardian					
C. Periodic hearings on the continued need for guardianship					
D. Other *(please specify)*					

11. Who reviews financial and personal status reports submitted by guardians appointed by your court? *(Check one for each type of reviewer.)*

	All or almost all reports	Most reports	About half the reports	Some reports	No reports
A. A judge					
B. Court personnel other than judges					
C. Volunteers					
D. Government agencies other than the court					
E. Other *(please specify)*					

12. What steps, if any, are taken to verify information in financial and personal status reports? *(Check one for each step.)*

	All or almost all reports	Most reports	About half the reports	Some reports	No reports
A. Information in personal status reports is verified.					
B. Information in financial reports is verified.					
C. Supporting documentation for financial information must be submitted (e.g., bank/brokerage statements).					
D. Other *(please specify)*					

13. Is your court required to document approval of financial and personal status reports? *(Check one.)*

A. Only required to document approval of financial reports
B. Only required to document approval of personal status reports
C. Required to document approval of both financial and personal status reports
D. No requirements for court to document approval of reports

14. Does your court use a computer(s) to track when financial and/or personal status reports are due and when they are filed? *(Check one.)*

A. Yes, for financial reports only
B. Yes, for personal status reports only
C. Yes, for both financial and personal status reports
D. No

15. About how many of the required guardianship reports for the elderly are filed on time? *(Check one.)*

A. All or almost all
B. Most
C. About half
D. Less than half
E. Few, if any
F. Do not know

Guardian Compensation

16. In the last 12 months, has your court approved any guardian compensation that was based on a percentage of the value of an elderly incapacitated person's *estate*? *(Check one.)*

A. Yes→ What is the range of percentages typically approved? _______ % to _______%

B. No

17. In the last 12 months, has your court approved any guardian compensation that was based on a percentage of an elderly incapacitated person's *income*? *(Check one.)*

A. Yes→ What is the range of percentages typically approved? _____ % to _______%

B. No

18. In the last 12 months, has your court approved any guardian compensation based on an hourly rate? *(Check one.)*

A. Yes→ What is the range of hourly rates typically approved? $_______ to $_______

B. No

19. How does your court handle petitions from guardians for compensation? *(Check one for each row.)*

	All	Some	None
A. Court personnel review petitions.			
B. Judges review petitions.			
C. Guardians are required to submit time and expense records to support their compensation petitions.			
D. Petitions are approved by court personnel or judge unless a problem surfaces.			
E. Final approval is required by circuit or state office.			
F. Other *(please specify)*			

Statistical Information

20. How many judges in your court hear guardianship petitions for the elderly? *(Enter number.)*

____

21. Of the judges in your court who hear guardianship petitions for the elderly, how many work more than half the time on guardianship matters? *(Enter number less than or equal to that given in Question 20.)*

____

22. How frequently is the elderly respondent (aged 65 and over) to a guardianship petition present at the appointment hearing? *(Check one.)*

A. Always or almost always
B. In most cases
C. In about half the cases
D. In less than half the cases
E. In few, if any, cases

23. Does your court keep counts of the number of people, ***elderly and non-elderly***, who have guardians appointed by the court? *(Check one.)*

A. Yes→ *Please continue*

B. No→ *Skip to Question 25*

24. Currently, how many people, ***elderly and non-elderly***, have active or continuing guardians appointed by your court? (*Please provide actual numbers, if possible. If they are not available, check the box under "Information is not available."*)

____

Information is not available.

25. Does your court keep counts of the number of people with active or continuing guardians appointed by your court who are ***elderly*** (aged 65 and over)? *(Check one.)*

A. Yes → Currently, how many ***elderly*** have guardians? __________
B. No

26. Currently, about what percentage of the people with guardians appointed by your court are elderly (aged 65 and over)? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

27. In the last 12 months, about what percentage of petitions for guardianship of elderly people resulted in the appointment of a guardian? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

28. Does your court keep counts of the types of guardians (e.g., family members, attorneys, or other guardians who receive payment from either public sources or the income and assets of the incapacitated person) appointed for elderly persons?

A. Yes
B. No

29. How frequently does your court appoint each of the following types of guardians for elderly persons? *(Check one for each type.)*

	Few, if any, cases	Less than half the cases	About half the cases	Most cases	All or almost all the cases
A. Guardians who are family members or friends					
B. Guardians who are attorneys					
C. Guardians, other than family members, friends, or attorneys, who receive payment for services from public sources (e.g. social service agencies, etc.)					
D. Guardians, other than family members, friends, or attorneys, who receive payment for services from the income or assets of the incapacitated person					
E. Other *(please specify)*					

30. About what percentage of the guardians appointed by your court are on the state registry? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

Enforcement

31. In the last 12 months, which actions has your court taken to enforce requirements for guardians for the elderly? *(Check one for each action.)*

	Yes	No
A. Asked guardians questions raised by submitted reports		
B. Sent follow-up letters to guardians when reports are late, incomplete, or inaccurate		
C. Sent show cause order, summons, or court notice for delinquent reports		
D. Investigated complaints about guardians		
E. Held hearings on complaints from incapacitated persons, family members, or other parties		
F. Other *(please specify)*		

32. Over the last three years, about how often has your court imposed the following penalties on guardians for the elderly for failure to fulfill their responsibilities? *(Check one estimate for each penalty.)*

	Never	1-5 times	6-10 times	More than 10	Do not know
A. Terminated appointment					
B. Reduced guardian's power over incapacitated person					
C. Fined or surcharged guardian for filing required reports late					
D. Surcharged bond for property mismanagement					
E. Denied guardian's petition for a new appointment					
F. Notified state registry of guardian's resignation or removal for cause					
G. Letter of reprimand					
H. Mandated additional training					
I. Withheld or reduced compensation					
J. Notified bar about attorneys who submit delinquent reports					
K. Awarded damages for civil actions against a guardian					
L. Issued contempt of court citation					
M. Convicted a guardian of a crime against the incapacitated person					
N. Other *(please specify)*					

33. Please provide any additional comments you may have concerning your policies and procedures for handling guardianships or any other topic related to the survey.

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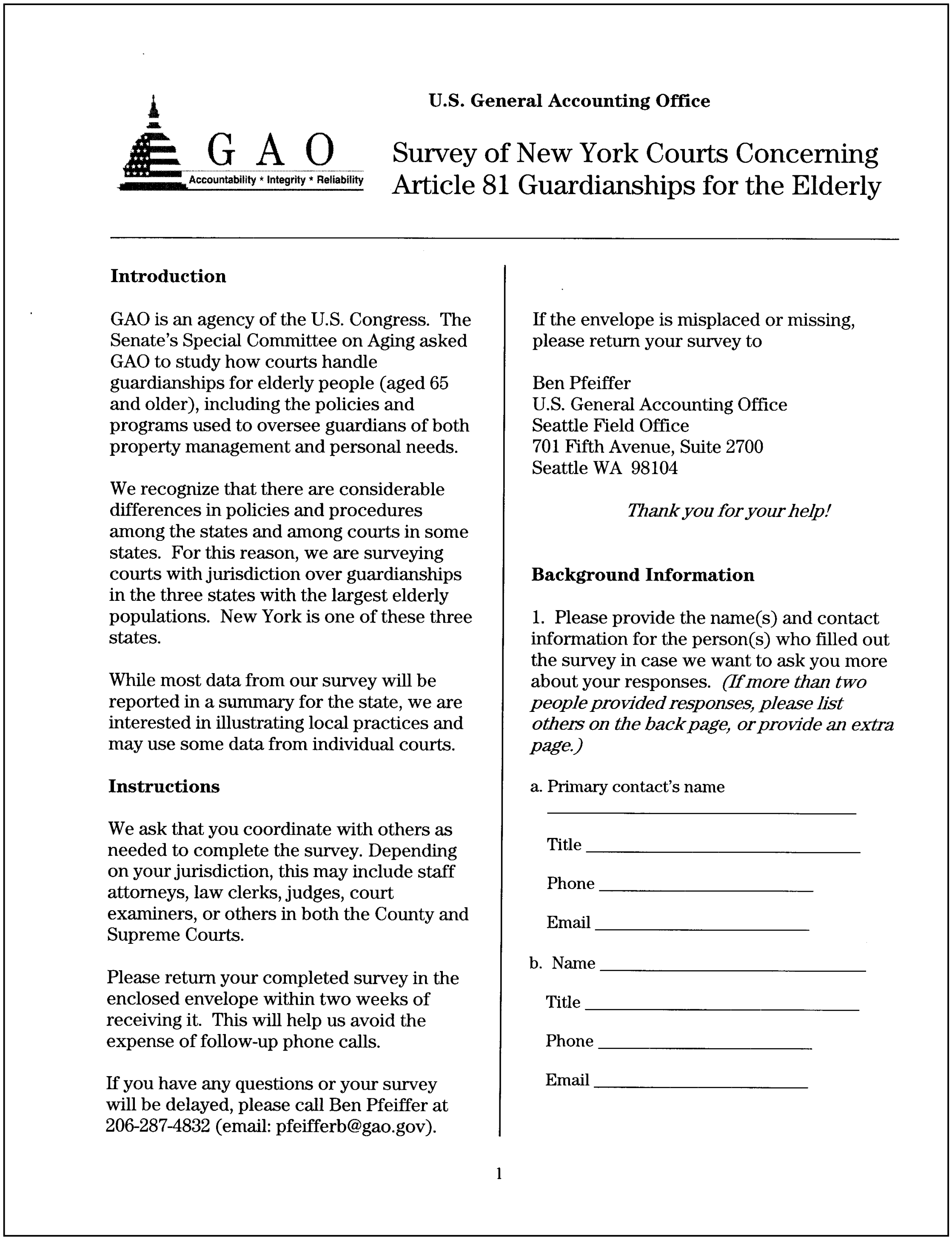

GAO
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U.S. General Accounting Office

Survey of New York Courts Concerning Article 81 Guardianships for the Elderly

Introduction

GAO is an agency of the U.S. Congress. The Senate's Special Committee on Aging asked GAO to study how courts handle guardianships for elderly people (aged 65 and older), including the policies and programs used to oversee guardians of both property management and personal needs.

We recognize that there are considerable differences in policies and procedures among the states and among courts in some states. For this reason, we are surveying courts with jurisdiction over guardianships in the three states with the largest elderly populations. New York is one of these three states.

While most data from our survey will be reported in a summary for the state, we are interested in illustrating local practices and may use some data from individual courts.

Instructions

We ask that you coordinate with others as needed to complete the survey. Depending on your jurisdiction, this may include staff attorneys, law clerks, judges, court examiners, or others in both the County and Supreme Courts.

Please return your completed survey in the enclosed envelope within two weeks of receiving it. This will help us avoid the expense of follow-up phone calls.

If you have any questions or your survey will be delayed, please call Ben Pfeiffer at 206-287-4832 (email: pfeifferb@gao.gov).

If the envelope is misplaced or missing, please return your survey to

Ben Pfeiffer
U.S. General Accounting Office
Seattle Field Office
701 Fifth Avenue, Suite 2700
Seattle WA 98104

Thank you for your help!

Background Information

1. Please provide the name(s) and contact information for the person(s) who filled out the survey in case we want to ask you more about your responses. *(If more than two people provided responses, please list others on the back page, or provide an extra page.)*

a. Primary contact's name
____

Title ______________________________

Phone ______________________________

Email ______________________________

b. Name ______________________________

Title ______________________________

Phone ______________________________

Email ______________________________

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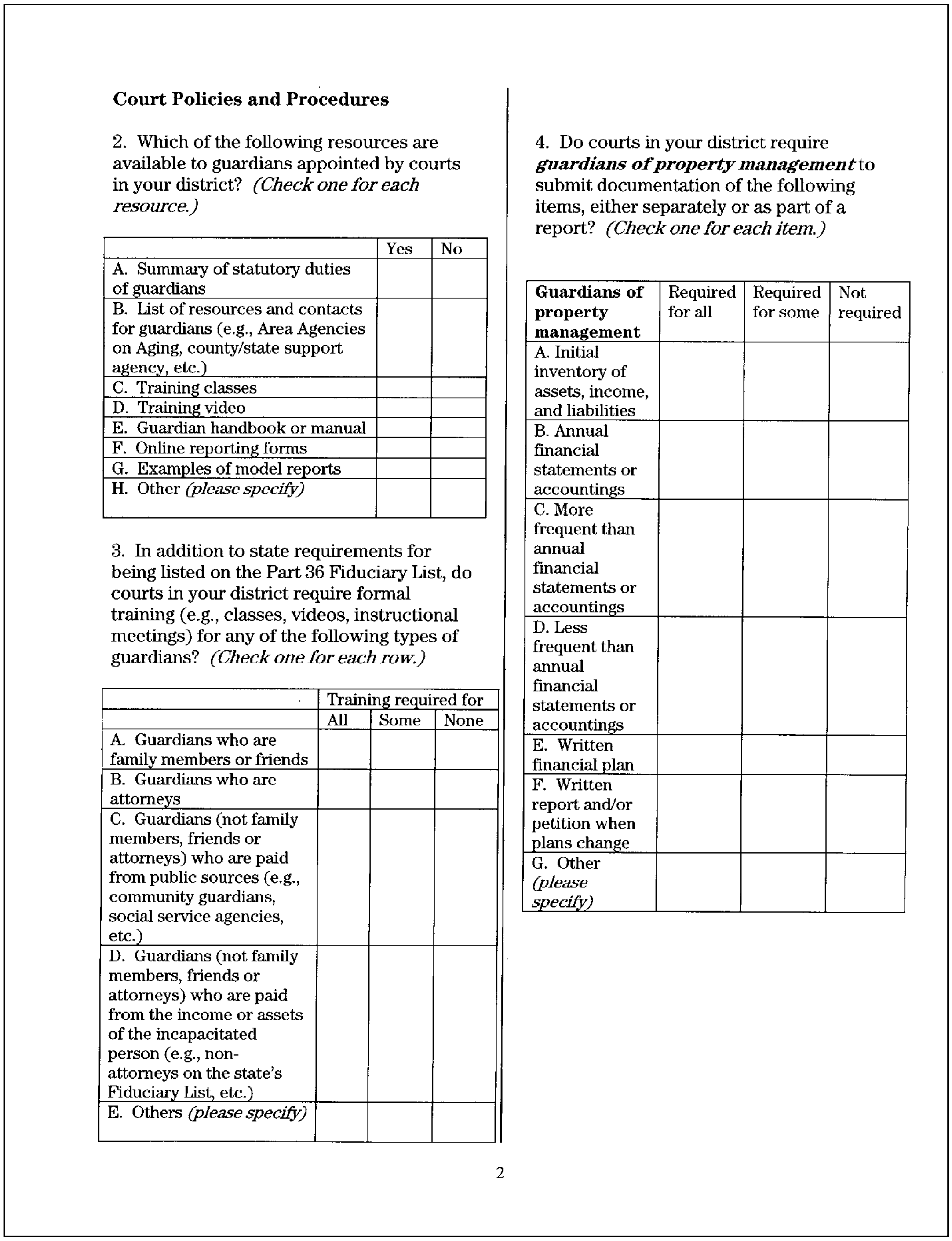


Court Policies and Procedures

2. Which of the following resources are available to guardians appointed by courts in your district? *(Check one for each resource.)*

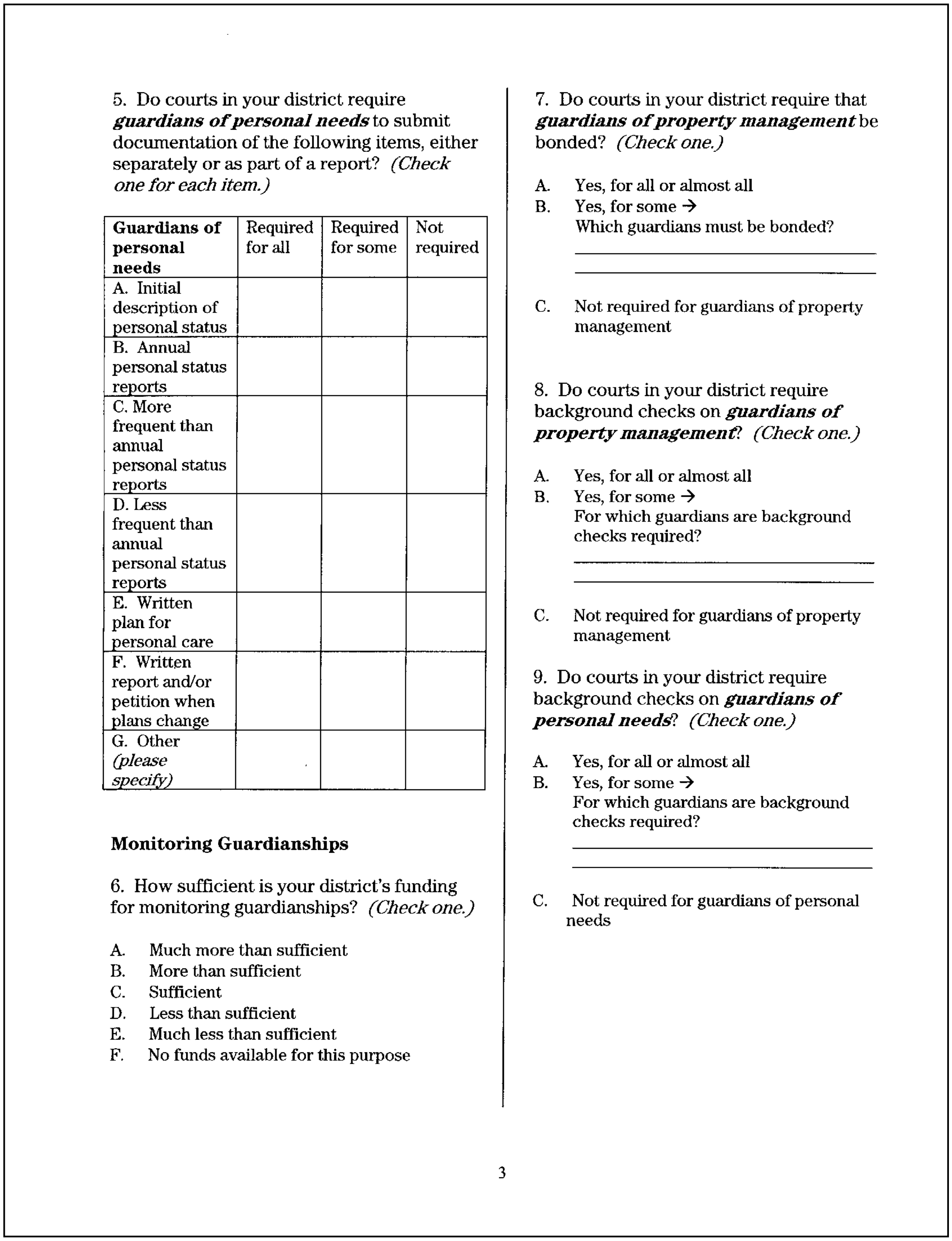
	Yes	No
A. Summary of statutory duties of guardians		
B. List of resources and contacts for guardians (e.g., Area Agencies on Aging, county/state support agency, etc.)		
C. Training classes		
D. Training video		
E. Guardian handbook or manual		
F. Online reporting forms		
G. Examples of model reports		
H. Other *(please specify)*		

3. In addition to state requirements for being listed on the Part 36 Fiduciary List, do courts in your district require formal training (e.g., classes, videos, instructional meetings) for any of the following types of guardians? *(Check one for each row.)*

	Training required for		
	All	Some	None
A. Guardians who are family members or friends			
B. Guardians who are attorneys			
C. Guardians (not family members, friends or attorneys) who are paid from public sources (e.g., community guardians, social service agencies, etc.)			
D. Guardians (not family members, friends or attorneys) who are paid from the income or assets of the incapacitated person (e.g., non-attorneys on the state's Fiduciary List, etc.)			
E. Others *(please specify)*			

4. Do courts in your district require ***guardians of property management*** to submit documentation of the following items, either separately or as part of a report? *(Check one for each item.)*

Guardians of property management	Required for all	Required for some	Not required
A. Initial inventory of assets, income, and liabilities			
B. Annual financial statements or accountings			
C. More frequent than annual financial statements or accountings			
D. Less frequent than annual financial statements or accountings			
E. Written financial plan			
F. Written report and/or petition when plans change			
G. Other *(please specify)*			



5. Do courts in your district require ***guardians of personal needs*** to submit documentation of the following items, either separately or as part of a report? *(Check one for each item.)*

Guardians of personal needs	Required for all	Required for some	Not required
A. Initial description of personal status			
B. Annual personal status reports			
C. More frequent than annual personal status reports			
D. Less frequent than annual personal status reports			
E. Written plan for personal care			
F. Written report and/or petition when plans change			
G. Other *(please specify)*			

Monitoring Guardianships

6. How sufficient is your district's funding for monitoring guardianships? *(Check one.)*

A. Much more than sufficient
B. More than sufficient
C. Sufficient
D. Less than sufficient
E. Much less than sufficient
F. No funds available for this purpose

7. Do courts in your district require that ***guardians of property management*** be bonded? *(Check one.)*

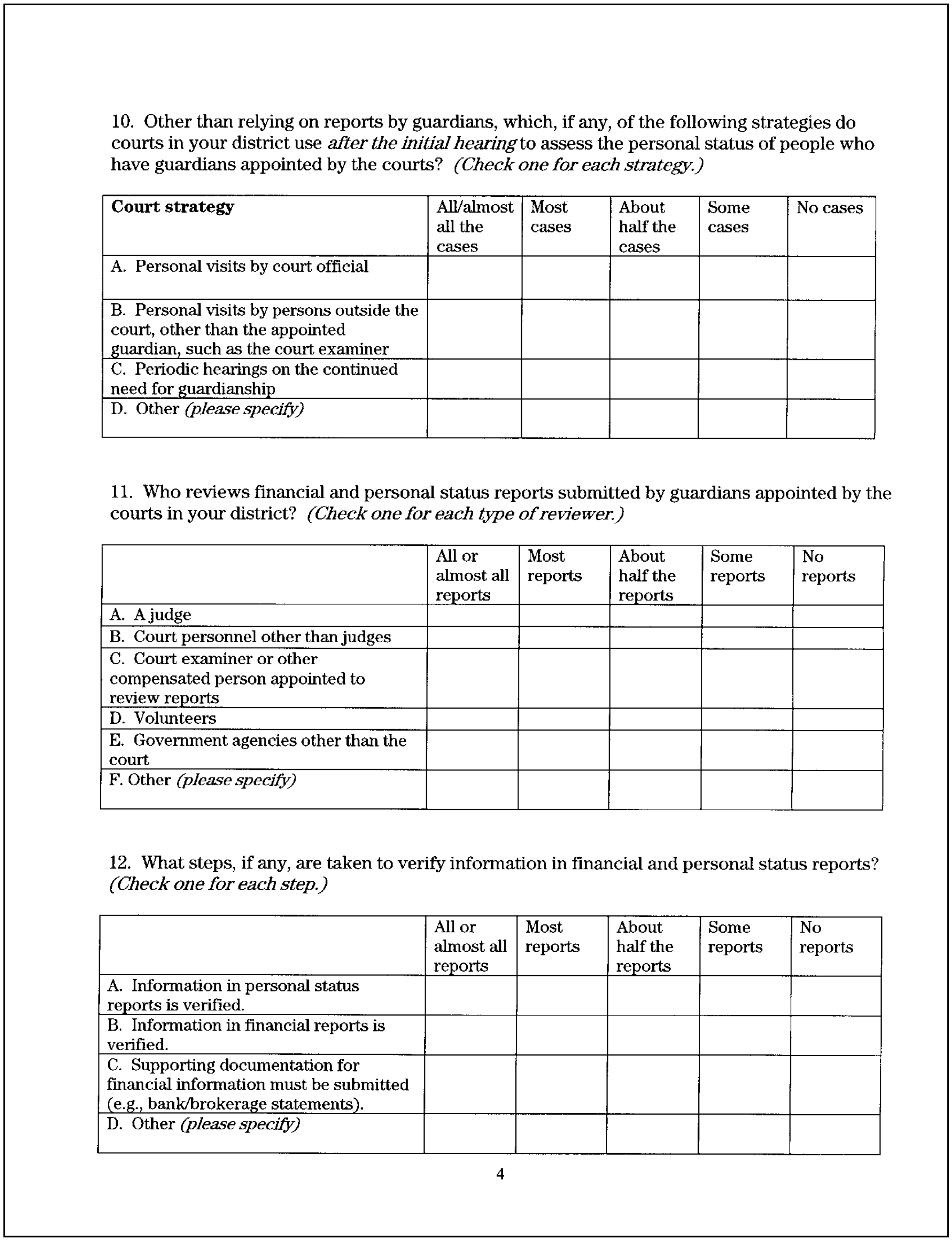
A. Yes, for all or almost all
B. Yes, for some →
Which guardians must be bonded?
____
____
C. Not required for guardians of property management

8. Do courts in your district require background checks on ***guardians of property management***? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
For which guardians are background checks required?
____
____
C. Not required for guardians of property management

9. Do courts in your district require background checks on ***guardians of personal needs***? *(Check one.)*

A. Yes, for all or almost all
B. Yes, for some →
For which guardians are background checks required?
____
____
C. Not required for guardians of personal needs



10. Other than relying on reports by guardians, which, if any, of the following strategies do courts in your district use *after the initial hearing* to assess the personal status of people who have guardians appointed by the courts? *(Check one for each strategy.)*

Court strategy	All/almost all the cases	Most cases	About half the cases	Some cases	No cases
A. Personal visits by court official					
B. Personal visits by persons outside the court, other than the appointed guardian, such as the court examiner					
C. Periodic hearings on the continued need for guardianship					
D. Other *(please specify)*					

11. Who reviews financial and personal status reports submitted by guardians appointed by the courts in your district? *(Check one for each type of reviewer.)*

	All or almost all reports	Most reports	About half the reports	Some reports	No reports
A. A judge					
B. Court personnel other than judges					
C. Court examiner or other compensated person appointed to review reports					
D. Volunteers					
E. Government agencies other than the court					
F. Other *(please specify)*					

12. What steps, if any, are taken to verify information in financial and personal status reports? *(Check one for each step.)*

	All or almost all reports	Most reports	About half the reports	Some reports	No reports
A. Information in personal status reports is verified.					
B. Information in financial reports is verified.					
C. Supporting documentation for financial information must be submitted (e.g., bank/brokerage statements).					
D. Other *(please specify)*					

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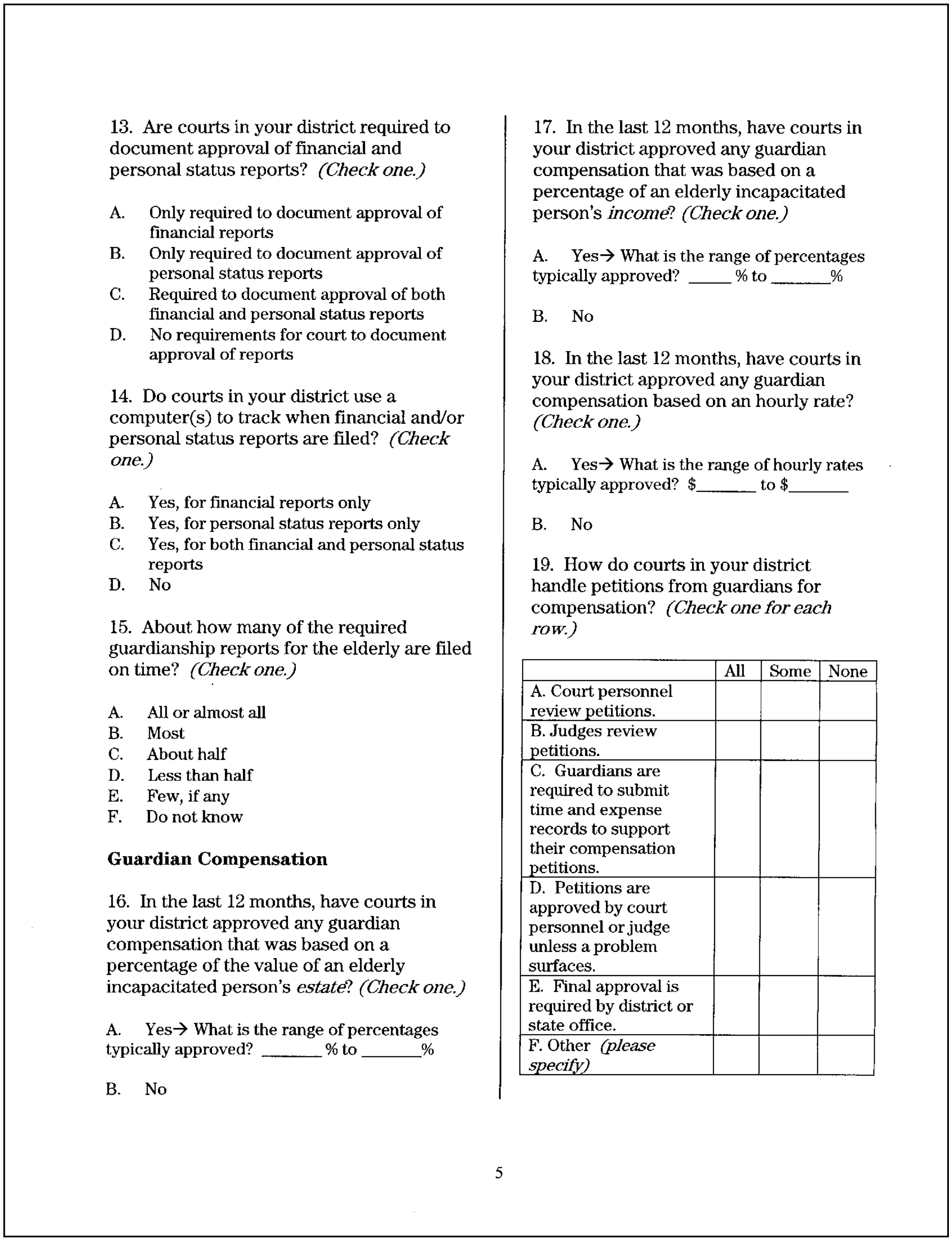

13. Are courts in your district required to document approval of financial and personal status reports? *(Check one.)*

A. Only required to document approval of financial reports
B. Only required to document approval of personal status reports
C. Required to document approval of both financial and personal status reports
D. No requirements for court to document approval of reports

14. Do courts in your district use a computer(s) to track when financial and/or personal status reports are filed? *(Check one.)*

A. Yes, for financial reports only
B. Yes, for personal status reports only
C. Yes, for both financial and personal status reports
D. No

15. About how many of the required guardianship reports for the elderly are filed on time? *(Check one.)*

A. All or almost all
B. Most
C. About half
D. Less than half
E. Few, if any
F. Do not know

Guardian Compensation

16. In the last 12 months, have courts in your district approved any guardian compensation that was based on a percentage of the value of an elderly incapacitated person's *estate*? *(Check one.)*

A. Yes→ What is the range of percentages typically approved? _______ % to _______%

B. No

17. In the last 12 months, have courts in your district approved any guardian compensation that was based on a percentage of an elderly incapacitated person's *income*? *(Check one.)*

A. Yes→ What is the range of percentages typically approved? _____ % to _______%

B. No

18. In the last 12 months, have courts in your district approved any guardian compensation based on an hourly rate? *(Check one.)*

A. Yes→ What is the range of hourly rates typically approved? $_______ to $_______

B. No

19. How do courts in your district handle petitions from guardians for compensation? *(Check one for each row.)*

	All	Some	None
A. Court personnel review petitions.			
B. Judges review petitions.			
C. Guardians are required to submit time and expense records to support their compensation petitions.			
D. Petitions are approved by court personnel or judge unless a problem surfaces.			
E. Final approval is required by district or state office.			
F. Other *(please specify)*			

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Statistical Information

20. How many judges in your district hear guardianship petitions for the elderly? *(Enter number.)*

____

21. Of the judges in your district who hear guardianship petitions for the elderly, how many work more than half the time on Article 81 guardianship matters? *(Enter number less than or equal to that given in Question 20.)*

____

22. How frequently is the elderly respondent (aged 65 and over) to a guardianship petition present at the appointment hearing? *(Check one.)*

A. Always or almost always
B. In most cases
C. In about half the cases
D. In less than half the cases
E. In few, if any, cases

23. Does your district keep counts of the number of people, ***elderly and non-elderly***, who have guardians appointed by the courts in your district? *(Check one.)*

A. Yes→ *Please continue*

B. No→ *Skip to Question 25*

24. Currently, how many people, ***elderly and non-elderly***, have active or continuing guardians appointed by the courts in your district? (*Please provide actual numbers, if possible. If they are not available, check the box under "Information is not available."*)

____

Information is not available.

25. Does your district keep counts of the number of people with active or continuing guardians appointed by courts in your district who are ***elderly*** (aged 65 and over)? *(Check one.)*

A. Yes → Currently, how many ***elderly*** have guardians? __________
B. No

26. Currently, about what percentage of the people with guardians appointed by the courts in your district are elderly (aged 65 and over)? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

27. In the last 12 months, about what percentage of petitions for guardianship of elderly people resulted in the appointment of a guardian? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

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28. Does your district keep counts of the types of guardians (e.g., family members, attorneys, or other guardians who receive payment from either public sources or the income and assets of the incapacitated person) appointed for elderly persons? *(Check one.)*

A. Yes
B. No

29. About what percentage of the guardians appointed by courts in your district are on the state's Part 36 Fiduciary List? *(Check one.)*

A. All or almost all
B. More than half
C. About half
D. Less than half
E. Few, if any
F. Information is not available

30. How frequently do the courts in your district appoint each of the following types of guardians for elderly persons? *(Check one for each type.)*

	Few, if any, cases	Less than half the cases	About half the cases	Most cases	All or almost all the cases
A. Guardians who are family members or friends					
B. Guardians who are attorneys					
C. Guardians, other than attorneys or family members, who receive payment for services from public sources (e.g., community guardians, social service agencies, etc.)					
D. Guardians, other than attorneys or family members, who receive payment for services from the income or assets of the incapacitated person (e.g., non-attorneys on the state Fiduciary List, etc.)					
E. Other *(please specify)*					

Enforcement

31. In the last 12 months, which actions have courts or court examiners in your district taken to enforce requirements for guardians for the elderly? *(Check one for each action.)*

	Yes	No
A. Asked guardians questions raised by submitted reports		
B. Sent follow-up letters to guardians when reports are late, incomplete, or inaccurate		
C. Sent show cause order, summons, or court notice for delinquent reports		
D. Investigated complaints about guardians		
E. Held hearings on complaints from incapacitated persons, family members, court examiners, or other parties		
F. Other *(please specify)*		

32. Over the last three years, about how often have courts in your district imposed the following penalties on guardians for the elderly for failure to fulfill their responsibilities? *(Check one estimate for each penalty.)*

	Never	1-5 times	6-10 times	More than 10 times	Do not know
A. Terminated appointment					
B. Reduced guardian's power over incapacitated person					
C. Fined or surcharged guardian for filing required reports late					
D. Surcharged bond for property mismanagement					
E. Denied guardian's petition for a new appointment					
F. Recommended that a guardian's certification be suspended or their name removed from the Fiduciary List					
G. Letter of reprimand					
H. Mandated additional training					
I. Withheld or reduced compensation					
J. Notified bar about attorneys who submit delinquent reports					
K. Awarded damages for civil actions against a guardian					
L. Issued contempt of court citation					
M. Convicted a guardian of a crime against the incapacitated person					
N. Other *(please specify)*					

33. Please provide any additional comments you may have concerning your policies and procedures for handling guardianships or any other topic related to the survey.

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Appendix III: Results from GAO Surveys of Courts in California, Florida, and New York

Below are tabulations of survey responses received from 42 of the 58 superior courts in California, 55 of the 67 superior courts in Florida, and 9 of the12 judicial districts in New York. In some cases, respondents to the survey did not respond to particular items in the survey.

Court Policies and Procedures

Which of the following resources are available to guardians appointed by your court?[a] (Check one for each resource.)

	California		Florida		New York	
	Yes	No	Yes	No	Yes	No
A. Summary of statutory duties of guardians	31	5	18	30	6	2
B. List of resources and contacts for guardians (e.g., Area Agencies on Aging, county/state support agencies, etc.)	25	10	14	30	6	3
C. Training classes	2	29	30	20	7	2
D. Training video	18	19	13	33	7	2
E. Guardian handbook or manual	40	1	17	29	6	3
F. Online reporting forms	4	24	5	39	3	6
G. Examples of model reports	8	24	10	33	7	2
H. Other (please specify)	2	5	2	5	1	0

[a] Surveys to courts in California use the term “conservators.” In California guardians are appointed to protect minors and conservators are appointed to protect adults. For convenience, for the purposes of this report, we use the term “guardian” rather than “conservator.”

Does your court require formal training (e.g., classes, videos, instructional meetings) for any of the following types of guardians? (Check one for each row.)

	Training required for								
	California			Florida			New York		
	All	Some	None	All	Some	None	All	Some	None
A. Guardians who are family members or friends	10	3	27	31	16	6	4	4	1
B. Guardians who are attorneys	9	1	31	8	5	38	4	2	3
C. Guardians (not family members, friends or attorneys) who are paid from public sources (e.g., social service agencies, etc.)	6	3	31	28	9	11	3	0	5
D. Guardians (not family members, friends or attorneys) who are paid from the income or assets of the incapacitated person (e.g., non-attorneys on the state registry)	9	5	27	37	9	6	4	2	3
E. Others (please specify)	1	0	8	0	1	7	1	0	0

Does your court require guardians of the property to submit documentation of the following items, either separately or as part of a report? (Check one for each item.)

	California				Florida			New York		
Guardians of the property	Required for all	Required for some	Not required	Annual, then biennial[a]	Required for all	Required for some	Not required	Required for all	Required for some	Not required
A. Initial inventory of assets, income, and liabilities	38	3	1		53	2	0	9	0	0
B. Annual financial statements or accountings	13	11	3	15	50	5	0	9	0	0
C. More frequent than annual financial statements or accountings	0	9	30		0	15	39	0	2	7
D. Less frequent than annual financial statements or accountings	5	14	6	15	0	10	43	0	2	7
E. Written financial plan	5	9	26		18	12	24	3	5	1
F. Written report and/or petition when plans change	9	12	18		25	7	21	8	1	0
G. Other (please specify)	3	1	6		0	0	3	0	0	0

[a] California state law generally requires an accounting and report by the end of the first year following the appointment and at 2-year intervals (biennially) thereafter.

Does your court require *guardians of the person* to submit documentation of the following items, either separately or as part of a report? (Check one for each item.)

Guardians of the person	California				Florida			New York		
	Required for all	Required for some	Not required	Annual, then biennial[a]	Required for all	Required for some	Not required	Required for all	Required for some	Not required
A. Initial description of personal status	31	3	8	0	51	2	2	9	0	0
B. Annual personal status reports	9	9	18	3	46	6	2	7	2	0
C. More frequent than annual personal status reports	1	8	29	0	0	10	44	0	4	5
D. Less frequent than annual personal status reports	9	10	18	2	0	6	48	0	1	8
E. Written plan for personal care	7	8	23	1	44	6	5	7	1	1
F. Written report and/or petition when plans change	9	12	19	0	31	10	13	9	0	0
G. Other (please specify)	3	0	5	0	1	0	3	0	0	0

[a] California state law generally requires an accounting and report by the end of the first year following the appointment and at 2-year intervals (biennially) thereafter.

Monitoring Guardianships

How sufficient is your court's funding for monitoring guardianships? (Check one.)

	California	Florida	New York
A. Much more than sufficient	0	0	0
B. More than sufficient	0	0	0
C. Sufficient	7	15	2
D. Less than sufficient	13	5	1
E. Much less than sufficient	9	5	2
F. No funds available for this purpose	10	28	3

Do courts in your county require that guardians of the property be bonded? (Check one.)

	California	Florida	New York
A. Yes, for all or almost all	26	15	4
B. Yes, for some	13	36	4
C. Not required for guardians of the property	3	4	1

Do courts in your county require background checks on guardians of the property? (Check one.)

	California	Florida	New York
A. Yes, for all or almost all	15	8	2
B. Yes, for some	10	31	1
C. Not required for guardians of the property	17	13	6

Do courts in your county require background checks on guardians of the person? (Check one.)

	California	Florida	New York
A. Yes, for all or almost all	17	7	1
B. Yes, for some	8	28	2
C. Not required for guardians of the person	17	17	6

Other than relying on reports by guardians, which, if any, of the following strategies does your court use after the initial hearing to assess the personal status of people who have guardians appointed by the court? (Check one for each strategy.)

Court strategy	All almost all the cases	Most cases	About half the cases	Some cases	No cases
California					
A. Personal visits by court official	32	3	0	1	5
B. Personal visits by persons outside the court, other than the appointed guardian	3	1	0	10	23
C. Periodic hearings on the continued need for guardianship	20	5	2	8	5
D. Other (please specify)	1	0	0	1	8
Florida					
A. Personal visits by court official	0	0	0	7	44
B. Personal visits by persons outside the court, other than the appointed guardian	1	0	1	6	45
C. Periodic hearings on the continued need for guardianship	0	4	1	14	32
D. Other (please specify)	2	0	0	3	7
New York					
A. Personal visits by court official	0	1	0	1	7
B. Personal visits by persons outside the court, other than the appointed guardian	1	0	0	3	5
C. Periodic hearings on the continued need for guardianship	0	1	1	5	2
D. Other (please specify)	0	0	0	0	0

Who reviews financial and personal status reports submitted by guardians appointed by your court? (Check one for each type of reviewer.)

Court strategy	All/almost all the cases	Most cases	About half the cases	Some cases	No cases
California					
A. A judge	30	1	0	7	1
B. Court personnel other than judges	25	2	0	1	11
C. Volunteers	1	0	0	2	30
D. Government agencies other than the court	0	0	0	5	27
E. Other (please specify)	6	0	0	1	10
Florida					
A. A judge	28	2	0	6	6
B. Court personnel other than judges	47	0	0	0	4
C. Volunteers	0	0	0	1	36
D. Government agencies other than the court	4	0	0	6	28
E. Other (please specify)	7	0	1	3	5
New York					
A. A judge	5	0	0	1	3
B. Court personnel other than judges	7	0	0	0	2
C. Court examiner or other compensated person appointed to review reports[a]	8	0	0	0	1
D. Volunteers	0	0	0	0	7
E. Government agencies other than the court	1	0	0	2	6
F. Other (please specify)	0	0	0	0	0

[a] This item was included only in the surveys to New York judicial districts.

What steps, if any, are taken to verify information in financial and personal status reports? (Check one for each step.)

	All or almost all reports	Most reports	About half the reports	Some reports	No reports
California					
A. Information in personal status reports is verified.	22	1	0	5	10
B. Information in financial reports is verified.	16	3	0	11	7
C. Supporting documentation for financial information must be submitted (e.g., bank/brokerage statements).	24	2	0	8	5
D. Other (please specify)	3	0	0	1	7
Florida					
A. Information in personal status reports is verified.	19	2	1	9	18
B. Information in financial reports is verified.	29	1	0	7	11
C. Supporting documentation for financial information must be submitted (e.g., bank/brokerage statements).	48	2	0	4	1
D. Other (please specify)	5	0	0	0	5
New York					
A. Information in personal status reports is verified.	5	1	0	1	2
B. Information in financial reports is verified.	6	1	0	1	1
C. Supporting documentation for financial information must be submitted (e.g., bank/brokerage statements).	5	2	0	2	0
D. Other (please specify)	0	0	0	0	0

Is your court required to document approval of financial and personal status reports? (Check one.)

	California	Florida	New York
A. Only required to document approval of financial reports	12	11	0
B. Only required to document approval of personal status reports	0	0	0
C. Required to document approval of both financial and personal status reports	20	39	6
D. No requirement for court to document approval of reports	8	4	3

Does your court use a computer(s) to track when financial and/or personal status reports are due and when they are filed? (Check one.)

	California	Florida	New York
A. Yes, for financial reports only	4	2	0
B. Yes, for personal status reports only	2	0	0
C. Yes, for both financial and personal status reports	22	37	4
D. No	13	15	5

About how many of the required guardianship reports for the elderly are filed on time? (Check one.)

	California	Florida	New York
A. All or almost all	5	4	0
B. Most	18	16	2
C. About half	6	15	2
D. Less than half	6	14	1
E. Few, if any	3	1	0
F. Do not know	4	5	4

Guardian Compensation

In the last 12 months, has your court approved any guardian compensation that was based on a percentage of the value of an elderly incapacitated person's estate? (Check one.)

	California	Florida	New York
Yes	11	3	7
No	30	48	2

If "Yes," what is the range of percentages typically approved?

California		Florida		New York	
Lowest	Highest	Lowest	Highest	Lowest	Highest
0.75%	5%	0.5%	1.5%	0.03%	5%

In the last 12 months, has your court approved any guardian compensation that was based on a percentage of an elderly incapacitated person's income? (Check one.)

	California	Florida	New York
Yes	4	2	6
No	37	51	3

If "Yes," what is the range of percentages typically approved?

California		Florida		New York	
Lowest	**Highest**	**Lowest**	**Highest**	**Lowest**	**Highest**
0.9%	10%	0%	5%	1%	5%

In the last 12 months, has your court approved any guardian compensation based on an hourly rate? (Check one.)

	California	Florida	New York
Yes	31	35	6
No	11	18	3

If "Yes," what is the range of hourly rates typically approved?

California		Florida		New York	
Lowest	**Highest**	**Lowest**	**Highest**	**Lowest**	**Highest**
$7	$250	$8	$85	$25	$400

How does your court handle petitions from guardians for compensation? (Check one for each row.)

	California			Florida			New York		
	All	Some	None	All	Some	None	All	Some	None
A. Court personnel review petitions.	27	5	8	26	6	19	6	1	2
B. Judges review petitions.	34	7	0	46	1	2	7	2	0
C. Guardians are required to submit time and expense records to support their compensation petitions.	24	12	5	40	6	4	6	3	0
D. Petitions are approved by court personnel or judge unless a problem surfaces.	32	4	6	34	3	6	7	1	1
E. Final approval is required by circuit or state office.	0	0	34	12	2	25	3	0	6
F. Other (please specify)	0	1	7	1	0	5	1	0	0

Statistical Information

How many judges in your court hear guardianship petitions for the elderly? (Enter number.)

	California	Florida	New York
Minimum	1	1	3
Maximum	11	8	32
Mean	1.60	1.62	10.78
Median	1	1	8

Of the judges in your court who hear guardianship petitions for the elderly, how many work more than half the time on guardianship matters? (Enter number less than or equal to that given in Question 20.)

	California	Florida	New York
Minimum	0	0	0
Maximum	1	2	5
Mean	0.34	0.42	1.44
Median	0	0	1

How frequently is the elderly respondent (aged 65 and over) to a guardianship petition present at the appointment hearing? (Check one.)

	California	Florida	New York
A. Always or almost always	3	4	2
B. In most cases	5	3	3
C. In about half the cases	8	6	3
D. In less than half the cases	16	12	1
E. In few, if any, cases	8	28	0

Does your court keep counts of the number of people, elderly and non-elderly, who have guardians appointed by the court? (Check one.)

	California	Florida	New York
Yes	13	12	3
No	29	41	6

Currently, how many people, elderly and non-elderly, have active or continuing guardians appointed by your court? (Please provide actual numbers, if possible. If they are not available, check the box under "Information is not available.")

	California	Florida	New York
Minimum	103	2	1,131
Maximum	2,034	7,412	3,150
Mean	853	1,225	2,217
Median	833	590	2,370
Number of responses	9	11	3

Does your court keep counts of the number of people with active or continuing guardians appointed by your court who are elderly (aged 65 and over)? (Check one.)

	California	Florida	New York
Yes	4	4	2
No	37	50	7

If "Yes," currently, how many elderly have guardians?

	California	Florida	New York
Minimum	0	2	1,165
Maximum	103	1,073	2,520
Mean	52	538	1,842
Median	52	538	1,842
Number of responses	2	2	2

Currently, about what percentage of the people with guardians appointed by your court are elderly (aged 65 and over)? (Check one.)

	California	Florida	New York
A. All or almost all	1	4	2
B. More than half	22	10	2
C. About half	0	6	1
D. Less than half	1	8	0
E. In few, if any, cases	1	2	0
F. Information is not available	17	20	4

In the last 12 months, about what percentage of petitions for guardianship of elderly people resulted in the appointment of a guardian? (Check one.)

	California	Florida	New York
A. All or almost all	28	43	8
B. More than half	8	3	0
C. About half	0	0	0
D. Less than half	0	0	0
E. Few, if any	0	0	0
F. Information is not available	6	9	1

Does your court keep counts of the types of guardians (e.g., family members, attorneys, or other guardians who receive payment from either public sources or the income and assets of the incapacitated person) appointed for elderly persons?

	California	Florida	New York
Yes	3	4	3
No	39	50	6

How frequently does your court appoint each of the following types of guardians for elderly persons? (Check one for each type.)

	Few, if any, cases	Less than half the cases	About half the cases	Most cases	All or almost all the cases
California					
A. Guardians who are family members or friends	2	8	14	14	1
B. Guardians who are attorneys	33	3	0	1	0
C. Guardians, other than family members, friends, or attorneys, who receive payment for services from public sources (e.g., social service agencies, etc.)	12	19	6	1	1
D. Guardians, other than family members, friends, or attorneys, who receive payment for services from the income or assets of the incapacitated person	14	21	3	0	0
E. Other (please specify)	4	3	1	1	0
Florida					
A. Guardians who are family members or friends	0	3	10	20	15
B. Guardians who are attorneys	44	2	0	0	0
C. Guardians, other than family members, friends, or attorneys, who receive payment for services from public sources (e.g., social service agencies, etc.)	35	7	2	1	0
D. Guardians, other than family members, friends, or attorneys, who receive payment for services from the income or assets of the incapacitated person	23	12	7	4	0
E. Other (please specify)	1	0	0	0	1
New York					
A. Guardians who are family members or friends	0	1	1	5	1
B. Guardians who are attorneys	3	4	1	0	0
C. Guardians, other than family members, friends, or attorneys, who receive payment for services from public sources (e.g., social service agencies, etc.)	3	4	0	0	0
D. Guardians, other than family members, friends, or attorneys, who receive payment for services from the income or assets of the incapacitated person	6	1	0	0	0
E. Other (please specify)	0	0	0	0	0

About what percentage of the guardians appointed by your court are on the state registry? (Check one.)

	California	Florida	New York
A. All or almost all	0	2	2
B. More than half	0	2	1
C. About half	1	2	0
D. Less than half	13	6	4
E. Few, if any	17	12	1
F. Information is not available	10	30	1

Enforcement

In the last 12 months, which actions has your court taken to enforce requirements for guardians for the elderly? (Check one for each action.)

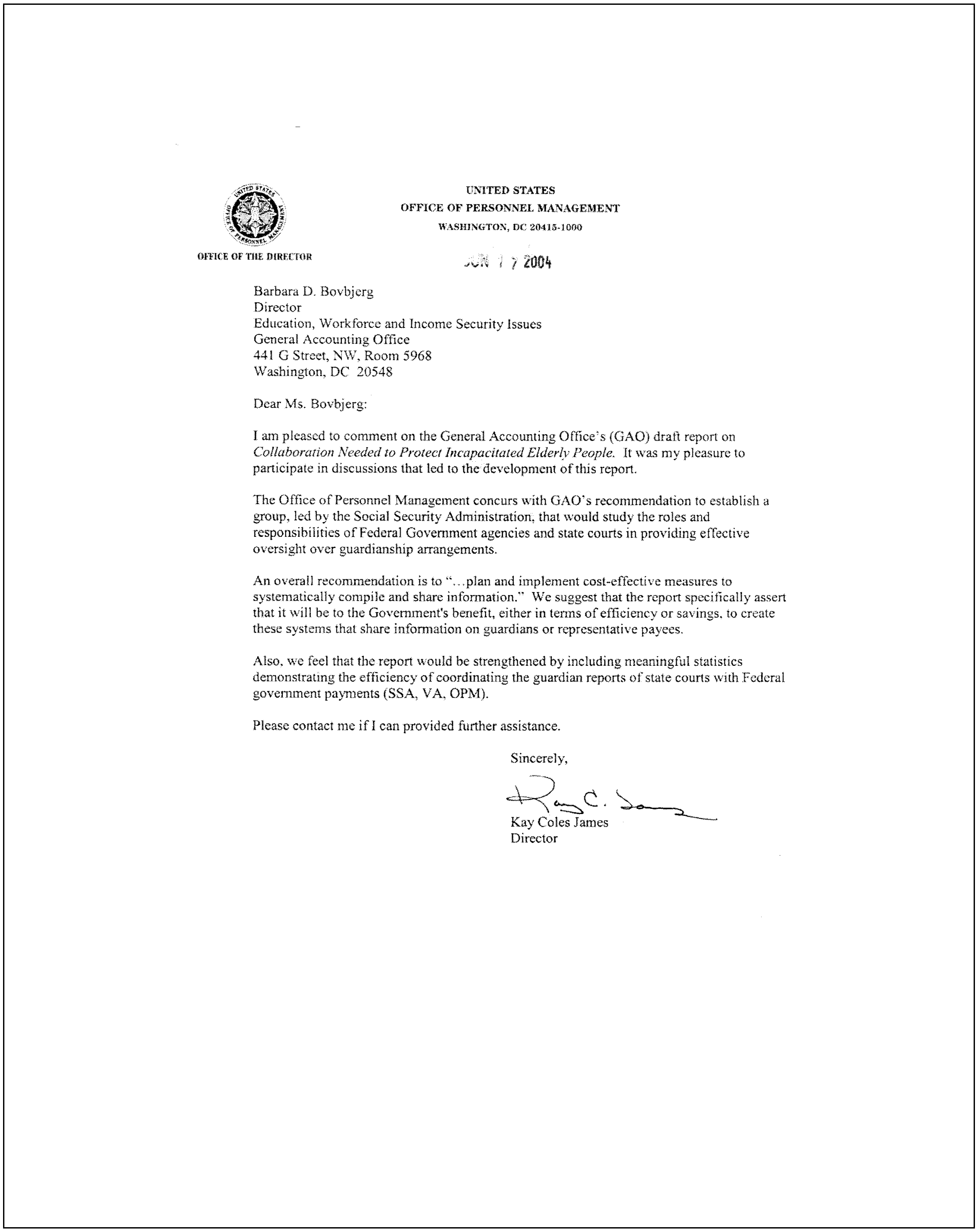
	California		Florida		New York	
	Yes	No	Yes	No	Yes	No
A. Asked guardians questions raised by submitted reports	35	5	43	6	8	1
B. Sent follow-up letters to guardians when reports are late, incomplete, or inaccurate	25	14	44	6	8	1
C. Sent show cause order, summons, or court notice for delinquent reports	33	7	43	7	7	2
D. Investigated complaints about guardians	30	9	27	21	7	2
E. Held hearings on complaints from incapacitated persons, family members, or other parties	32	8	35	15	8	1
F. Other (please specify)	3	2	3	4	1	0

Over the last 3 years, about how often has your court imposed the following penalties on guardians for the elderly for failure to fulfill their responsibilities? (Check one estimate for each penalty.)

	Never	1-5 times	6-10 times	More than 10	Do not know
California					
A. Terminated appointment	6	20	3	5	5
B. Reduced guardian’s power over incapacitated person	11	15	1	3	10
C. Fined or surcharged guardian for filing required reports late	21	9	1	2	7
D. Surcharged bond for property mismanagement	16	11	3	3	7
E. Denied guardian’s petition for a new appointment	14	15	1	1	7
F. Notified state registry of guardian’s resignation or removal for cause	29	1	0	0	8
G. Letter of reprimand	31	1	0	0	7
H. Mandated additional training	33	1	0	0	6
I. Withheld or reduced compensation	9	11	4	9	6
J. Notified bar about attorneys who submit delinquent reports	32	0	0	0	7
K. Awarded damages for civil actions against a guardian	25	5	0	0	9
L. Issued contempt of court citation	15	7	4	8	6
M. Convicted a guardian of a crime against the incapacitated person	17	11	0	0	12
N. Other (please specify)	4	0	0	1	4
Florida					
A. Terminated appointment	11	20	6	6	6
B. Reduced guardian’s power over incapacitated person	20	13	3	2	10
C. Fined or surcharged guardian for filing required reports late	38	3	0	2	5
D. Surcharged bond for property mismanagement	32	9	3	0	4
E. Denied guardian’s petition for a new appointment	26	13	0	2	7
F. Notified state registry of guardian’s resignation or removal for cause	40	0	0	0	8
G. Letter of reprimand	29	5	0	4	9
H. Mandated additional training	26	8	2	3	8
I. Withheld or reduced compensation	17	12	2	10	7
J. Notified bar about attorneys who submit delinquent reports	33	6	0	1	8
K. Awarded damages for civil actions against a guardian	29	7	0	1	10
L. Issued contempt of court citation	18	11	1	11	8
M. Convicted a guardian of a crime against the incapacitated person	31	8	0	1	8
N. Other (please specify)	4	1	0	2	4

	Never	1-5 times	6-10 times	More than 10	Do not know
New York					
A. Terminated appointment	0	4	0	2	3
B. Reduced guardian's power over incapacitated person	2	3	0	1	3
C. Fined or surcharged guardian for filing required reports late	2	3	1	0	3
D. Surcharged bond for property mismanagement	3	2	1	0	3
E. Denied guardian's petition for a new appointment	5	0	0	0	4
F. Notified state registry of guardian's resignation or removal for cause	6	1	0	0	2
G. Letter of reprimand	7	0	0	0	1
H. Mandated additional training	8	0	0	0	1
I. Withheld or reduced compensation	1	2	0	3	2
J. Notified bar about attorneys who submit delinquent reports	7	0	0	0	2
K. Awarded damages for civil actions against a guardian	7	0	0	0	2
L. Issued contempt of court citation	4	2	0	1	2
M. Convicted a guardian of a crime against the incapacitated person	6	1	0	0	2
N. Other (please specify)	1	0	0	0	1

Appendix IV: Comments from the Office of Personnel Management



UNITED STATES
OFFICE OF PERSONNEL MANAGEMENT
WASHINGTON, DC 20415-1000

OFFICE OF THE DIRECTOR

JUN 17 2004

Barbara D. Bovbjerg
Director
Education, Workforce and Income Security Issues
General Accounting Office
441 G Street, NW, Room 5968
Washington, DC 20548

Dear Ms. Bovbjerg:

I am pleased to comment on the General Accounting Office's (GAO) draft report on *Collaboration Needed to Protect Incapacitated Elderly People.* It was my pleasure to participate in discussions that led to the development of this report.

The Office of Personnel Management concurs with GAO's recommendation to establish a group, led by the Social Security Administration, that would study the roles and responsibilities of Federal Government agencies and state courts in providing effective oversight over guardianship arrangements.

An overall recommendation is to "...plan and implement cost-effective measures to systematically compile and share information." We suggest that the report specifically assert that it will be to the Government's benefit, either in terms of efficiency or savings, to create these systems that share information on guardians or representative payees.

Also, we feel that the report would be strengthened by including meaningful statistics demonstrating the efficiency of coordinating the guardian reports of state courts with Federal government payments (SSA, VA, OPM).

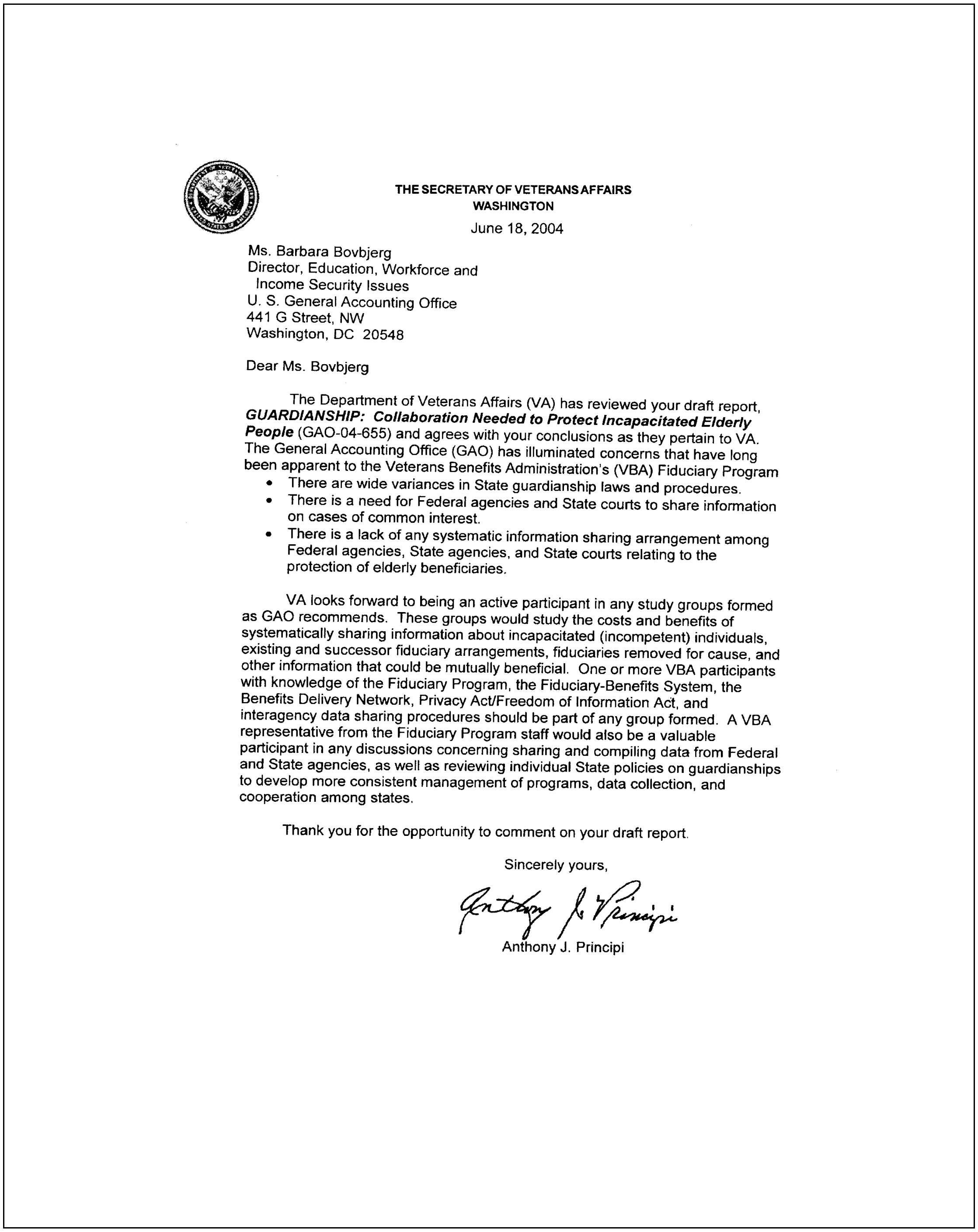
Please contact me if I can provided further assistance.

Sincerely,

Kay C. James

Kay Coles James
Director

Appendix V: Comments from the Department of Veterans Affairs



THE SECRETARY OF VETERANS AFFAIRS
WASHINGTON

June 18, 2004

Ms. Barbara Bovbjerg
Director, Education, Workforce and
Income Security Issues
U. S. General Accounting Office
441 G Street, NW
Washington, DC 20548

Dear Ms. Bovbjerg

The Department of Veterans Affairs (VA) has reviewed your draft report, ***GUARDIANSHIP: Collaboration Needed to Protect Incapacitated Elderly People*** (GAO-04-655) and agrees with your conclusions as they pertain to VA. The General Accounting Office (GAO) has illuminated concerns that have long been apparent to the Veterans Benefits Administration's (VBA) Fiduciary Program

- There are wide variances in State guardianship laws and procedures.
- There is a need for Federal agencies and State courts to share information on cases of common interest.
- There is a lack of any systematic information sharing arrangement among Federal agencies, State agencies, and State courts relating to the protection of elderly beneficiaries.

VA looks forward to being an active participant in any study groups formed as GAO recommends. These groups would study the costs and benefits of systematically sharing information about incapacitated (incompetent) individuals, existing and successor fiduciary arrangements, fiduciaries removed for cause, and other information that could be mutually beneficial. One or more VBA participants with knowledge of the Fiduciary Program, the Fiduciary-Benefits System, the Benefits Delivery Network, Privacy Act/Freedom of Information Act, and interagency data sharing procedures should be part of any group formed. A VBA representative from the Fiduciary Program staff would also be a valuable participant in any discussions concerning sharing and compiling data from Federal and State agencies, as well as reviewing individual State policies on guardianships to develop more consistent management of programs, data collection, and cooperation among states.

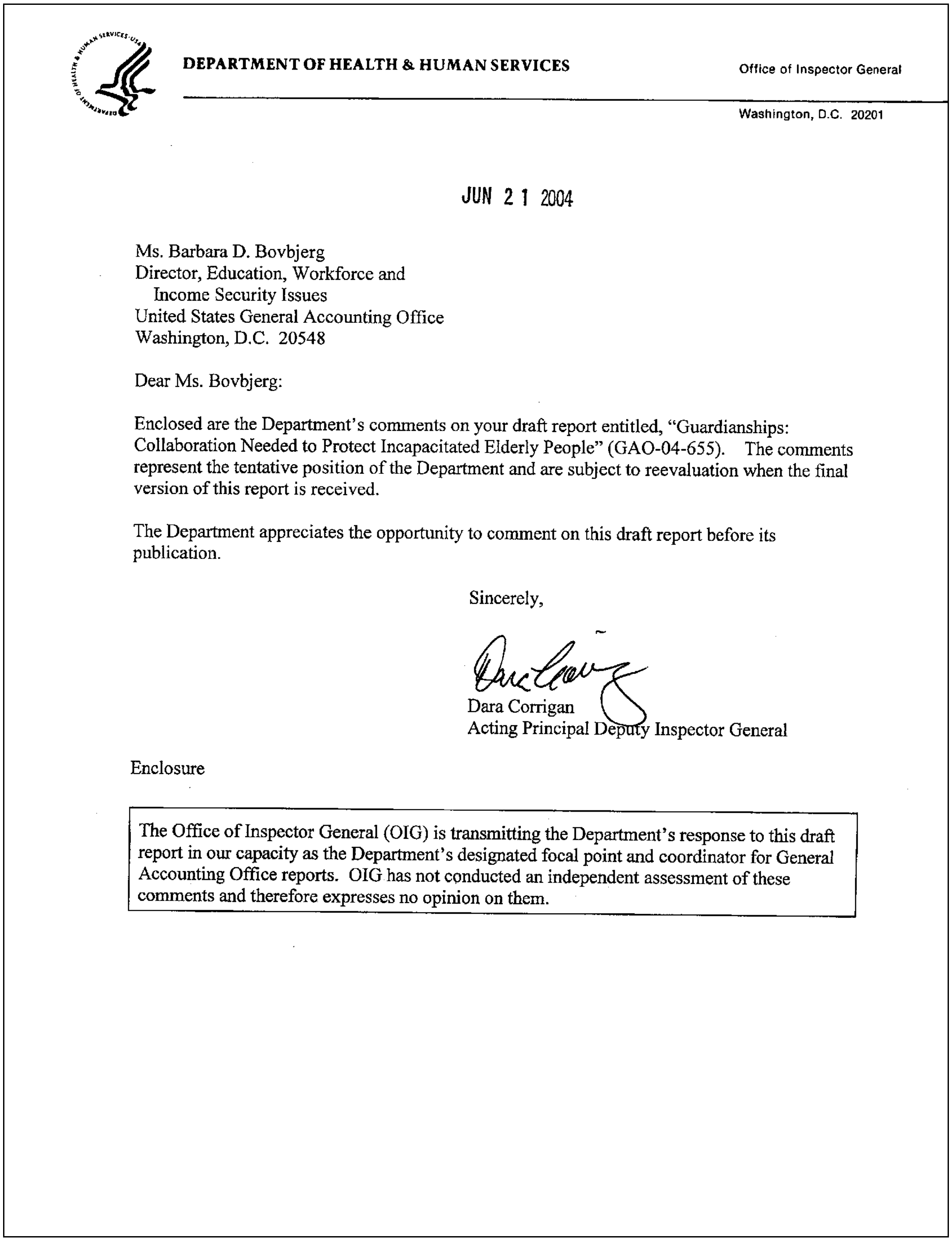
Thank you for the opportunity to comment on your draft report.

Sincerely yours,

Anthony J. Principi

Anthony J. Principi

Appendix VI: Comments from the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

JUN 21 2004

Ms. Barbara D. Bovbjerg
Director, Education, Workforce and
Income Security Issues
United States General Accounting Office
Washington, D.C. 20548

Dear Ms. Bovbjerg:

Enclosed are the Department's comments on your draft report entitled, "Guardianships: Collaboration Needed to Protect Incapacitated Elderly People" (GAO-04-655). The comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department appreciates the opportunity to comment on this draft report before its publication.

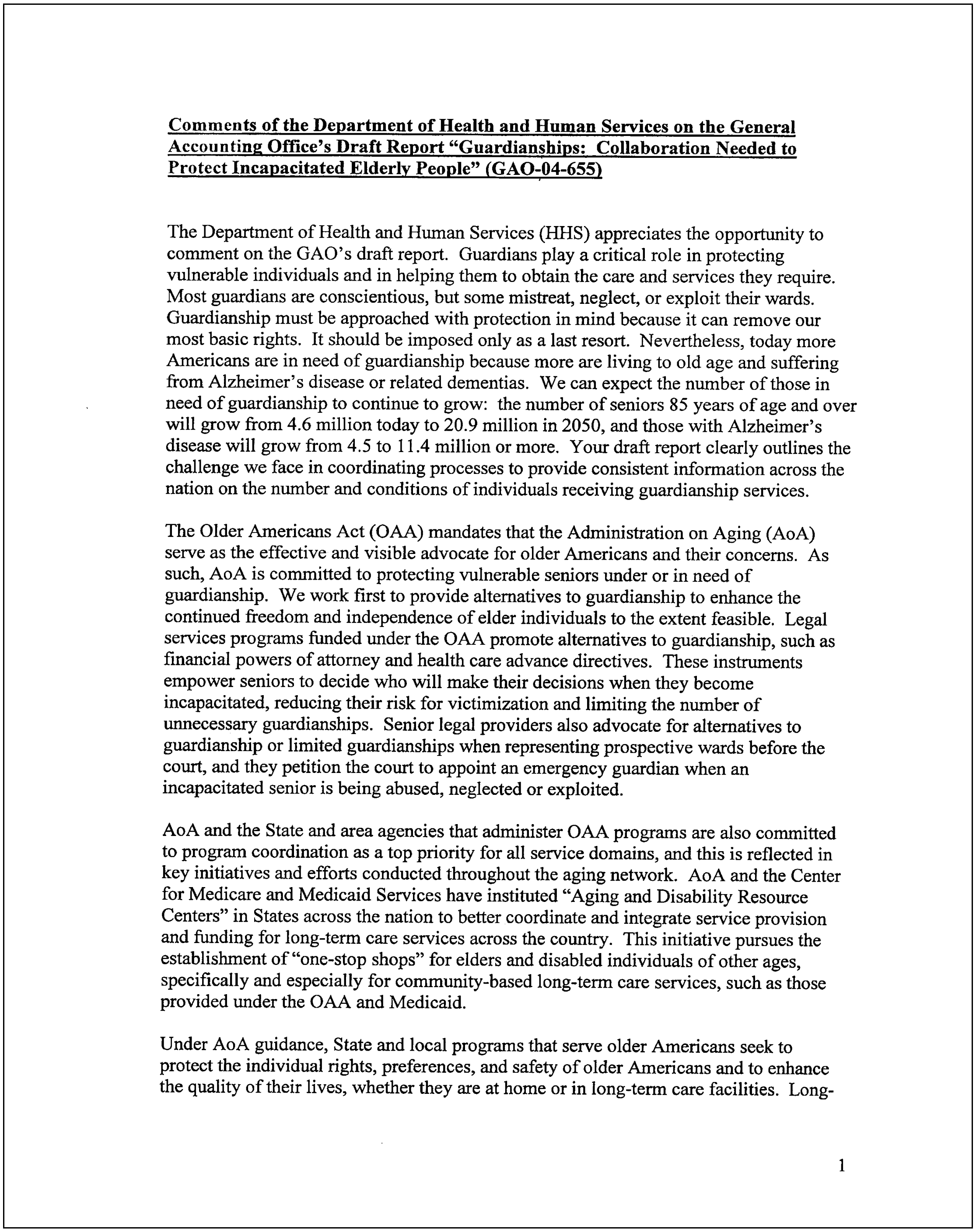
Sincerely,

Dara Corrigan
Acting Principal Deputy Inspector General

Enclosure

The Office of Inspector General (OIG) is transmitting the Department's response to this draft report in our capacity as the Department's designated focal point and coordinator for General Accounting Office reports. OIG has not conducted an independent assessment of these comments and therefore expresses no opinion on them.

Appendix VI: Comments from the Department of Health and Human Services



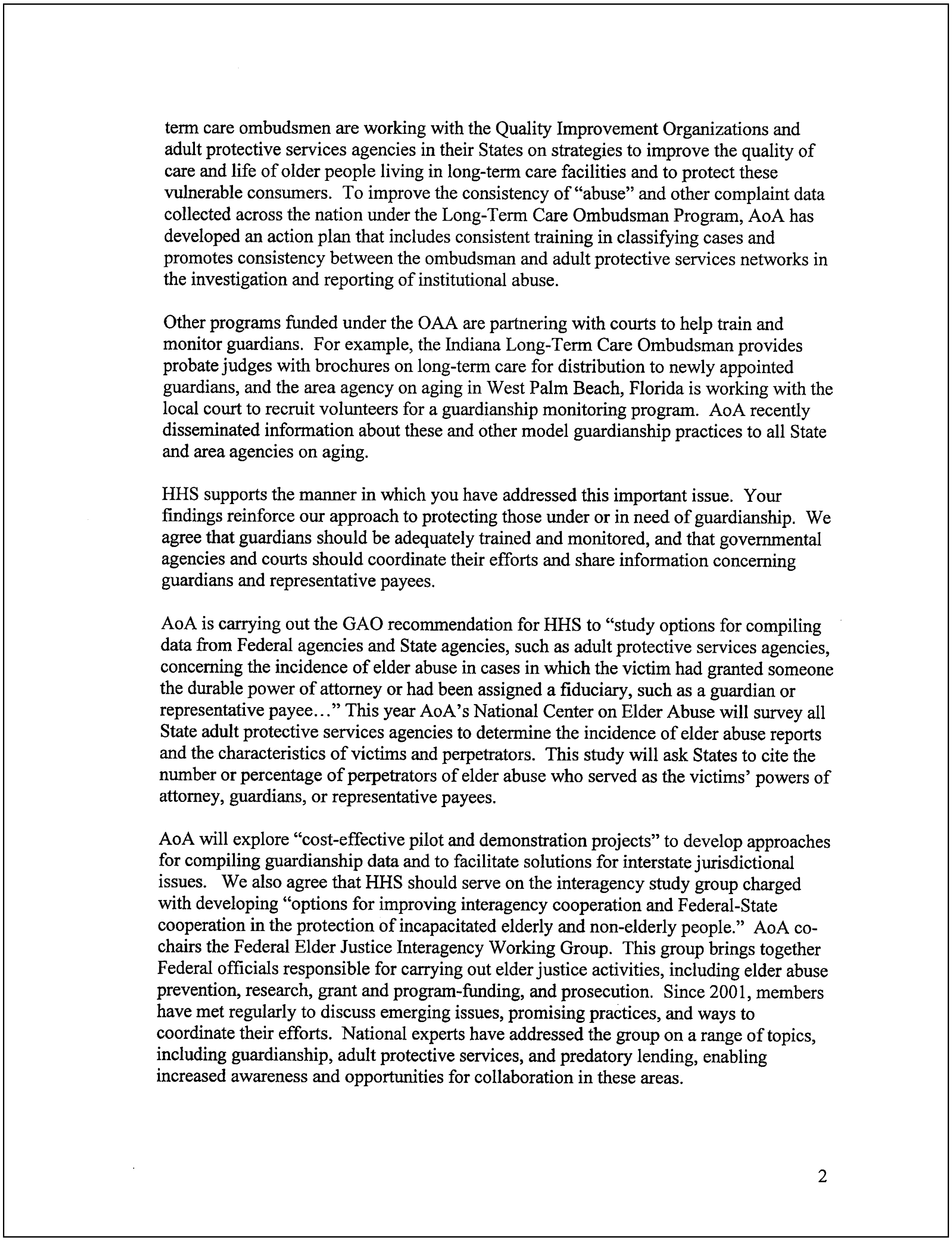
Comments of the Department of Health and Human Services on the General Accounting Office's Draft Report "Guardianships: Collaboration Needed to Protect Incapacitated Elderly People" (GAO-04-655)

The Department of Health and Human Services (HHS) appreciates the opportunity to comment on the GAO's draft report. Guardians play a critical role in protecting vulnerable individuals and in helping them to obtain the care and services they require. Most guardians are conscientious, but some mistreat, neglect, or exploit their wards. Guardianship must be approached with protection in mind because it can remove our most basic rights. It should be imposed only as a last resort. Nevertheless, today more Americans are in need of guardianship because more are living to old age and suffering from Alzheimer's disease or related dementias. We can expect the number of those in need of guardianship to continue to grow: the number of seniors 85 years of age and over will grow from 4.6 million today to 20.9 million in 2050, and those with Alzheimer's disease will grow from 4.5 to 11.4 million or more. Your draft report clearly outlines the challenge we face in coordinating processes to provide consistent information across the nation on the number and conditions of individuals receiving guardianship services.

The Older Americans Act (OAA) mandates that the Administration on Aging (AoA) serve as the effective and visible advocate for older Americans and their concerns. As such, AoA is committed to protecting vulnerable seniors under or in need of guardianship. We work first to provide alternatives to guardianship to enhance the continued freedom and independence of elder individuals to the extent feasible. Legal services programs funded under the OAA promote alternatives to guardianship, such as financial powers of attorney and health care advance directives. These instruments empower seniors to decide who will make their decisions when they become incapacitated, reducing their risk for victimization and limiting the number of unnecessary guardianships. Senior legal providers also advocate for alternatives to guardianship or limited guardianships when representing prospective wards before the court, and they petition the court to appoint an emergency guardian when an incapacitated senior is being abused, neglected or exploited.

AoA and the State and area agencies that administer OAA programs are also committed to program coordination as a top priority for all service domains, and this is reflected in key initiatives and efforts conducted throughout the aging network. AoA and the Center for Medicare and Medicaid Services have instituted "Aging and Disability Resource Centers" in States across the nation to better coordinate and integrate service provision and funding for long-term care services across the country. This initiative pursues the establishment of "one-stop shops" for elders and disabled individuals of other ages, specifically and especially for community-based long-term care services, such as those provided under the OAA and Medicaid.

Under AoA guidance, State and local programs that serve older Americans seek to protect the individual rights, preferences, and safety of older Americans and to enhance the quality of their lives, whether they are at home or in long-term care facilities. Long-



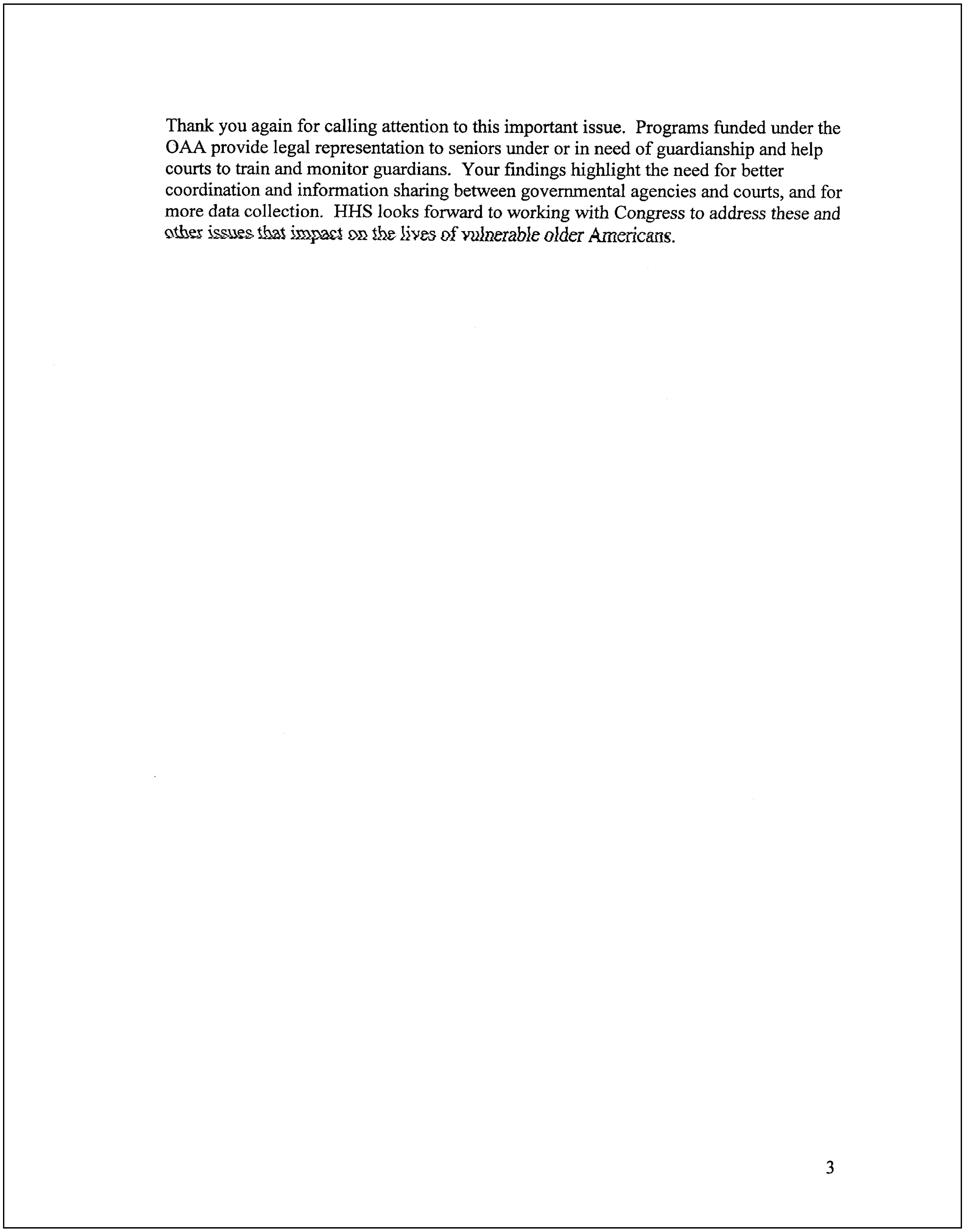
term care ombudsmen are working with the Quality Improvement Organizations and adult protective services agencies in their States on strategies to improve the quality of care and life of older people living in long-term care facilities and to protect these vulnerable consumers. To improve the consistency of "abuse" and other complaint data collected across the nation under the Long-Term Care Ombudsman Program, AoA has developed an action plan that includes consistent training in classifying cases and promotes consistency between the ombudsman and adult protective services networks in the investigation and reporting of institutional abuse.

Other programs funded under the OAA are partnering with courts to help train and monitor guardians. For example, the Indiana Long-Term Care Ombudsman provides probate judges with brochures on long-term care for distribution to newly appointed guardians, and the area agency on aging in West Palm Beach, Florida is working with the local court to recruit volunteers for a guardianship monitoring program. AoA recently disseminated information about these and other model guardianship practices to all State and area agencies on aging.

HHS supports the manner in which you have addressed this important issue. Your findings reinforce our approach to protecting those under or in need of guardianship. We agree that guardians should be adequately trained and monitored, and that governmental agencies and courts should coordinate their efforts and share information concerning guardians and representative payees.

AoA is carrying out the GAO recommendation for HHS to "study options for compiling data from Federal agencies and State agencies, such as adult protective services agencies, concerning the incidence of elder abuse in cases in which the victim had granted someone the durable power of attorney or had been assigned a fiduciary, such as a guardian or representative payee…" This year AoA's National Center on Elder Abuse will survey all State adult protective services agencies to determine the incidence of elder abuse reports and the characteristics of victims and perpetrators. This study will ask States to cite the number or percentage of perpetrators of elder abuse who served as the victims' powers of attorney, guardians, or representative payees.

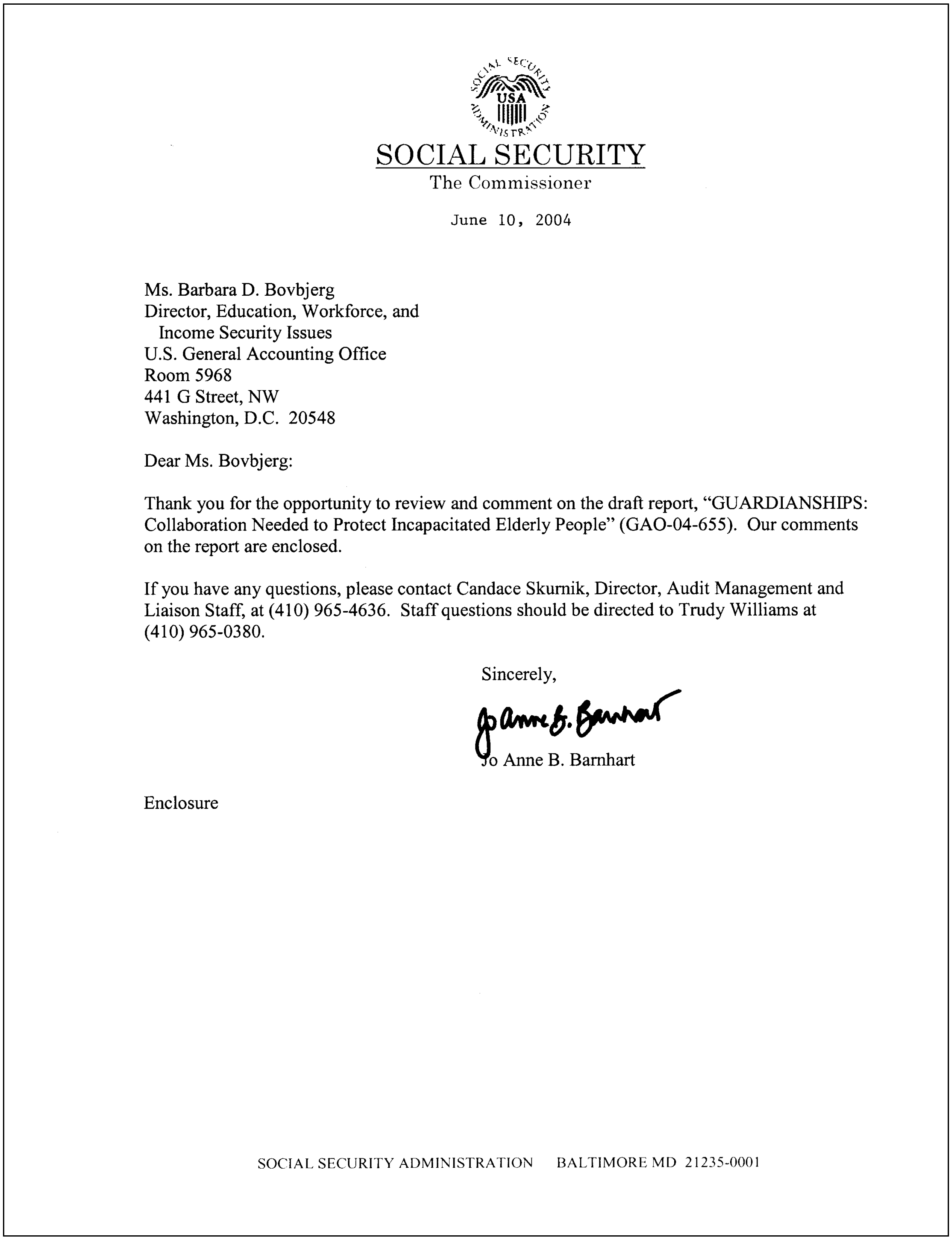
AoA will explore "cost-effective pilot and demonstration projects" to develop approaches for compiling guardianship data and to facilitate solutions for interstate jurisdictional issues. We also agree that HHS should serve on the interagency study group charged with developing "options for improving interagency cooperation and Federal-State cooperation in the protection of incapacitated elderly and non-elderly people." AoA co-chairs the Federal Elder Justice Interagency Working Group. This group brings together Federal officials responsible for carrying out elder justice activities, including elder abuse prevention, research, grant and program-funding, and prosecution. Since 2001, members have met regularly to discuss emerging issues, promising practices, and ways to coordinate their efforts. National experts have addressed the group on a range of topics, including guardianship, adult protective services, and predatory lending, enabling increased awareness and opportunities for collaboration in these areas.



Thank you again for calling attention to this important issue. Programs funded under the OAA provide legal representation to seniors under or in need of guardianship and help courts to train and monitor guardians. Your findings highlight the need for better coordination and information sharing between governmental agencies and courts, and for more data collection. HHS looks forward to working with Congress to address these and other issues that impact on the lives of vulnerable older Americans.

3

Appendix VII: Comments from the Social Security Administration



SOCIAL SECURITY
The Commissioner

June 10, 2004

Ms. Barbara D. Bovbjerg
Director, Education, Workforce, and
Income Security Issues
U.S. General Accounting Office
Room 5968
441 G Street, NW
Washington, D.C. 20548

Dear Ms. Bovbjerg:

Thank you for the opportunity to review and comment on the draft report, "GUARDIANSHIPS: Collaboration Needed to Protect Incapacitated Elderly People" (GAO-04-655). Our comments on the report are enclosed.

If you have any questions, please contact Candace Skurnik, Director, Audit Management and Liaison Staff, at (410) 965-4636. Staff questions should be directed to Trudy Williams at (410) 965-0380.

Sincerely,

Jo Anne B. Barnhart

Enclosure

SOCIAL SECURITY ADMINISTRATION BALTIMORE MD 21235-0001

COMMENTS ON THE GENERAL ACCOUNTING OFFICE (GAO) DRAFT REPORT, "GUARDIANSHIPS: COLLABORATION NEEDED TO PROTECT INCAPACITATED ELDERLY PEOPLE" (GAO-04-655)

Thank you for the opportunity to comment on the subject draft report. Our response to the report and to the specific recommendations is provided below.

The protection of the elderly, or others who may become incapacitated, is of significant importance, not only to our Agency, but to society in general. We support the need for vigilance in ensuring our representative payees (Rep Payees) are accountable for using Social Security benefits appropriately and that funds are not misused.

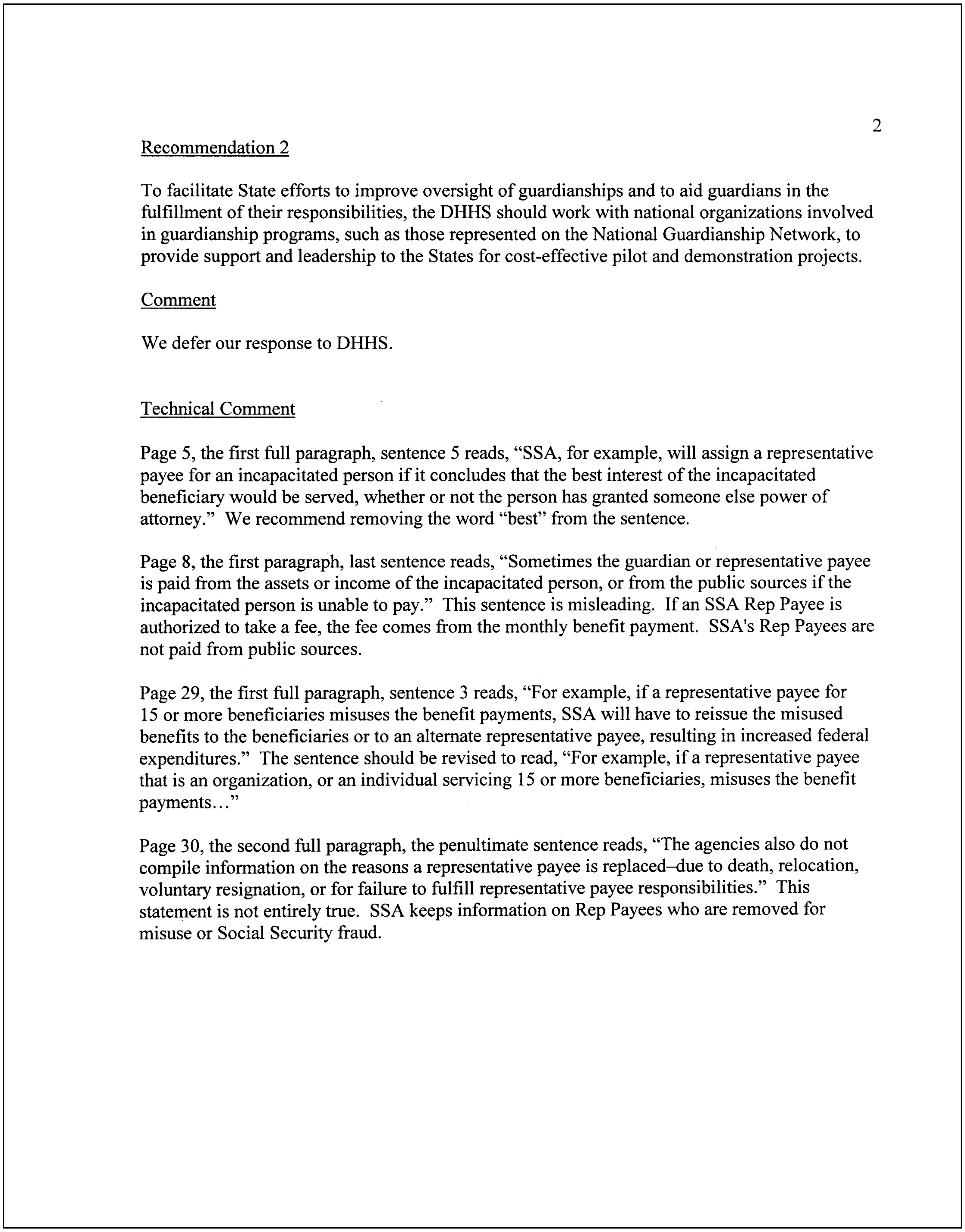
In 1998, the Social Security Administration (SSA) funded a grant for the American Bar Association (ABA) to look into a nearly identical issue; i.e., can there be better coordination between State court guardianship actions and the SSA Rep Payee program? The results of the ABA project were very similar to GAO's conclusions and recommendations with respect to SSA. The two biggest hurdles facing SSA in adopting the ABA recommendations were the Privacy Act and the fact that a statement of routine use, allowing SSA to share Rep Payee information with State courts, does not exist. A Rep payeeship is the most limited type of guardianship (restricted only to management of benefits), whereas State court guardianships are almost invariably more complicated. To the extent that SSA's policies differ from State court and other agencies' policies, SSA is bound by the Social Security Act and the Privacy Act. SSA may only disclose information to State courts or other Federal agencies in accordance with the Privacy Act and section 1106 of the Social Security Act, including SSA's regulation at 20 C.F.R. Part 401

Recommendation 1

To increase the ability of Rep Payee programs to protect Federal benefit payments from misuse, SSA should convene an interagency study group that includes representatives from the Department of Health and Human Services (DHHS), Federal agencies with Rep Payee programs, including the Veterans' Administration (VA) and the Office of Personnel Management, and State courts that wish to participate in order to: study the costs and benefits of options for improving interagency cooperation and Federal-State cooperation in the protection of incapacitated elderly and non-elderly people.

Comment

We disagree. Although we share your concern about this very vulnerable segment of our beneficiary population, we do not believe the proposed effort is within the purview of SSA. SSA receives appropriations from Congress to ensure that the benefits paid to payees are used for the maintenance and welfare of incapacitated individuals. The effort GAO has proposed goes far beyond the statutory responsibilities of SSA. Moreover, we believe that it would be extremely difficult for agencies to develop a systematic way to share information when we consider the number of State and local courts that exist and the differing laws of the State and Federal agencies regarding capability. In addition, there are privacy implications that could preclude information sharing among the many different jurisdictions.



Recommendation 2

To facilitate State efforts to improve oversight of guardianships and to aid guardians in the fulfillment of their responsibilities, the DHHS should work with national organizations involved in guardianship programs, such as those represented on the National Guardianship Network, to provide support and leadership to the States for cost-effective pilot and demonstration projects.

Comment

We defer our response to DHHS.

Technical Comment

Page 5, the first full paragraph, sentence 5 reads, "SSA, for example, will assign a representative payee for an incapacitated person if it concludes that the best interest of the incapacitated beneficiary would be served, whether or not the person has granted someone else power of attorney." We recommend removing the word "best" from the sentence.

Page 8, the first paragraph, last sentence reads, "Sometimes the guardian or representative payee is paid from the assets or income of the incapacitated person, or from the public sources if the incapacitated person is unable to pay." This sentence is misleading. If an SSA Rep Payee is authorized to take a fee, the fee comes from the monthly benefit payment. SSA's Rep Payees are not paid from public sources.

Page 29, the first full paragraph, sentence 3 reads, "For example, if a representative payee for 15 or more beneficiaries misuses the benefit payments, SSA will have to reissue the misused benefits to the beneficiaries or to an alternate representative payee, resulting in increased federal expenditures." The sentence should be revised to read, "For example, if a representative payee that is an organization, or an individual servicing 15 or more beneficiaries, misuses the benefit payments…"

Page 30, the second full paragraph, the penultimate sentence reads, "The agencies also do not compile information on the reasons a representative payee is replaced–due to death, relocation, voluntary resignation, or for failure to fulfill representative payee responsibilities." This statement is not entirely true. SSA keeps information on Rep Payees who are removed for misuse or Social Security fraud.

Appendix VIII: GAO Contacts and Staff Acknowledgments

GAO Contacts

Alicia Puente Cackley (202) 512-7022
Benjamin P. Pfeiffer (206) 287-4832

Staff Acknowledgments

Carolyn M. Boyce, Nicole E. Gore, Jill M. Johnson, Corinna A. Nicolaou, Daniel A. Schwimer, Derald Seid, and John E. Trubey also contributed to this report.

(130247)

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Washington, D.C. 20548

Beyond Guardianship:

Toward Alternatives That Promote Greater Self-Determination

National Council on Disability

March 22, 2018

National Council on Disability (NCD)
1331 F Street NW, Suite 850
Washington, DC 20004

Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination

National Council on Disability, March 22, 2018
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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

March 22, 2018

President Donald J. Trump
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit its report, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities*, which provides a comprehensive review of guardianship against the backdrop of the civil rights advancements of individuals with disabilities in the past several decades. While people with a variety of disabilities may face guardianship, the burgeoning aging population in America has forced issues surrounding guardianship to the fore in national media coverage and policy debates in recent years, making NCD's report a timely contribution to policy discussions.

Guardianship generally involves a state-court determination that an individual lacks the capacity to make decisions with respect to their health, safety, welfare, and/or property. Although guardianship is governed by state law, it entails the removal of rights protected by the U.S. Constitution. Additionally, individuals who are subject to guardianship are also protected by the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, which are laws intended to increase the ability of individuals to live and work in the community, encourage participation in civic life, and to promote self-determination for individuals with disabilities.

The *Beyond Guardianship* report explains how guardianship law has evolved, explores due process and other concerns with guardianships, offers an overview of alternatives to guardianship, and identifies areas for further study. The report includes a review of existing scholarship on the topic as well as the results of a qualitative study of individuals with experience in guardianship and its alternatives, and offers major findings and recommendations to Congress, the Administration, and to state and local government.

We stand ready to work with you and your Administration to work for improvements to the way in which individuals with disabilities who may require decision assistance are treated in the legal system and provided with assistance.

Respectfully,

Neil Romano

Neil Romano
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Contents

Glossary

Adjudication: The process of a judicial determination; an adult under guardianship has generally been "adjudicated" to lack capacity.

Adult: An individual who is at least 18 years of age, regardless of disability.

Advance Directive: A witnessed document or documents that a person can use to provide instructions regarding their desires and preferences about medical treatment in the event that they become incapacitated. Such medical treatment may include, for example, life prolonging treatment or psychiatric treatment during a crisis. Often, an Advance Directive will include a power of attorney and a health care surrogate designation.

Agent: A person with the legal authority to act on behalf of another.

Alleged Incapacitated Person (AIP): A person who is the subject of a petition to determine capacity or guardianship, but who has not yet been adjudicated incapacitated.

Annual Accounting: A report states may require a guardian of the property to file itemizing expenditures and receipts made on behalf of the person subject to guardianship in the previous year. Some states allow the court to waive this requirement, particularly if the only income the person has is Social Security and the guardian is also the representative payee of such funds.

Annual Guardianship Plan: A report, filed by the guardian of the person, that some states require to be submitted to the court each year specifying the medical, mental, and physical care of the person subject to guardianship for the upcoming year.

Attorney ad Litem: An attorney who is appointed by the court to act as a legal advocate in the best interest of a child or incapacitated adult. Unlike attorneys in a normal attorney-client relationship, they do not necessarily advocate for the desired outcome of the individual they represent, but may advocate for an outcome the attorney deems in the person's best interest.

Best Interest: A type of decision making standard that may be used when making a decision on behalf of another person, particularly in court cases involving child custody or welfare. Compared to substituted judgment, it is seen as a more objective standard; emphasis is on the person's safety and wellbeing.

Capacity: An individual's ability to perform a specific task, such as to sign a contract; also refers to the legal ability to perform an act and to subsequently be bound by the act. May also be referred to as *competency*.

Clerk of the Court: Court officer responsible for filing papers, administration of cases, and keeping records of court proceedings. In some courts, the Clerk of the Court may play a role in reviewing accountings and reports filed by guardians.

Conflict of Interest: Situations in which an individual may receive financial or material gain or advantage from a decision made on behalf of another person, with whom they have a relationship.

Court Visitor or Monitor: Individual appointed to advise the court regarding whether an individual needs a guardian (and, if so, who it should be) or to report to the court whether an existing guardianship continues to be appropriate or necessary, what the condition of the individual subject to guardianship is, or whether the decisions being made on behalf of that individual are appropriate.

Durable Power of Attorney: A durable power of attorney is effective even after the principal becomes incapacitated. The attorney-in-fact can continue to act within the scope of authority granted under this power of attorney.

Family Guardian: A nonprofessional guardian who serves as guardian for an individual who is subject to guardianship. Although *family guardians* usually are related to the individual subject to guardianship, they may instead be friends or even volunteers. Although they can be reimbursed out of the estate, they are not serving as guardians in order to make a living. The definition of *family guardian* may vary from state to state.

Guardian: A person, institution, or agency appointed by a court to manage the affairs of another individual. The guardian may have the authority to manage personal and/or financial matters. Each state has specific laws that govern guardianship proceedings and the guardian's activities. States have separate laws and procedures for guardianship for minors and for adults with disabilities. States may use different terms to refer to guardians, such as *conservators*.

Guardian ad Litem: A person appointed to advise the court regarding the needs and best interests of a child or individual who either lacks capacity or, in some states, has been alleged to lack capacity.

Guardianship of the Person: A guardianship where the guardian is granted the authority by the court to make personal decisions for an individual. This means that the right to make personal decisions has been removed from the individual and transferred to a guardian. These rights may include, for example, the right to decide where to live, with whom to associate, and what medical treatment to receive or not receive.

Guardianship of the Property: A guardianship where the guardian is granted the authority by the court to manage and make decisions about another person's financial matters, benefits, real estate, and other property. This means that the right to make property decisions has been removed from the individual and transferred to the guardian. This is sometimes referred to as a *conservatorship* or *guardianship of the estate*.

Health Care Surrogate: An agent who has been given the authority to make health care decisions for a person either by the person through a durable power of attorney for health care or by operation of law.

Indigent: An individual with little to no resources and who may be entitled to an attorney paid for by the state, the appointment of a public guardian, and/or the waiver of court costs and fees.

Informed Consent: Consent, usually to a medical procedure or legal representation, given by a person after information disclosing the risks, benefits, and costs of undertaking a given action are divulged, so the person may make a free and uncoerced decision.

Limited Guardianship: A guardianship where the guardian only has the authority specifically given by court order. The person subject to a limited guardianship retains all other decision making rights not specifically outlined by the court order.

Magistrate Judge: A state official who makes decisions in legal cases just like a judge, but does not have as much power as a judge. Magistrates generally handle minor cases and, in some jurisdictions, may handle guardianships cases, especially those that are uncontested.

Plenary Guardianship: A guardianship where the court gives the guardian the power to exercise all legal rights and duties on behalf of the person subject to guardianship. The guardianship is of both the person and the property, and the individual subject to guardianship has been adjudicated completely incapacitated. This is the most restrictive form of guardianship.

Power of Attorney: A legal instrument, executed under state law, by which one person (called the *principal*) voluntarily appoints someone else (called the *attorney-in-fact* or *agent*) to legally act on their behalf with respect to certain decisions and under certain circumstances. A *durable power of attorney* is operative even after the individual has lost capacity. A *power of attorney for health care* is generally operative when the person becomes incapacitated.

Professional Guardian: A professional guardian is generally a private individual or organization who serves as guardian for numerous individuals subject to guardianship and is not a member of those individuals' families. Professional guardianship charge fees for carrying out their duties. They are generally paid out of the resources of the person subject to guardianship, when that person has such resources.

Public Guardian: A guardian who generally is either employed or funded by the state to provide guardianship services to individuals who have been determined incapacitated. Often, public guardians serve people who are indigent and/or are the responsibility of a state agency or entity.

Representative Payee: An individual, agency, or organization appointed by the Social Security Administration (SSA) to receive, manage, and spend Social Security benefits on behalf of and for the benefit of an individual who is entitled to the benefits but who has been determined by SSA to be unable to manage the resource.

Respondent: A person who is responding to a lawsuit or legal action. In guardianship, the alleged incapacitated person who is the subject of a petition for guardianship is the *respondent*.

Special Needs Trust: A type of trust that is established for the benefit of a person with disabilities. The assets in this type of trust are intended to supplement and protect public benefits, specifically Medicaid. The advantage of this type of trust is that its assets do not negatively impact the beneficiary's eligibility for Medicaid or other government programs as long as the trust is administered properly.

Standard of Proof: Refers to the duty or burden carried by the party responsible for proving the case. There are generally three standards of proof that can apply in legal cases: "beyond a reasonable doubt" (highest standard, applies in criminal cases and in guardianship cases in New Hampshire.), "clear and convincing" (second highest standard, which applies in most states' guardianship cases), and "preponderance of the evidence" (lowest standard, which applies in some states' guardianship cases and also may be the burden of proof in restoration cases).

Substituted Judgment: A standard of decision-making that should generally be used when making decisions on behalf of an adult with a disability, according to the National Guardianship Association. It refers to making a decision on behalf of an individual that is aligned with the decision they would have made for themselves if they had the capacity to do so. This includes understanding and considering the values and preferences of the individual for whom decisions are being made either as currently expressed or as expressed prior to the determination that the individual was incapacitated.

Trust: A fiduciary arrangement where the trustee manages money or property for the benefit of a beneficiary or beneficiaries. A trust is a separate legal entity that owns assets that are managed by the trustee for the benefit of the beneficiary or beneficiaries in accordance with the rules established by the trust. There are many different kinds of trusts, each of which provides different benefits.

Executive Summary

This report by the National Council on Disability (NCD) seeks to explain, evaluate, and contextualize a system that impacts a large number of people with disabilities, particularly intellectual, cognitive, and age-related disabilities. Although it has been an important part of Western law since the ancient Greeks, guardianship has not garnered the attention of policymakers and disability rights advocates the way other issues have. In fact, although NCD has consistently supported and encouraged the adoption of policies that promote the self-determination of people with disabilities, as well as the adoption of the Convention on the Rights of Persons with Disabilities and its Article 12 imperative "that all people with disabilities retain their legal capacity, even those who may need significant and intensive support to effectuate it,"[1] the Council has not, until now, explored how guardianship impacts people with disabilities or made recommendations regarding how to transform the way in which we assist people with disabilities who may need help managing money or property or making decisions that impact their health and welfare. Guardianship is a creature of state law, with a federal footprint that has historically been fairly small. However, guardianship has a profound impact on the people subject to it, as well as on their families and communities. The existence of a process through which an adult can essentially be found legally incapable of making decisions for themselves and another adult appointed to make decisions on behalf of that individual raises fundamental civil rights issues that are deserving of thorough examination. Additionally, the increase in the number of older Americans as the baby-boom generation enters retirement and growing concern over elder abuse has increased the level of interest in this topic among federal policymakers.

A foundational principal in our democracy is the legal presumption that once an individual reaches the "age of majority" and becomes an adult, he or she is capable of making decisions and taking certain legal actions is a foundational principle in our democracy.[2] Once a person turns 18, he or she can vote; sign contracts; make a will; and choose where to live, go to school, and work. Eighteen is not a magic number; people who are younger than 18 may make very rational decisions and individuals who are over that age often make poor decisions. However, mistakes are part of how we learn to make future decisions. As one of the guardianship professionals interviewed for the report explained, "We have to acknowledge that everyone . . . makes bad decisions, so we frequently have to acknowledge and respect the right for the person to make a 'wrong' decision."

The presumption of one's right to liberty, self-determination, and personal autonomy is fundamental to American culture, democracy and economy. In the first chapter of his 1869 book, *On Liberty*, English philosopher John Stuart Mill writes:

> The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.[3]

In theory, people with disabilities are entitled to the presumption of capacity along with their peers without disabilities. However, throughout history, as law professor and recognized guardianship expert Robert Dinerstein notes:

> Society assumes that adults of typical intelligence, psychosocial functioning, and sensory ability are able to engage in all aspects of life—deciding where to live, whom (or whether) to marry, how to spend one's money (or to whom to leave it), for whom to vote—on an autonomous basis. . . . But for adults with disabilities, the picture has been and continues to be quite different. States have assumed that the mere status of having an intellectual or psychosocial disability (or some sensory disabilities) provides a sufficient basis to presume that the individual is unable to participate fully and autonomously in society, in other words, that the individual lacks the legal capacity to exercise his or her rights.[4]

Indeed, Mill offers this caveat: "those who are still in a state to require being taken care of by others must be protected against their own actions as well as against external injury." It is worth noting that he also denies that personal autonomy applies to ". . . those backward states of society in which the race itself may be considered as in its nonage." So, while Mill firmly establishes personal autonomy as the foundation of liberty, his words also serve as a reminder that the history of America is one of gradually expanding these fundamental principles to include people who were not, at its inception, assumed to possess the full complement of inalienable rights.

As we will explore throughout this report, Mills' and others' understanding of the implications of being dependent on others for personal care is antithetical to the Americans with Disabilities Act (ADA). However, Lawrence A. Frolik—another thoughtful scholar on guardianship whose thoughts will appear throughout this report—has argued that "[i]t is possible that the reform goals of personal autonomy and dignity are so at odds with reality so as to be unattainable."[5] That is a fair point to be considered if we are going to understand guardianship and propose reforms that are not only philosophically consistent with disability rights, but also serve as practical solutions for people with disabilities and their families. As one person interviewed for this report put it, ". . . if the Council were to connect the idea of autonomy with dignity, I think that would be such a powerful statement."

Indeed, throughout this report, NCD will explore the connections among autonomy, dignity, independence, and protection, and provide the reader with a better understanding of guardianship, which directly impacts the lives of an estimated 1.3 million Americans with disabilities. It has often been noted that an individual subject to guardianship moves through the world indistinguishable from the rest of the population, except that he or she has undergone "a kind of civil death" and is "no longer permitted to participate in society without mediation through the actions of another if at all."[6] As one person with disabilities interviewed for this report explained, "I would feel kind of like a prisoner, knowing that all my decisions were up to someone else." On the other hand, there are those who view guardianship not as a restriction of rights, but as a form of protection and assistance. One guardian who was interviewed emphasized that guardianship "is in the best interest of the individual, and it's not a means or stripping rights or controlling." An attorney at a public guardian agency added that, without a finding of incapacity to contract, "what happens if that person signs a contract [but] . . . read[s at a] second grade level? [Now] they bought a car or . . . sold their house."

Throughout this report, NCD seeks to balance and recognize both of these viewpoints while remaining unwavering in the belief that "people who are [seniors] and people with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence."[7] This is as true of individuals who need help making decisions as it is when they need housing, medical care, assistance with personal care, or any other kind of support. Guardianship must be measured not only by how well it protects individuals, but also by how well it advances their dignity, autonomy, and self-determination, and NCD seeks to explore both measurements throughout this report.

Summary of Methodology

This report provides an overview of the current state of guardianship law and practice and an overview of policy reforms and analysis of how effective or ineffective these efforts have been. In preparation for this report in October 2016, an extensive literature review was conducted of the relevant scholarship available in English with a preference for studies concluded within the past decade. The resources identified in that review form the backbone of the report. Additionally, in order to better understand the experiences with guardianship and decision making alternatives of people with disabilities, their families, and other stakeholders, qualitative interviews were conducted with 46 individuals with a range of experiences with guardianship. Although this is an insufficient number from which to glean statistically significant information, their responses helped guide the direction of this report. We report on the qualitative interviews in Chapter 9, and references to the interviews appear throughout the report. Additionally, the qualitative data is collected in a "white paper" that will appear on NCD's website as a companion to this report along with the literature review previously referenced.

This report is organized into 10 chapters. Chapter 1 will explain what "guardianship" is, where it comes from in terms of history and jurisprudence, and how it is used in modern times. Chapter 2 will trace the history of disability discrimination in the United States and describe the growth of the disability rights movement and how we think about what it means to be a person with a disability. Chapter 3 will provide background on past and current guardianship reforms, including the motivation behind them. Chapter 4 will provide a snapshot of the current state of guardianship in the United States. Chapter 5 will examine the key concept of *capacity* and how experts and courts evaluate whether or not an individual is capable of making decisions for themselves. Chapter 6 continues the discussion of due process rights for individuals facing guardianship and the ongoing rights of individuals who are subject to guardianship, as well as an examination of some of the financial costs associated with guardianship. Chapter 7 examines specific issues that often arise in guardianship such as financial abuse and exploitation, health care decision making, and other areas that can be problematic and deserve close examination. Chapter 8 examines alternatives to guardianship and suggests ways that they can be made stronger and more viable sources of support for people with disabilities who need or want decision making assistance. Chapter 9 reports the findings from the study conducted for this report and brings forward the voices of people who have knowledge and experience that can enhance our understanding of guardianship and alternatives. Finally, Chapter 10 offers the findings and recommendations of the Council in the area of guardianship in light of the information presented in this report.

Findings and Recommendations

Finding 1: There is a lack of data on existing guardianships and newly filed guardianships.

Most states do not track on a statewide basis how many individuals are subject to guardianship, much less describe those guardianships in terms of basic demographic information, whether the guardian is a professional or family guardian, the extent of the guardian's authority, the assets involved, and other basic questions that would help policymakers and stakeholders make determinations about what reforms may be needed in guardianships or where resources should be directed to improve guardianship outcomes for people with disabilities.

Recommendations:

NCD recommends that Congress and the Administration develop initiatives to produce effective and comprehensive data on guardianship. There are two ways production of this data should be approached:

- Federal agencies such as the Social Security Administration (SSA), the Centers for Medicare and Medicaid Services (CMS), the U.S. Department of Veterans Affairs (VA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and other relevant agencies should collect data on whether or not individuals they serve are subject to guardianship.

Findings and Recommendations, *continued*

- States should be offered incentives and technical assistance with developing electronic filing and reporting systems that collect basic information about guardianships from the moment a petition is filed. A searchable, computerized system for aggregating information on adult guardianship cases would not only yield better usable data on guardianships, but would also improve that ability of courts to monitor and audit individual guardianships. Systems such as the "My Minnesota Conservator" reporting and data project are already in use in a few states and could be adopted across the country. Data collected must be detailed enough to allow for drawing conclusions and should include demographics, type of guardianship (limited vs. plenary, guardian over property vs. person, etc.), type of guardian (public guardians, private professional guardian, family guardian), age at which the person was subject to guardianship, court audits, timeliness of reports, amount of funds/property in the estate, and the involvement of the person in federal programs (Social Security benefits, Supplemental Security Income [SSI], Medicaid, Medicare, VA benefits, etc.). The data should also include whether the initial petition was contested, whether there is any time limitation to the guardianship, and whether there is any periodic review of the continued need for guardianship.

Finding 2: People with disabilities are widely (and erroneously) seen as less capable of making autonomous decisions than other adults regardless of the actual impact of their disability on their cognitive or decision making abilities. This can lead to guardianship petitions being filed when it is not appropriate and to guardianship being imposed when it is not warranted by the facts and circumstances.

Recommendations:

- The Department of Justice (DOJ), in collaboration with the Department of Health and Human Services (HHS), should issue guidance to states (specifically Adult Protective Services [APS] agencies and probate courts) on their legal obligations pursuant to the Americans with Disabilities Act (ADA). Such guidance should address NCD's position that: 1) the ADA is applicable to guardianship proceedings; 2) the need for assistance with activities of daily living or even with making decisions does not give rise to a presumption of incapacity; and 3) guardianship should be a last resort that is imposed only after less restrictive alternatives have been determined to be inappropriate or ineffective.

(continued)

Findings and Recommendations, *continued*

- In January 2017, the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) issued school-to-adult transition-related guidance that recognized alternatives to guardianship, including the use of supported decision making (SDM) and powers of attorney for adult students with disabilities. While this policy development is promising, OSERS needs to do more to ensure consistent implementation of this guidance across state and local educational agencies—for example, the creation of model supported decision making and powers-of-attorney forms geared toward transition-age youth. School transition teams must inform parents/caregivers and students of less-restrictive decision making support options for adults, rather than promoting the overuse of guardianship or involuntary educational representatives.
- The Department of Education Office of Special Education Programs (OSEP) should instruct Parent Training and Information Centers to prioritize and provide meaningful training on school-to-adult transition and alternatives to guardianship.
- HHS should issue guidance regarding the responsibility of medical professionals and hospitals to accommodate the needs of individuals who may need assistance making medical decisions and to adequately explain procedures and draft documents provided to patients in plain language.
- Although the Federal Government generally leaves the content of medical school training to the accrediting bodies, federal advisory group recommendations, and federal grants from CMS, HHS, and other federal agencies can influence the content of medical training and curriculum. Educating medical professionals about the ADA and the need to accommodate people with disabilities, including those with intellectual disabilities and cognitive impairments, should be prioritized as a part of medical training.
- The National Home and Community-Based Services Quality Enterprise (NQE) should include decision making assistance and use of alternatives to guardianship such as supported decision making in their priorities and include best practices as part of its resources, training, and technical assistance.
- The Administration for Community Living (ACL) has funded numerous projects that are geared toward expanding alternatives to guardianship, such as supported decision making. The agency also provides state grants to enhance adult protective services. Such funding should be allocated specifically to assist state adult protective services systems to develop greater awareness of ways to enhance the self-determination of adults considered vulnerable or in need of services, as well as the availability and use of alternatives to guardianship.

Findings and Recommendations, *continued*

- The Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities (UCEDDs), and the Protection and Advocacy (P&A) organizations should link work that has been done on advancing the self-determination of people with intellectual and developmental disabilities (ID/DD) with avoiding guardianship. There needs to be recognition that the appointment of guardians is not necessarily the preferred outcome for people with disabilities. Such appointments instead can be the result of systems failing to fully recognize people's right to direct their own life and to support them in developing self-determination and communication skills, use and build natural support networks, and have access to less-restrictive alternatives. UCEDDs in particular have a role in educating physicians, medical professionals, and parents of people with ID/DD on self-determination, supported decision making (SDM), and other alternatives to guardianship.

Finding 3: People with disabilities are often denied due process in guardianship proceedings.

Guardianship is viewed as a benevolent measure that is sought in the best interest of people with disabilities and/or older adults who are seen as needing protection. Guardianship cases are often dispensed with as quickly as possible with little concern for due process or protecting the civil rights of individuals facing guardianship.

Recommendations:

- The Elder Abuse Prevention and Prosecution Act (P.L. 115-70) calls upon the Attorney General to publish best practices for improving guardianship proceedings and model legislation relating to guardianship proceedings for the purpose of preventing elder abuse. The Attorney General's model legislation should incorporate the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA), including its provisions for preventing unnecessary guardianships.
- To ensure that due process requirements are met, it is especially important that alleged incapacitated individuals facing guardianship have qualified, independent legal representation that will advocate for the individual's desired outcome, especially if that person expresses a desire to avoid guardianship or objects to the proposed guardian. However, many courts lack sufficient resources to fund this type of representation and families often find that such representation is cost-prohibitive. Federal grant money should be made available to help promote the availability of counsel.

(continued)

Findings and Recommendations, *continued*

- A state guardianship court improvement program should be funded to assist courts with developing and implementing best practices in guardianship, including training of judges and court personnel on due process rights and less-restrictive alternatives.
- The degree of due process provided in a guardianship matter should not be contingent on the type of disability that is the alleged cause of an individual's incapacity or inability to make and carry out decisions. The DOJ should take the position that such practices are discriminatory on the basis of the ADA.

Finding 4: Capacity determinations often lack a sufficient scientific or evidentiary basis.

Courts rely too heavily on physicians who lack the training, knowledge, and information needed to make an accurate determination.

Recommendations:

- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), National Institutes of Health, and other agencies that fund scientific research should provide grants to researchers who are trying to develop a better understanding of how people make decisions and how a variety of conditions—such as dementia, intellectual disabilities, brain injuries, and other disabilities—impact the ability of individuals to make and implement informed decisions.
- *Capacity* is a social and legal construct that is not necessarily provable or disprovable through scientific methods. Resources also should be geared toward developing functional approaches to capacity assessments that take into account the possibility that someone may need decision making assistance but not necessarily a surrogate or substitute decision maker.

Finding 5: Guardianship is considered protective, but courts often fail to protect individuals.

In some cases, guardians use their position to financially exploit people or subject them to physical neglect and abuse. Courts lack adequate resources, technical infrastructure, and training to monitor guardianships effectively and to hold guardians accountable for the timely and accurate submission of required plans, accountings, and other reports, as well as for conforming to standards of practice for guardians.

Findings and Recommendations, *continued*

Recommendations:

- The court improvement program proposed earlier could also enhance the ability of courts to monitor guardianships and should include the adoption of programs such as My MNConservator, which requires guardians to file reports electronically, allows for the flagging potential problems in filed accountings, and facilitates the periodic audit of guardianship files.
- Although professional and family guardians can both be the perpetrators of abuse in guardianship, there have been several high-profile cases of abuse by professional guardians. In most states, these professionals operate with minimal oversight except by the court. States should be provided with incentives to establish statewide boards that can provide for the accreditation and oversight of professional guardians.
- States should require family guardians to undergo training to ensure they understand their ongoing responsibilities to the person subject to the guardianship and to the court.

Finding 6: Most state statutes require consideration of less-restrictive alternatives, but courts and others in the guardianship system often do little to enforce this requirement.

Courts often find that no suitable alternative exists when, in fact, supported decision making or another alternative might be appropriate.

Recommendations:

- ACL currently funds the National Resource Center for Supported Decision-Making and several demonstration projects at the state and local levels. These grants should be expanded to be able to fund more geographically- and demographically-diverse projects and pilots that specifically test SDM models and use SDM and the court systems to restore people's rights as a matter of law, particularly for people who are older adults with cognitive decline, people with psychosocial disabilities, and people with severe intellectual disabilities.
- The DOJ should make funding available to train judges in the availability of alternatives to guardianship including, but not limited to, supported decision making. This training should also include information about the home and community-based–services system and the workforce development system so that judges understand the context in which decisions are being made by and for people with disabilities. See Finding 3.

(continued)

Findings and Recommendations, *continued*

- It's important that states adopt provisions of the UGCOPAA that recognize alternatives to guardianship can be used in place of guardianship even when it is determined that the individual meets the definition of incapacity. DOJ should develop guidance to this effect.

Finding 7: Every state has a process for restoration, but this process is rarely used and can be complex, confusing, and cost-prohibitive.

Data on restorations is seriously lacking, making it impossible to tell how many individuals are in unnecessary guardianship or whether individuals who would like to try to have their rights restored have access to information about their right to restoration, receive an appropriate response to their request for restoration, or have access to resources and representation to assist them in that effort.

Recommendations:

- As a part of the effort to improve data collection and monitoring, electronic filing and auditing systems ought to include data about restoration, including whether the individual was given information about restoration and whether the continued need for guardianship was reviewed by the court.
- The state court improvement program referenced throughout these recommendations should include improvements to the restoration process. DOJ should publish guidance regarding the right to restoration and best practices.
- A grant should be given to the Protection and Advocacy system to provide legal assistance to individuals who are trying to have their rights restored or avoid guardianship.

List of Acronyms

ACL	Administration for Community Living
ADA	Americans with Disabilities Act
ADAA	ADA Amendments Acti of 2008
AIP	alleged incapacitated person
AP	Associated Press
APS	Adult Protective Services
CMS	Centers for Medicare and Medicaid Services
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DOJ	U.S. Department of Justice
EAHCA	Education for All Handicapped Children Act
FHAA	Fair Housing Amendments Act of 1988
HCBS	Medicaid Home and Community-Based Services
HHS	Department of Health and Human Services
ID/DD	intellectual and developmental disabilities
IDEA	Individuals with Disabilities Education Act
IEP	individualized education program
NCD	National Council on Disability
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NQE	National Home and Community-Based Services Quality Enterprise
OSEP	Department of Education Office of Special Education Programs
OSERS	U.S. Department of Education Office of Special Education and Rehabilitative Services
P&A	Protection and Advocacy
SAMHSA	Substance Abuse and Mental Health Services Administration
SDM	supported decision making
SSA	Social Security Administration
SSI	Supplemental Security Income
UCEDDs	University Centers for Excellence in Developmental Disabilities
UGCOPAA	Uniform Guardianship, Conservatorship & Other Protective Arrangements Act
UGPPA	Uniform Guardianship and Protective Proceedings Act
VA	U.S. Department of Veterans Affairs
WINGS	Working Interdisciplinary Networks of Guardianship Stakeholders

> "The typical [person subject to guardianship] has fewer rights than the typical convicted felon. . . . By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty."
>
> —Congressman Claude Pepper (1987)

Chapter 1: Guardianship Basics

Guardianship Fundamentals

Questioning the Assumptions of Guardianship

According to the National Guardianship Association, Inc.: "Guardianship, also referred to as conservatorship, is a legal process, utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence. Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after alternatives to guardianship have proven ineffective or are unavailable."[8]

Before we can begin evaluating guardianship or making recommendations for how to improve it, it is important to define and ensure a basic understanding of what guardianship is. Although the previous quote may seem like a reasonable definition from which to start, it contains value judgments—which are worthy of consideration—such as what constitutes "safe or sound decisions"; who gets to make that determination for an individual; and how an individual's safety should balance against his or her right to experience the dignity of risk.

Despite the oft-cited proposition that all people have certain inalienable rights, once someone is declared incapacitated and is appointed a guardian, many of their rights are taken away and their ability to make decisions in a wide variety of areas given to another person. Therefore, although guardianship is largely a creature of state law, it nonetheless raises fundamental questions concerning federal civil rights and constitutional due process. An adult usually becomes subject to guardianship when the court finds that:

> *[O]nce someone is declared incapacitated and is appointed a guardian, many of their rights are taken away and their ability to make decisions in a wide variety of areas given to another person.*

- the individual is incapable of making all or some of their own financial or personal decisions, and
- it is necessary to appoint a guardian to make those choices on their behalf.

Rights at Risk in Guardianships

Guardianships are typically separated into two categories, guardianships of the person and guardianships of the property (also sometimes referred to as *conservatorship*). When the

REMOVABLE RIGHTS UNDER GUARDIANSHIP

…that *cannot* be exercised by another person

- Marry
- Vote
- Drive
- Seek or Retain Employment

…that *can* be exercised by another person

- Contract
- Sue and Defend Lawsuits
- Apply for Governemnt Benefits
- Manage Money or Property
- Decide Where to Live
- Consent to Medical Treatment
- Decide with Whom to Associate or be Friends

…that can be exercised by another person *only with a court order*

- Committing Someone to an Institution
- Consenting to Experiments
- Filing for Divorce
- Consenting to Termination of Parental Rights
- Consenting to Sterilization or Abortion

When Does an Adult Become Subject to Guardianship?

An adult usually becomes subject to guardianship when the court finds that:

- the individual is incapable of making all or some of their own financial or personal decisions, and
- it is necessary to appoint a guardian to make those choices on their behalf.

guardian controls decisions regarding both person and property, the guardianship is called *plenary*. However, there are really three types of rights that are at issue in guardianships:

- Rights that can be taken from an individual but not given to another individual
- Rights that can be taken from a person and exercised by someone else on their behalf
- Rights that a guardian needs a court order to exercise on the individual's behalf

A person who is determined *incapacitated* generally can have the following rights removed, but these rights cannot be exercised by someone else. These include the right to:

- marry,
- vote,
- drive, or
- seek or retain employment.

Still, other rights can be removed and transferred to a guardian who can exercise these rights on behalf of the individual, such as the right to:

- contract,
- sue and defend lawsuits,
- apply for government benefits,
- manage money or property,
- decide where to live,
- consent to medical treatment, and
- decide with whom to associate or be friends.

In many states, there are also some rights that a guardian can exercise on behalf of the individual subject to guardianship, but only after the court has issued a specific order allowing the action, such as:

- committing the person to a facility or institution,
- consenting to biomedical or behavioral experiments,
- filing for divorce,
- consenting to the termination of parental rights, and
- consenting to sterilization or abortion.

Types of Rights at Issue in Guardianships

- Rights that can be taken from an individual but not given to another individual
- Rights that can be taken from a person and exercised by someone else on their behalf
- Rights that a guardian needs a court order to exercise on the individual's behalf

This list is a general description of the way various rights are treated under guardianship laws across the country; for state-specific information consult the table in Appendix A for a reference to guardianship laws in each state.

A Word on Language

When a petition is filed with the court that alleges that the individual is incapacitated, the individual is often referred to as the *alleged incapacitated person*, or *AIP* for short. If the court finds that the person does lack capacity and appoints a guardian to manage some or all of their affairs, the individual is often referred to as the *ward*. In this report, we will use the term *AIP*, but because the term *ward* is viewed by many as stigmatizing and inappropriate, whenever possible, consistent with NCD's longstanding commitment of avoiding stigmatizing language, we will refer to individuals for whom a guardian has been appointed as an *individual subject to guardianship*. This is also consistent with the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA), which is the latest iteration of the uniform guardianship statute that has been approved by the Uniform Law Commission.[9] However, it should be noted that the term *ward* will appear when it appears in a direct quote.

Process of Obtaining Guardianship

Overview

Guardianship petitions may be filed in a wide variety of situations: by parents when a child with an intellectual disability turns 18; by a son or daughter when a parent begins to show signs of dementia severe enough that there is concern for their safety; for a person with a severe disability due to sudden trauma; or when there is concern that a bad actor is exercising undue influence over a person with a disability in order to exploit the individual in some way. There are also times when guardianship is filed for less altruistic reasons, such as to gain access to the person's assets or public benefits or to exploit the individual. Whether the guardianship is over person, property, or both, or whether it is limited or plenary may be determined, at least in part, by the circumstances that give rise to the perceived need for guardianship. Due to our federalist system of government, guardianship is a creature of state, rather than federal law, and all 50 states and the District of Columbia have revised their statutes regarding guardianship numerous times. However, it is not clear that in statute or in practice guardianship law has been able to keep pace with the nation's changing understanding of disability, autonomy, and due process.

> *[I]t is not clear that in statute or in practice guardianship law has been able to keep pace with the nation's changing understanding of disability, autonomy, and due process.*

Although the process is different in every state, making it difficult to provide a singular description of the guardianship process, there are certain generalities that are helpful to discuss before examination of whether or not guardianship is working for people with disabilities, their families, and communities. The following steps are generalities that may or may not align with the laws in a given state, so it is important for interested individuals to consult their state's laws for more accurate, detailed information.

General Steps to Guardianship

1. Filing the petitions
2. Notice that a guardianship petition has been filed
3. Appointment of an attorney to represent the alleged incapacitated person
4. Capacity evaluation
5. Hearing
6. Letters of guardianship
7. Guardianship plan and initial reports

Steps to Guardianship

Step 1—Filing the petitions

In virtually all states, the guardianship process begins with filing a petition in the court with jurisdiction that alleges that a named individual is incapacitated and needs a guardian. In some jurisdictions, these are two separate petitions that actually result in two cases going forward. In Florida, for example, the petition for a determination of capacity commences a confidential proceeding and the court file of the case remains confidential as it invariably contains personal and medical information. However, the guardianship petition commences a public proceeding and the ultimate establishment of the guardianship is necessarily public information since the role of the guardian is to engage with others on behalf of the individual subject to guardianship. From that point in the process until the person is determined to lack, or not lack, capacity, the named individual is known as the AIP. Once a guardian is appointed, the individual is generally referred to as the *ward*, although, as noted previously, we will use *individual subject to guardianship* throughout this report. Usually the petitioner knows the AIP well, and is often a parent, an adult child, or a social worker for the AIP. Generally speaking, most jurisdictions require that the following basic information be provided to the court in the petition:

- A description of the nature and type of disability of the AIP and how it impacts the individual's decision making
- Any relevant medical documentation to which the petitioner has access
- A statement asserting the need for guardianship and justifications supporting this opinion
- The suggested guardian's name, who must be a person who is willing and statutorily qualified (e.g., over 18, not a felon), with a description of his or her relationship to the AIP

Step 2—Notice that a guardianship petition has been filed

Most states require that certain interested parties such as next of kin, existing "attorney-in-fact," or health care proxy receive notice that a guardianship or determination of capacity petition has been filed. This notice usually includes:

- the name of the AIP;
- the names of the AIP's closest relative(s);
- the name of the person or facility that is providing care for or has custody of the AIP; and
- the name of the proposed guardian or his or her attorney (some states require the guardian to be represented).

Additionally, many states recognize that someone who is facing guardianship may have difficulty understanding the notice they are given. In these states, there are statutory requirements that attempt to ensure that the person has the best chance of understanding the information. For example, in Virginia, the AIP must receive a brief statement in at least 14-point type of the purpose of the proceedings, his or her right to counsel and to a hearing, and a statement warning him or her in bold capital letters that the hearing may result in the individual losing many of his or her rights and a guardian being appointed to make decisions for him or her.[10] Another example is in Florida, where an attorney is appointed by the court as soon as the petition is filed, and that attorney is required to visit the individual within 24 hours of the filing of the petition to read the petition to him or her and explain exactly what it means.[11]

Step 3—Appointment of an attorney to represent the AIP

The right to counsel is a basic procedural right of respondents in guardianship proceedings. The Uniform Guardianship and Protective Proceedings Act (UGPPA) and the National Probate Court Standards both require appointment of counsel to represent the AIP, and most states have put these provisions into practice. However, the role of the attorney varies significantly from state to state, "with some states requiring counsel as vigorous advocate and others specifying that counsel should act as guardian ad litem."[12]

Legal representation should be seen as necessary in all guardianship proceedings—even under the most benevolent and caring circumstances—because guardianship represents a deprivation of liberty, which implicates due process.[13] The role of legal counsel in guardianship proceedings raises a number of interesting questions and will be discussed in greater detail later, with a close examination in Chapter 6.

Step 4—Capacity evaluation

The procedures for determining capacity vary a great deal from state to state and sometimes depend on the type of incapacity that is alleged.[14] Generally, the determination that an individual lacks capacity will be informed by an evaluation by an expert; this is discussed in greater detail in Chapter 5. As will be discussed in Chapter 5, some states also have separate procedures for people with developmental disabilities.[15] Additionally, a few states provide examiners who are called upon to make capacity determinations after receiving specialized instruction or training in how to make such a determination under the state law.[16]

Step 5—Hearing

Generally, the guardianship hearing occurs within a relatively short period of time following the petition and the capacity evaluation.[17] Because some courts now recognize that capacity may change over time, the information and evidence the court will use to make a decision regarding the need for guardianship should be contemporary in order to serve as relevant evidence.[18] Usually, there is a requirement that all interested parties, including the AIP, next of kin, and possibly others have received notice and know when and where the hearing will be. Finally, most jurisdictions require the AIP to be physically present at the hearing unless the judge determines there is good cause for them not to be there.

Guardianship hearings can be very brief and uncomplicated if the court determines the capacity evaluation presents clear and convincing evidence that the individual lacks capacity, if the AIP does not dispute or agrees to a guardian, and if the court and AIP agree on who the guardian should be. However, the hearings can also become fairly adversarial with witnesses being called and contradicting evidence presented if there is disagreement about whether the individual is incapacitated or who should be appointed guardian.

Step 6—Letters of guardianship

If the court determines that the individual is incapacitated, the judge generally will enter a judgment describing the incapacity and issue letters of guardianship, which outline the extent of the guardian's authority and outline his or her duties and responsibilities. At this point, the AIP becomes an individual subject to guardianship. In some states, guardians are required to have completed certain training and certification requirements prior to appointment. There are three broad types of guardians:

- Public guardians, who are publicly funded to provide guardianship services to individuals with no family willing to serve as guardian. In some states a public guardian is only appointed if the individual is indigent.
- Professional guardians, who are paid out of the estate of the individual subject to

guardianship or a court fund to provide guardianship services

- Family guardians, who are usually family members, but may also be unrelated friends who are not acting as guardians for multiple individuals

Generally, guardians—even family guardians—can be reimbursed out of the estate of the individual subject to guardianship for activities on behalf of the individual such as paying bills, consulting with medical professionals, or making living arrangements. As the name suggests, professional guardians provide these services to large caseloads of individuals subject to guardianship and are paid, usually after authorization from the court, out of the individual's assets. Payment is generally only authorized by the court at a rate the court deems "reasonable," which may differ from jurisdiction to jurisdiction within the state depending on prevailing rates for professional services. Additionally, what is reasonable may depend on the task performed and the level of expertise required. This is will be discussed in greater detail in Chapter 6.

Step 7—Guardianship plan and initial reports

There are best practices outlined by organizations such as the National Guardianship Association and a few initial steps that most guardians take—as determined by state law. The specific requirements may depend on whether the guardianship is over person, property, or both. One of the first steps of a guardian of the property is to determine what assets and liabilities the individual subject to guardianship has and to make an initial report to the court providing a summary of their finances. In many jurisdictions, annual reports, including a detailed accounting of how the money of the individual subject to guardianship is being spent, are required as long as a guardianship of the property is in place.

For guardians of the person, many jurisdictions require the guardian to submit a plan soon after appointment that describes his or her proposed plan of care for the individual subject to guardianship as well as history of past care. These plans may be reviewed by the judge overseeing the case, by the clerk of the court, or by a court monitor appointed to assist the court with oversight. This provides a baseline that enables the court to measure the guardian's future performance. Some jurisdictions require that a guardian be represented by an attorney who ensures that the annual accountings and reports are filed accurately and timely. A guardian's attorney may work at the direction of the guardian, but he or she has a fiduciary responsibility to the individual subject to guardianship and can be held accountable for mismanagement of funds, misrepresentations to the court, or any action that is contrary to the best interest of the individual subject to guardianship.[19]

Court Determination of Incapacity

Generally speaking, a person who is incapacitated has been determined by a court to be "unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care."[20] It should be noted that the word *incapacitated* is essentially interchangeable with the word *incompetent*, which used to be the preferred term. This change in parlance occurred largely due to reforms that began in the 1980s and continue to this day.[21] Although there is quite a bit of debate in scholarly circles about the semantic differences in the two terms, it is enough to understand that being declared incompetent is associated with a time when the law declared an individual to be an "idiot," "lunatic," "person of unsound mind," or "spendthrift," and therefore generally "incompetent" and unable to exercise any rights.[22] *Incapacitated,* on the other hand, is the current term used by most courts that employ a combination of medical and functional criteria to reach a determination that a person cannot exercise specific rights. The court generally applies a two-pronged legal test to determine whether an individual is incapacitated.[23] The court must make two findings:

1. The existence of a disabling condition, such as "mental illness," "mental disability," "intellectual disability," "mental condition," "mental infirmity," or "mental deficiency."
2. That such condition causes an inability to adequately manage one's personal or financial affairs.[24]

Two-Step Legal Test to Determine Incapacity

The court must make two findings:

1. The existence of a disabling condition, such as "mental illness," "mental disability," "intellectual disability," "mental condition," "mental infirmity," or "mental deficiency."
2. That such condition causes an inability to adequately manage one's personal or financial affairs.

> *[I]t is enough to understand that being declared incompetent is associated with a time when the law declared individuals "idiot," "lunatic," "person of unsound mind," or "spendthrift" . . .*

Capacity and Scope of the Guardian's Authority

Although it used to be the case that guardians were appointed to exercise virtually all the rights of the individual subject to guardianship, it is now possible for judges to decide that a person can exercise some rights but not others on their own.[25] For example, a person may be able to understand medical information and make informed decisions based on that information but not be able to remember to pay their bills on time. Such a person may retain the right to make medical decisions but lose the right to manage property or sign contracts. This arrangement is called a *limited guardianship.* As one woman who has guardianship over her adult daughter with disabilities put it, "[s]he doesn't really understand the concept of money but as far as decisions [about] where to live, what to eat, where to go, what entertainment to do, she makes all those decisions." Conversely, when an individual is determined to lack capacity to exercise *any* of the rights described at the beginning of this chapter, the guardianship is considered *plenary* or *general.*

In many states, there is an explicit statutory preference for limited guardianship that only gives the guardian the right to make decisions the individual is truly incapable of making. Unfortunately, as we will explore in Chapter 4, empirical studies indicate that courts do not often take advantage of the limited guardianship option and rarely limit a guardian's authority.[26]

Lawyers and judges who work in the area of guardianship will also sometimes refer to a *guardian of the person* or a *guardian of the property*. In some states, guardianship of the property is sometimes referred to as *conservatorship,* but we will continue to use the more generic and descriptive term *guardianship of the property* to refer to these arrangements throughout the report. All these terms simply indicate whether or not the guardian has been given authority to manage any personal affairs or make medical decisions for the individual subject to guardianship, the authority to manage the individual's property, or both.[27] A *plenary guardian* is generally considered the guardian of both person and property.[28]

Although a determination of incapacity is a legal decision made by a judge, "[t]he court customarily evaluates the medical condition of the proposed individual subject to guardianship by considering the individual's medical history, any diagnosis of mental illness [or other impairment], and a psychological evaluation."[29] In many cases, the determination of incapacity and the need for a guardian (as opposed to using a less restrictive alternative) must be proved by clear and convincing evidence.[30] One final factor that can impact the scope of the guardian's authority is whether the guardian makes decisions on behalf of the individual based on a "substituted judgment or best interest" standard; in some jurisdictions the statute or case law will specify which standard should be used and under what circumstances. The substituted judgment standard takes into account the individual's preferences, beliefs, and patterns of behavior as well as the individual's wishes, which may have been expressed when the individual had capacity. While the "best interest" standard should also include a consideration of these factors, it is generally more geared toward making decisions the guardian believes are in the individual's best interest with the person's well-being, health, and safety being the central concerns. These standards not only impact how the guardian makes decisions, but also how a court might review those decisions.

[E]mpirical studies indicate that courts do not often take advantage of the limited guardianship option and rarely limit a guardian's authority.

Ending a Guardianship

Once a guardianship is put in place, in most circumstances, it lasts either until the individual subject to guardianship dies, until all of his or her rights are restored, or until it is determined by the court that, although the person continues to lack capacity with regard to one or more of the rights that had been removed, there is a less restrictive alternative that will protect the individual's property and/or health and welfare without the need for a guardian. If the guardian dies and a court has not restored the individual's rights or found a less restrictive alternative appropriate, a successor guardian is appointed to replace him or her.

Unfortunately, restoration of rights is an alarmingly rare occurrence. This will be discussed at greater length in Chapter 7, but for now, it is enough to understand that all states have a process for restoration of the rights of the individual subject to guardianship. Usually, either the individual or another interested party can ask the court to restore some or all of the rights that were removed when the guardianship was established. The procedures vary from state to state, but in many cases, the court will convene a hearing regarding restoration and receive evidence, sometimes including an independent capacity evaluation, and make a ruling regarding whether some or all of the individual's rights should be restored. A court order will specify which of the individual's rights were restored. If property rights are restored, generally the guardian of the property is required to file a final accounting and "wrap-up" the guardianship by providing any documents the individual will need to regain control of his or her property and assets.

Unfortunately, restoration of rights is an alarmingly rare occurrence.

In the event that the guardianship ends because the individual subject to guardianship dies, the guardian will have to file the death certificate with the court within a specified period of time and relinquish control of the "guardianship estate" to the executor of the individual's will or the individual's next of kin. Finally, the guardian may be required to file a final accounting that identifies how assets in the guardianship estate have been managed since the last accounting as well as where assets are to be found with the court that had overseen the guardianship.

Chapter 2: Guardianship Against the Backdrop of Disability Rights Law

The table that follows originally appeared in NCD's *Rising Expectations: The Developmental Disabilities Act Revisited* report and has been updated.[31]

Table 1. Timeline of Major Legislative and Policy Initiatives Affecting People with Developmental Disabilities, 1960–2010

1960–1965	▪ President Kennedy delivers a Message to Congress, calling for a "bold new approach" in the United States for responding to people with mental illnesses and intellectual disabilities and releases the *National Plan to Combat Mental Retardation.* ▪ The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 creates a national network of research centers and university-affiliated facilities. ▪ The Social Security Act of 1965 establishes the Medicare and Medicaid programs.
1966–1970	▪ The number of residents in large state institutions for people with intellectual disabilities reaches its peak at 194,650 in 1967.
1971–1975	▪ In 1971, amendments to Title XIX of the Social Security Act authorize Medicaid reimbursements for intermediate care facility services. ▪ The Civil Rights Division of the U.S. Department of Justice begins intervening in disability rights cases, starting with a judge's invitation in *Wyatt v. Stickney.* In *Wyatt,* 325 F.Supp. 781 (M.D. Ala. 1971), a federal court held for the first time that people with mental illnesses or intellectual disabilities who are involuntarily committed to state institutions have a constitutional right to treatment that will afford them a realistic opportunity to return to society. ▪ The Social Security Amendments of 1972 establishes the Supplemental Security Income (SSI) program for seniors and people with disabilities. ▪ The Rehabilitation Act of 1973 revises earlier vocational rehabilitation legislation to emphasize serving people with severe disabilities and includes a nondiscrimination clause (see 1976–1980). ▪ The Education for All Handicapped Children Act of 1975 mandates that children with disabilities ages 3–21 receive a free and appropriate education in the least restrictive environment based on an individualized education program and with due process guarantees.

(continued)

1971–1975	▪ On May 5, 1975, the New York Governor signed the Consent Decree that ended the legal battle to improve conditions at the Willowbrook State School in Staten Island, New York. The Decree established that residents of Willowbrook had a constitutional right to be protected from harm and required New York state to take immediate steps to improve the lives of those who lived there and to "ready each resident . . . for life in the community at large" in the "least restrictive and normal living conditions possible."
1976–1980	▪ Regulations implementing Section 504 of the Rehabilitation Act of 1973 are signed in 1977, implementing the nondiscrimination clause that prohibits the exclusion of people with disabilities from any program or activity receiving federal financial assistance. ▪ A U.S. District Court found that residents of the Pennhurst institution had three distinct sets of constitutional rights, including the right to habilitation, the right to be free from harm, and the right to nondiscriminatory and nonsegregated habilitation.
1980–1985	▪ The Medicaid Home and Community-Based Services (HCBS) waiver program is established. ▪ The Civil Rights of Institutionalized Persons Act of 1980 provides the DOJ with the statutory authority to bring cases to protect people living in institutions.
1986–1990	▪ 1986 Amendments to Education for All Handicapped Children Act provide funding to states to offer early intervention programs for infants and toddlers. ▪ The Technology Related Assistance for Individuals with Disabilities Act of 1988 establishes grant programs to encourage the development and distribution of assistive technology for people with disabilities. ▪ The Fair Housing Amendments Act (FHAA) of 1988 amended Title VIII of the Civil Rights Act of 1968, which prohibits discrimination on the basis of race, color, religion, sex, or national origin in housing sales, rentals, or financing. The FHAA extends this protection to people with disabilities and families with children. ▪ The 1990 Americans with Disabilities Act prohibits discrimination based on disability.
1991–1995	▪ The 1992 Education for All Handicapped Children Act is changed to Individuals with Disabilities Education Act (IDEA), and language is added to support the transition from school to adulthood.
1996–2000	▪ The Ticket to Work and Work Incentives Improvement Act of 1999 establishes new programs and work incentives for SSI and Social Security Disability Income beneficiaries. ▪ In 1999, the U.S. Supreme Court holds in the case of *Olmstead v. L.C.* that the unnecessary segregation of people with disabilities in institutions may constitute discrimination based on disability. This case had and continues to have significant public policy implications for people with disabilities.
2001–2005	▪ In 2001, the New Freedom Initiative includes a set of proposals designed to ensure that Americans with disabilities have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in their communities. ▪ The No Child Left Behind Act of 2001 is designed to ensure that all children have a fair, equal, and significant opportunity to obtain a high-quality education and requires that states develop accountability systems.

2006–2010	- Congress enacts the ADA Amendments Act of 2008 (ADAA), making it easier for a person to establish that he or she has a disability within the meaning of the statute. Congress overturned several Supreme Court decisions that had interpreted the definition of *disability* too narrowly, resulting in a denial of protection for many people with impairments such as cancer, diabetes, and epilepsy. The ADAA states that the definition of *disability* should be interpreted in favor of broad coverage of individuals. - The Convention on the Rights of Persons with Disabilities (CRPD) is an international disability treaty modeled on the ADA. The CRPD is a vital framework for creating legislation and policies around the world that embraces the rights and dignity of all people with disabilities. The United States signed the CRPD in 2009, but Congress has not yet ratified it.

Guardianship as a Disability Policy Issue

Guardianship is often overlooked, and, when it becomes part of the national policy conversation, it is often viewed as an issue impacting older Americans and not thought of as an important disability issue. However, guardianship must be understood as a disability policy issue worthy of examination, reflection, and reform. After all, an adult becomes subject to guardianship only if a court has determined that he or she cannot manage property or meet essential requirements for health and safety. Additionally, at least 11 states have laws that provide for alternate, and generally less rigorous, procedures when the individual who allegedly needs a guardian is an adult with intellectual and/or developmental disabilities. The Table of Authorities in Appendix A at the end of this report references the statutes that make this distinction. Regardless of whether one is a young adult with a congenital developmental disability subject to guardianship because the court determined he or she lacked the ability to make decisions him or herself, or whether one is in his or her 80s and the court believes that Alzheimer's disease has advanced to the point where he or she can no longer make decisions for his or herself, the reason to impose guardianship is disability in both instances.

> *[A]t least 11 states have laws that provide for alternate, and generally less rigorous, procedures when the individual who allegedly needs a guardian is an adult with intellectual and/or developmental disabilities.*

In order to fully understand guardianship as a disability issue, we need to come from a common understanding of it within the context of the evolution of disability policy, particularly as it relates to issues of liberty, autonomy, and self-determination. This chapter provides an overview of the evolution of disability policy from the eugenics movement to the CRPD in order to provide context for our discussion of guardianship and to help ground our recommendations in NCD's long tradition of advancing policies that promote the dignity, self-determination, and maximum independence of all people with disabilities regardless of their age.

History of Discrimination

The Eugenics Movement

Disability is a natural part of the human experience that has always been a part of the fabric of American society.[32] However, a movement that was an important part of American politics from the 1890s until the 1920s aimed specifically to remove people with disabilities and other minority groups from society.[33] The eugenics movement relied upon fear and pseudoscience to enact public policies to segregate people with disabilities from their families and communities and to impede their ability to procreate, so that their alleged "bad genes" would not burden society for another generation, as the narrative went.[34] Even those considered among the best legal minds of the age embraced the noxious policy of eugenics, including U.S. Supreme Court Justice Oliver Wendell Holmes Jr., who penned the infamous *Buck v. Bell* decision in 1927 and found state statutes permitting compulsory sterilization of people with disabilities were not unconstitutional.[35] Fortunately, the eugenics movement fell into public disrepute after discovery of the Nazis' horrific acts committed in reliance on eugenic ideas.[36] In fact, mass exterminations in Nazi Germany in the 1940s began with the killing of institutionalized Germans with disabilities in the T4 program—actions based on eugenic theories imported from the United States more than a decade earlier.[37]

While the end of World War II marked a de-escalation of the eugenics movement, many forcible sterilization laws, of which the eugenics movement had facilitated enactment, persisted well into the 1970s.[38] The policies that began during the eugenics movement's heyday reverberate through laws that are still on the books today and have a profound impact on American society's understanding of disability. As NCD pointed out in its 2012 report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, over two decades after the passage of the ADA, several states still have laws on their books that authorize involuntary sterilization and affirm in statute that the "best interests of society would be served by preventing them [people with disabilities] from procreating."[39]

> ***Eugenics attempted to control whether people with disabilities made fundamental decisions for themselves about having intimate relationships and children; during the same time period many individuals were denied the right to determine where and how to live because they were committed to large state institutions.***

Underlying these historic laws and other practices to be described later in this chapter is a base assumption that people with disabilities are incapable of making decisions for themselves, and that society must be protected from the consequences of the decisions that people with disabilities might make. Eugenics attempted to control whether people with disabilities made fundamental decisions for themselves about having intimate relationships and children; during the same time period many individuals were denied the right to determine where and how to live because they were committed to large state institutions.

Institutionalization

As a result of state statutes authorizing involuntary sterilization in 30 states, by 1970 more than 65,000 Americans had been involuntarily sterilized, and to this day several states have not removed these statutes from their books.[40] In addition to the practice of eugenic sterilization, from the mid-1800s through the early 1970s, states regularly practiced segregation of people with disabilities via institutionalization, which also represented a fundamental violation of their human rights.[41] With respect to people with intellectual disabilities, these sprawling institutions started in many cases as benevolent organizations with a mission to impart a "practical education" to the students who were expected to one day return to their communities as productive members. However, as early as the late 1850s, the goal of the institutions had already become strictly custodial in nature. People with disabilities placed in them were effectively warehoused away from the rest of society, and few individuals who found themselves living in them could ever expect to leave them in their lifetimes.[42] As the goals of these institutions shifted, fewer resources were directed at providing for a quality of life for the people who resided there. Any federal money available to states was only available for purposes of building the facilities, and between 1950 and 1970, there was a building boom of these institutions in which states built, refurbished, or expanded institutions more than during any other time in American history. Despite the high level of building investment, by the 1960s, the largest institutions had become chronically understaffed, overcrowded, and underfunded.[43] In particular, the horrific conditions at Willowbrook—the largest facility for people with intellectual and psychiatric disabilities in the country that housed more than 6,000 people—prompted U.S. Senator Robert Kennedy to call the New York institution a "snake pit" in 1965.[44] While Kennedy's commentary brought about some minor changes at Willowbrook and other facilities of its kind, it was not until the media picked up the story in the late 1960s and early 1970s that Americans were confronted with the extent of the country's moral failure to uphold the humanity of people with psychiatric and intellectual disabilities.

> *[T]hese sprawling institutions started in many cases as benevolent organizations with a mission to impart a "practical education" to the students who were expected to one day return to their communities. . . . However, as early as the late 1850s, the goal . . . had already become strictly custodial in nature.*

Geraldo Rivera famously exposed New Yorkers to the horrifying conditions inside Willowbrook, and Bill Baldini similarly brought the conditions at Pennhurst State Hospital into living rooms in Pennsylvania.[45] These reporters and others forced a nation to grapple with images that rivaled those that some remembered from black and white

newsreels following World War II. Americans now saw emaciated children who were unable to walk because they had never been lifted from their cribs, covered in flies, and lying in filth.[46] They saw adults with hollow eyes wandering aimlessly, often sedated to keep them compliant and under control.[47] These exposés led parents who had been told that they were doing the right thing by placing their children in the state's care to file lawsuits to improve the conditions at these facilities, and led legislatures to increase or restore funding to improve conditions.[48] Advocates and the legal community mobilized around these issues as well, working not only to improve the conditions in these large facilities, but also to ensure that people with psychiatric disabilities were afforded due process before being committed to a facility and to expand opportunities for integration in education and community services for people with intellectual disabilities.

Civil Rights Expansion and Joining the Community

Deinstitutionalization

The deinstitutionalization movement led to major shifts in disability policy and the cultural understanding of disability. Since people under adult guardianship—even those who are in the aging population—are people with disabilities by definition, these changes impacted guardianship laws, drove many of the guardianship reforms outlined in Chapter 3, and continue to drive guardianship reform conversations today. More directly, guardianship played an integral part in deinstitutionalization. Many individuals who were slated to leave closing institutions were separated from their families as children. In order to move individuals who were determined to lack the ability to consent to new placements outside of the institutions, it was deemed necessary to find guardians who were willing to sign off on integrating them into the community.[49] However, for a variety of reasons including estrangement from family or not having family members who were appropriate guardians, one study found that 1,643 individuals in institutional placement in Florida between 1983 and 1985 were "incompetent" but did not have guardians who could help them with a move to a less restrictive setting.[50] On the other hand, guardians have sometimes objected to moving individuals under their care into the community. Recently, advocates trying to implement "Money Follows the Person" federal grants designed to help move individuals into community settings have found that it can be difficult to obtain guardian consent to move the individual into the community.[51] A report from the Connecticut experience with Money Follows the Person describes guardians who worry that their loved ones need 24/7 care, that they will not be able to access in the community, or that the guardian will be expected to manage services on a day-to-day basis.[52]

> *[A]dvocates trying to implement "Money Follows the Person" federal grants designed to help move individuals into community settings have found that it can be difficult to obtain guardian consent to move the individual into the community.*

Independent Living

Around the same time that society was awakening to the neglectful and cruel treatment of people with psychiatric, intellectual, and developmental disabilities in large institutions, people with disabilities themselves were beginning to demand better treatment in other segments of society. In 1962, the University of California at Berkeley admitted Ed Roberts as a student but forced him to live in the campus medical facility due to his quadriplegia and reliance on a ventilator after contracting polio as a teenager.[53] Roberts organized his fellow students with disabilities on campus into a student group that began pushing the university to become more accessible and provide support services so that students with disabilities could live more independently.[54] Roberts and others went on to found the Berkeley Center for Independent Living. The core values they established, "dignity, peer support, consumer control, civil rights, integration, equal access, and advocacy," remain at the heart of the independent living and disability rights movements to this day.[55] People with disabilities, their families, and advocates who had worked with them and witnessed some of the injustices first hand began to assert the right of people with disabilities to live in the world, ". . . on the streets, the highways and byways, in public buildings, and other public places, in the schools and colleges, in the public service and private callings, in the factories, shops and offices, in short, in all the places where men are, go, live, work, and play . . ." and to demand that the laws work toward the goal of integration for people with disabilities.[56] People were awakening to the idea that people with disabilities could be fiercely independent and, to the extent that they were viewed as dependent, that it might be a function of society's failure to accommodate their different needs rather than a condition that was inherent in one's physical or mental disability itself.

Once people with both physical and mental disabilities began to insist on their independence, guardianship as a legal construct came under scrutiny. Guardianship is a protective measure that is predicated on the idea that people with disabilities are incapable of caring for themselves and that they need others to make decisions for them about their care, relationships, and other aspects of everyday life. One interviewee described it in the following way: "One other thing that is to me most frustrating is that the general public does not think of guardianship in increments . . . [W]hen you say guardianship, they think that the person can't do anything . . . [They] will start speaking directly . . . to the guardian as opposed to the individual."

People were awakening to the idea that people with disabilities could be fiercely independent and, to the extent that they were viewed as dependent, that it might be a function of society's failure to accommodate their different needs. . . .

Rehabilitation Act

The Rehabilitation Act of 1973 was one of the earliest federal laws to recognize the civil rights of people with disabilities, providing that, "No otherwise qualified [person] with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."[57] This kind of legislative language and much of the original law's stated purposes to "prepare [those with the most severe disabilities] for and engage in gainful employment" and to "improve [people with disabilities'] ability to live with greater independence and self-sufficiency" was a marked departure in tone from the laws passed during the eugenics movement that presumed disability equated with burden and incapacity.[58]

Although the Rehabilitation Act had the potential to reduce discrimination against people with disabilities in education, employment, housing, transportation, medical care, and access to public spaces, this potential went unrealized for many years as the community waited for the Department of Health, Education and Welfare (HEW) to publish regulations that would implement the law.[59] As noted in NCD's 2003 report, *Rehabilitating Section 504:*

> It took a nationwide sit-in at U.S. Department of Health, Education and Welfare (HEW) buildings by people with disabilities in 1977, including a month-long occupation in San Francisco, to persuade the Federal Government to issue regulations implementing Section 504 of the Rehabilitation Act.[60]

As demonstrated in advocacy leading up to the passage of the Rehabilitation Act and the sit-ins that preceded its implementation, during this time, people with disabilities were beginning to find their voice politically, insist that they speak for themselves, and demand equal access in society.

Developmental Disabilities Assistance and Bill of Rights Act

In the late 1960s and early 1970s, advocates for people with intellectual and developmental disabilities were busy working toward passing federal legislation that they hoped would shift federal funding away from institutions, build up resources in the community, and guarantee certain fundamental rights for people with intellectual and developmental disabilities (ID/DD). This activism led to the creation of Developmental Disabilities Councils, the Protection and Advocacy for Developmental Disabilities program that provided legal and advocacy services to protect people with ID/DD from abuse and neglect; and to the passage of the Developmental Disabilities Assistance and Bill of Rights Act in 1975, which was an amendment to the 1963 Mental Retardation Facilities Act.[61] The introduction of the DD Bill of Rights was one of the first times that the individual human rights of people with disabilities were expressly recognized in a U.S. law. It required that people with disabilities be included in forming habilitation plans and expressly granted this population with privacy rights and rights to free association in the context of receiving services—ideas that were unheard of when things like eugenic sterilization and segregation were the norm.[62]

[The DD Bill of Rights] . . . expressly granted . . . privacy rights and rights to free association in the context of receiving services—ideas that were unheard of when things like eugenic sterilization and segregation were the norm.

During this time period, policymakers increasingly recognized that people with disabilities, particularly those with intellectual disabilities, had not always been provided the opportunity to make and learn from their mistakes; they were denied the experience of the dignity of risk. As one family member interviewed for this report expressed, "[O]ne of the things that happens frequently for people with disabilities is they just literally are not accustomed to making choices because nobody gives them the opportunity." Self-advocates and others argued that the focus on protecting people with disabilities, while important, is better accomplished when it is balanced with independence, personal autonomy, and the development of decision making skills. As another interviewee noted, "It's not about protecting someone. It's about teaching them how to best protect themselves."

A Right to Public Education

Another important development that occurred during this time period was the Education for All Handicapped Children Act (EAHCA), which was later renamed the Individuals with Disabilities Education Act (IDEA). Passed in 1975, this law extended the right to a free and appropriate public education to children with disabilities who had often been denied entry into public schools.[63] Additionally, it gave children with disabilities the right to an individualized education program (IEP) designed by the school with input from their parents, and it gave parents of children with disabilities procedural due process rights that gave them an opportunity to ensure that their child's school was meeting its obligations.[64] IDEA and its predecessor EAHCA demonstrated a dramatic shift in assumptions about what people with disabilities could expect from their lives. The expectation became a public education in integrated school settings that would prepare them for lives as independent adults, even if they continued to need services and supports into adulthood.

Community Integration

Section 504, the DD Bill of Rights Act, and EAHCA reflected a culture of changing expectations for people with disabilities; it was no longer unthinkable that children with intellectual disabilities would grow up to become integrated into the fabric of society and experience a sense of purpose. These changes were also taking place in a society that was experiencing massive cultural shifts in the 1960s and 1970s; many people whose human and civil rights had long been denied in the United States were being recognized as autonomous, self-determined actors worthy of full and equal recognition before the law.[65] These cultural changes made viewing people with disabilities as anything other than fellow human beings much more difficult, and it led to skepticism of cultural norms and traditional sources of authority who had been complicit in the oppression of women, people of color, the LGBTQ community, and others, including "a growing intellectual skepticism of psychiatry which posited mental illness as a social construct and therapeutic intervention as a means to impose social conformity."[66] This "outsider critique" of psychiatry led mental health advocates to push to raise the bar regarding due process, making it more difficult for the state to use its police power to restrict the liberty of people with psychiatric disabilities by committing them to psychiatric hospitals and state institutions.[67] Additionally, it fueled judicial decisions that raised the bar on civil commitments to the "danger to self and others" standard adopted by the Supreme Court in *O'Conner v. Donaldson*.[68]

Mental health advocates' approach was somewhat different than the approach of advocates for people with intellectual and developmental disabilities. While the due process arguments advanced by mental health advocates asserted a right to be free from unwanted treatment and from confinement, advocacy efforts for people with ID/DD were often led by families whose essential demand was for services as well as integration. While advocates in the psychiatric disabilities community often raised legal challenges to confinement and fought for stronger due process protections to prevent unnecessary confinement, advocates in the developmental disabilities community often argued:

- that if the need for treatment was the justification for confinement, that treatment needed to meet constitutionally mandated minimums in terms of quality; and
- that Section 504 of the Rehabilitation Act and the DD Bill of Rights Act of 1975

> *The expectation became a public education in integrated school settings that would prepare them for lives as independent adults, even if they continued to need services and supports into adulthood.*

> contained an integration mandate that required services be provided in the least restrictive environment that would meet the needs of the individual.[69]

In other words, for people with psychiatric disabilities, advocacy focused on a right to be left alone, whereas for people with ID/DD, advocacy focused on a right to services in the community.[70]

One problem for people with ID/DD who want to receive services in the community rather than in institutional settings has been called the "institutional bias" in the Medicaid statute passed in 1965.[71] Simply put, under the Medicaid statute, treatment in an institutional care facility for the developmentally disabled and nursing care received in a nursing home are mandatory services that states must agree to pay for as a condition of accepting matching federal funds. However, there is no requirement in the statute that states provide home- and community-based services.[72] In 1981, the Omnibus Budget Reconciliation Act established the 1915(c) Home and Community Based Service Waivers (HCBS) program, allowing states to provide home- and community-based services to targeted groups of individuals as an alternative to institutional care.[73] While this statute did not create an entitlement to HCBS, it did create a funding mechanism that states have used to rebalance their Medicaid programs and provide more services in the community.[74] The waivers created a greater range of options for people with disabilities to receive supports that fit their needs and preferences and integrate in the community, and directed Medicaid providers to engage in person-centered planning with the people they served.[75] This range of options created a more consumer-driven system, which, in some ways, enhanced the decision-making authority of people with disabilities. However, paradoxically, this array of community options has potentially driven an increase in the number of guardianships because of the perceived need to have a decision maker to determine which services the person with ID/DD needs or wants, although this is difficult to quantify given the lack of data on guardianships discussed in Chapter 4.

As society continues to move toward greater community integration of people with disabilities, people with disabilities may need or want assistance making important decisions, such as where to live or work. Some may prefer that help to come from a guardian. One interviewee subject to guardianship reported, "I like having a guardian . . . they make sure that everything I do, I do the right way and they make sure that I'll be happy." Parents might also be concerned about the possibility not only that their children with disabilities will be unable to make choices about things like where to live and what services and supports they might need, but also that they might be vulnerable to exploitation or undue influence from individuals who are not acting in the best interest of their son or daughter. Parents who have advocated for their children with disabilities—often having to fight to get the school to provide the education their child was entitled to or to get the state Medicaid program to provide supports in the home and community—might understandably have a hard time imagining not making decisions for their children, whom they fear will not be able to advocate for themselves. These concerns might be driving what some have identified as an increase in the number of guardianships in the ID/DD population, but it's difficult to prove because of a lack of available data on guardianships generally, as we will explore in Chapter 4.

The ADA Generation

In 1990, more than a decade after the DD Act and EAHCA, President George H. W. Bush signed the ADA into law. The ADA was first proposed in a 1986 groundbreaking report by NCD, *Toward Independence*.[76] The Council recommended that Congress "enact a comprehensive law requiring equal opportunity for [people] with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap."[77] Unlike Section 504 of the Rehabilitation Act, which only outlawed discrimination on the part of programs receiving federal money, such a law would prohibit discrimination against people with disabilities in the same way that existing federal laws prohibited race and gender discrimination in virtually all areas of American life.[78] Furthermore, the integration mandate of Title II of the ADA requires that states provide services, activities, and programs in the most integrated and least restrictive setting appropriate to the needs of qualified people with disabilities.[79]

In 1999, nearly a decade after the signing of the ADA, the U.S. Supreme Court handed down the *Olmstead v. L.C.* decision interpreting the ADA.[80] The Supreme Court's decision in *Olmstead* has been described as similar in importance to the disability community as the *Brown v. Board of Education* decision was to the black civil rights movement.[81] *Olmstead v. L.C.* concerned two women with intellectual and psychiatric disabilities who had been deemed suitable for placement in the community by their doctors but had been denied the opportunity to move out of the Georgia state institution where they had lived for years.[82] The Court held that the unnecessary segregation of people with disabilities in institutions may constitute discrimination based on disability.[83] The Court further ruled that the ADA requires states to provide community-based services rather than institutional placements for people with disabilities if (a) community placement is appropriate, as determined by the state's professionals; (b) the transfer is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported services.[84] The Supreme Court found that "[u]njustified isolation . . . [of people with disabilities] is properly regarded as discrimination based on disability," and thus violates the ADA.[85]

The Supreme Court found that "[u]njustified isolation . . . [of people with disabilities] is properly regarded as discrimination based on disability," and thus violates the ADA.

Since the Supreme Court affirmed in *Olmstead* that unnecessary segregation and isolation of people with any type of disability is discrimination and violates the law, there have been countless legal complaints and initiatives to implement the broad policy goals spelled out in the decision: to affirm the right of people with disabilities to live in the world and to provide services in the least restrictive environment.[86]

Many of the guardianship reforms discussed in this report will rely on the fundamental principles of integration and least restrictive environments, as required both in the text of the ADA and in the Supreme Court's interpretation of the ADA. As will be explored in Chapter 3 and also in Chapter 8, some scholars have argued that the integration mandate applies to guardianship and that guardianship itself may constitute a violation of the ADA in many cases.[87]

CRPD—The ADA Goes Global

In 2006, the CRPD was finalized and opened for signature and ratification.[88] The CRPD is an international treaty that was inspired by U.S. leadership in recognition of the rights of people with disabilities.[89] The CRPD is widely seen as an expansion of the ADA to the world stage, although in some of the particulars it is more informed by international human rights law than the American civil rights framework that formed the basis of the ADA. To date:

- 175 countries have ratified or accessioned it.
- 160 countries have signed it.[90]
- 92 countries have ratified and signed the Optional Protocol, which establishes a complaint mechanism for violations of the Convention.[91]

The United States signed the treaty in 2009 but has not yet ratified it. NCD has repeatedly called for the ratification of the CRPD and reaffirms that recommendation in this report.[92] The CRPD is a vital framework for creating legislation and policies around the world that embrace the rights and dignity of all people with disabilities. As we will see in the next chapter, it has had a profound impact in the countries where it has been ratified, including in the area of guardianship practices.

Chapter 3: Evolution of Guardianship Law

Table 2. Timeline of Major Legislative and Policy Initiatives for Guardianship Law, 1975–2017

1975–1985	▪ 1975: *O'Conner v. Donaldson* decision that led to standards of civil confinement ▪ 1978: The Model Guardianship Statute was developed. ▪ 1982: Uniform Guardianship and Protective Proceedings Act (UGPPA)
1986–1999	▪ 1987: The Associated Press (AP) published Guardians of the Elderly: An Ailing System, a series of reports on the failures of guardianship law and lack of oversight. ▪ 1987: The U.S. House Select Committee on Aging met to respond to the allegations laid out in the AP story. ▪ 1987: The National Guardianship Association formed. ▪ 1988: Held First National Guardianship Symposium "Wingspread" ▪ 1989: UGPPA was amended. ▪ 1997: UGPPA was revised.
2000–2010	▪ 2001: "Wingspan" conference took place at Stetson College of Law, Florida. ▪ 2006: United Nations Convention on the Rights of Persons with Disabilities (CRPD) ▪ 2007: The Uniform Guardianship and Protective Proceedings Jurisdiction Act ▪ October 4, 2010: Yokohama Declaration Adopted by the First World Conference on Adult Guardianship Law, Yokohama, Japan
2011–2017	▪ 2012: The Third National Guardianship Summit created the Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS). ▪ 2012: New York County Surrogate Court decision, *In re Guardianship of Dameris L,* that terminated a guardianship in favor of supported decision making. ▪ 2013: New York, Oregon, Texas, and Utah piloted the WINGS groups. ▪ 2013: Virginia court decision, *Ross v. Hatch*, recognizes use of supported decision-making as an alternative to permanent plenary guardianship. ▪ 2016: The Elder Justice Innovation Grant expanded WINGS groups. ▪ 2017: UGPPA revised to UGCOPAA

Erica Wood, a noted expert in guardianship who is referenced throughout this report, has described guardianship as having a "front end" and a "back end."[93] The *front end* refers to the procedures for determining the individual's capacity and establishing the guardianship. The *back end* refers to the ongoing responsibility the guardian and the court have to the individual subject to guardianship, as well as the procedures for guardian oversight once the guardianship has been established. There is a long history of reform of both, particularly since the late 1980s. This chapter will trace the history of guardianship and guardianship reform and examine what reforms have already been tried and whether they have been successful. In some cases, these reforms are an integral part of ongoing issues in guardianship and will be discussed in greater detail later. Like the previous chapter, this chapter is not designed as a master class in guardianship reform; rather it is intended to survey the trends in guardianship law and highlight some of the issues in guardianship that led to these attempts to improve the system.

Ancient and British Roots

Guardianship may not be well understood in part because it is such a constant in our legal traditions. The son of the famous Greek playwright Sophocles attempted to obtain guardianship over his father as his health declined in his later years. Sophocles defended against the imposition of guardianship by reading from his latest play and the case was dismissed. Roman law allowed for the appointment of a "tutor" to manage the property of single women, orphans, and others who were not considered competent to manage property. However, the basis for American guardianship law is really British common law. Sometime in the late 1300s, the "royal prerogative" was enacted.[94] It described the king as the "father and guardian of his kingdom" and established that it was his responsibility "to take care of those who, by reason of their imbecility and want of understanding, are incapable of taking care of themselves."[95] Guardianship did not arise out of the spirit of altruism so much as from the need for the sovereign to make sure that land could remain in the hands of people who could dispose of it and otherwise exercise the rights of property ownership. Over the centuries, this royal prerogative evolved and the crown discharged its duty through agencies or private citizens who were appointed as curators or guardians.

Pre-Reform: Guardianship in America

American guardianship law is rooted in the royal prerogative as well, through its direct descendent the doctrine of *parens patriae*.[96] Parens patriae is Latin for "parent of the country," and refers to the role of the state in taking care of those who cannot care for themselves.[97] Federal power is derived from the Constitution, but under the 10th Amendment, powers not expressly granted to the Federal Government are reserved to the states, including the common law doctrine of parens patriae.[98] Therefore, guardianship remains a matter of state law. However, the state's authority to act under the doctrine of parens patriae is limited by constitutional requirements as well as other federal laws due to the "Supremacy Clause," which resolves conflicts between state and federal law in favor of the federal law.[99]

Initially, parens patriae was viewed as benevolent and there is little concern in early statutes with regard to due process. One scholar noted, “the states have traditionally exercised their parens patriae powers in an atmosphere of informality. Relaxed procedures were said to be justified because the proceedings were non-adversarial; the sole preoccupation of the court was to serve the individual’s best interest.”[100]

However, in the 1960s, advocates for people with intellectual and psychiatric disabilities began to push to make it more difficult to justify the use of the police power, which confers upon states the authority to act to promote the health, safety, and welfare of the community and confine individuals to institutions. Additionally, advocates began to assert that the state had an affirmative duty to treat the disability that had been used to justify the individual’s confinement rather than simply warehousing them in perpetuity.[101] Eventually this advocacy led to the development of the standard for civil commitment outlined in *O’Conner v. Donaldson* that states cannot constitutionally confine, “without more,” a person who is not a danger to himself or others. The former category includes the suicidal and the “gravely disabled,” who are unable to “avoid the hazards of freedom” either alone or with the aid of willing family or friends.[102] Subsequently, “all fifty states retooled their commitment laws to include adequate due process safeguards.”[103]

In addition to making it more difficult to commit a person to a mental facility or institution, the Supreme Court recognized a constitutional right to minimally adequate training related to the person’s liberty interest in avoiding unnecessary bodily restraint.[104] Although these cases concerned the police power and do not directly apply in guardianship cases, they did lead to a changed understanding of the constitutional implications of infringing on individual liberty due to disability or supposed incompetence.

Guardianship laws remained unchanged for more than 100 years and contained virtually no procedural due process protections. But in 1978, the American Bar Association developed a model guardianship statute, and in 1982, the Uniform Law Commission came out with the first UGPPA, now renamed the UGCOPAA.[105] The 1982 UGPPA was a groundbreaking document that emphasized autonomy and limited guardianship or conservatorship. However, it would be several more years before states began to look to these models to improve their guardianship statutes.

Guardianship laws remained unchanged for more than one hundred years and contained virtually no procedural due process protections . . .

Late 1980s, Early 1990s: First Wave of Guardianship Reform

As had happened a little over a decade earlier when Geraldo Rivera shined a much-needed light on the conditions at Willowbrook, the first significant wave of guardianship reform can be traced back to media attention on abuses within the system. In 1987, the Associated Press (AP) published a series of reports titled Guardians of the Elderly: An Ailing System, which splashed across front pages all across the country stories from “a dangerously overburdened and troubled system” that stripped seniors of their rights with the “stroke of a judge’s pen,” and subsequently failed to monitor the actions of the guardian or hold them accountable for the well-being of the individual subject to guardianship.[106]

The U.S. House Select Committee on Aging responded by convening a hearing where Chairman Claude Pepper famously observed the following:

> The typical [person subject to guardianship] has fewer rights than the typical convicted felon. . . . By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty.[107]

In 1987, the Associated Press (AP) published a series of reports . . . [about] "a dangerously overburdened and troubled system" that stripped seniors of their rights with the "stroke of a judge's pen," and subsequently failed to monitor the actions of the guardian or hold them accountable.

Although Congress did not adopt reforms that year, in response to the public outcry that followed the AP story, most states began the process of reconsidering and revising their statutes. Additionally, the National Guardianship Association formed in 1987 and, shortly thereafter, developed first-of-its-kind standards of practice and a code of ethics for guardians.[108] The Congressional hearing also laid the groundwork for the First National Guardianship Symposium held in 1988. Known as "Wingspread," the conference brought together an interdisciplinary group of "judges, attorneys, guardianship-service providers, physicians, aging-network staff, mental-health experts, ethicists, academicians, and others . . ." who issued 31 recommendations for reform of the 50 different guardianship systems across the country.[109] These recommendations were relevant to every aspect of guardianship process, including procedural due process and legal representation, determining incapacity, and accountability of guardians.[110]

[T]he National Guardianship Association formed in 1987 and, shortly thereafter, developed first-of-its-kind standards of practice and a code of ethics for guardians.

The Wingspread recommendations led to a comprehensive study of guardianship monitoring undertaken by the ABA Commission on the Mentally Disabled, the ABA Commission on Legal Problems of the Elderly, and the State Justice Institute (SJI).[111] In addition to the study, SJI funded projects on guardianship monitoring, pioneering the use of volunteers to be the "eyes and ears" of the court in guardianship cases, and the use of a national model of judicial review of guardian performance.[112] The National Probate Court Standards, which were published in 1993, incorporated some of the recommendations and the lessons learned from subsequent studies.[113] As a result, state reform efforts that were ignited by the 1987 AP story were informed not only by the available models from the ABA's model statute and/or

the 1982 UGPPA, but also by the Wingspread recommendations and subsequent reform initiatives. Consequently, throughout the late 1980s and early 1990s, state statutes were revised to include improved due process procedures, processes for determinations of capacity based on functional assessments rather than merely on diagnoses, and greater accountability, including reporting requirements and court monitoring practices. Finally, in 1997, the UGPPA was revised to emphasize limited guardianship, reporting requirements, and monitoring.[114] Many states also established a preference for limited guardianship in their statutes and required courts to find that there was no appropriate less restrictive alternative to guardianship before a guardian could be appointed.[115]

> *"I think we got the laws in pretty good shape, [but] it is less clear that these reform efforts were able to supplant deeply entrenched practices of guardianship law."*
>
> *—Interviewee*

These reform activities have been described as "a headlong rush of statutes, handbooks, training videos, legal and judicial curricula, and studies of public guardianship and court oversight."[116]

Early 2000s: Second Wave of Guardianship Reform

These early reform efforts clearly led to vast improvements in the statutory framework of guardianship, but it remained apparent in the decades that followed that guardianship is a much better idea in theory than in practice. As one person interviewed for this report noted, "I think we got the laws in pretty good shape" but, she added, "it is less clear that these reform efforts were able to supplant deeply entrenched practices of guardianship law." Unfortunately, as we'll examine in later chapters, there continues to be a gap between the lofty goals of the reforms codified in statute and the way that guardianship plays out in individual states, jurisdictions, and courtrooms across the country.

Realizing that there was more work to be done, in 2001, more than 80 national experts in guardianship law and practice gathered at Stetson College of Law in Florida for a conference that was dubbed "Wingspan," in homage to the original "Wingspread" conference held more than a decade before. The conferees at Wingspan assessed the strengths and weaknesses of implementation of the past reforms and, at the close of the conference, made 68 additional recommendations for reform.[117] In addition to the recommendations, the conference gave rise to a special edition of the Stetson Law Review that included articles prepared for the conference that largely examined whether the Wingspread reforms had been adopted and whether they had been transformative; and suggested avenues for better implementation.[118]

Overall, the Wingspan conference was less influential than its predecessor, offering mostly refinements to the original recommendations. However, it did aim to bring the still widely disparate state laws into greater alignment and addressed a concern that had largely been ignored by the Wingspread conferees: interstate jurisdictional issues. The first recommendation to come out of Wingspan encouraged "the development of procedures to resolve interstate jurisdiction controversies over which state's court has jurisdiction to appoint a guardian."[119] Additionally, the recommendation encouraged states to develop procedures to facilitate the transfer of existing guardianship cases among jurisdictions. Largely based on this recommendation, the Uniform Law commission drafted the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act, which has since been enacted in all but five states.[120] However, if "the challenge of Wingspan is the implementation of its recommendations,"[121] as A. Frank Johns and Charles Sabatino wrote in the introduction to the special edition of the *Stetson Law Review* devoted to papers emerging from Wingspan, then the success of Wingspan has been mixed.

In many ways, we are in a "third wave" of guardianship reform right now, ushered in by the demographic tsunami of the aging baby-boom generation . . .

Present Day: Third Wave of Guardianship Reform

In many ways, we are in a "third wave" of guardianship reform right now, ushered in by the demographic tsunami of the aging baby-boom generation whose members are entering the age when they might be at risk of guardianship due to declining health, dementia, and acquired disabilities. Indeed, those over age 85 are already the fastest growing demographic—and that does not even include the baby-boom generation members who are just now entering their 70s.[122] The sheer number of people who are living longer will put a strain on all the systems that we have traditionally used to support people as they advance in age, including guardianship. Additionally, the famously independent baby-boom generation will not be likely to accept traditionally paternalistic models of support that undermine their independence and self-determination.

The Third National Guardianship Summit in 2012 built on the work of the two previous conferences, Wingspan and Wingspread. This summit focused on post-appointment guardian performance, including developing person-centered plans for the individual subject to guardianship; meeting responsibilities to the court, including reporting and facilitating the court's monitoring of guardianships; and finally, involving the person in decision making and working toward restoring capacity whenever possible. The summit did not abandon the previous "wings" theme altogether; rather, the Working Interdisciplinary Networks of Guardianship Stakeholders, or "WINGS" groups, grew out of the summit. In 2013, the National Guardianship Network selected New York, Oregon, Texas, and Utah to pilot these WINGS groups, and each brought together stakeholders in each state to examine the state's guardianship system and make recommendations. Six additional states were subsequently provided with small amounts of funding to bring together stakeholders, and an additional six states created similar groups that were unfunded for eighteen total groups. Finally, in 2016, the ABA Commission on Law and Aging, with the National Center for State Courts, received an Elder Justice Innovation Grant from the U.S. Administration on Community Living (ACL) to establish, expand, and enhance state WINGS groups. This grant provides funding for WINGS projects in eight states.[123]

The focus of WINGS groups in individual states varies, but in general the goal of the project is to ". . . improve the ability of state and local guardianship systems to develop protections less restrictive than guardianship, advance guardianship reforms, and address abuse."[124] The work of individual WINGS groups will be discussed later in the report. Several of the groups have undertaken studies of their state guardianship systems that have added to what we know about guardianship, which will be the focus of Chapter 4, and some have begun developing tangible solutions to some of the most difficult issues in guardianship, including advancements in the data collection, monitoring, and development of viable less-restrictive alternatives to guardianship. The WINGS groups are an important model for reform because they bring together local stakeholders from a variety of perspectives and create a nationwide network that allows for the effective sharing of information and ideas, allowing states to drive reforms supported in part by federal funding.

[I]n general the goal of [WINGS groups] is to ". . . improve the ability of state and local guardianship systems to develop protections less restrictive than guardianship, advance guardianship reforms, and address abuse."

In addition to the Third National Guardianship Summit and the WINGS groups, as indicated in Chapter 2, the adoption of the United Nations Convention on the Rights of Persons with

Disabilities in 2006 has also been an important driver of guardianship reform worldwide in countries outside the United States. Article 12 of the CRPD provides that people with disabilities are entitled to "equal protection before the law" and requires states to recognize "that [people] with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and to "take appropriate measures to provide access by [people] with disabilities to the support they may require in exercising their legal capacity."[125] The implications of Article 12 mandates for guardianship law and the practice of substituting the decisions of a guardian for that of a person with a disability are staggering—particularly given the CRPD committee has taken the consistent and unanimous view that all forms of guardianship violate this article. As one scholar noted, "Article 12 is arguably the most controversial provision in the Convention. It is also arguably the most important and 'revolutionary.'"[126]

One interviewee described supported decision making as "what really good family and friends do. It's having conversations with each other about needs and wants and coming to a decision with their help when needed."

The Dawn of Supported Decision Making

The CRPD has led to a sea of change in guardianship laws of signatory countries, and, philosophically, it has impacted the way that guardianship is understood in the United States even though it has not been ratified by the United States as Dr. Robert Dinerstein summarized: "[A] contextual reading of the Article and its provenance certainly calls into question the continued viability of surrogate decision-making arrangements such as guardianship." Important as some of the past reforms to guardianship may have been:

> . . . they still accept the predominance of a legal regime that locates decision making in the surrogate or guardian and not in the individual being assisted. In contrast, supported decision making, which Article 12 embraces, retains the individual as the primary decision maker, while recognizing that the [person] with a disability may need some assistance—and perhaps a great deal of it—in making and communicating a decision.[127]

This rejection of surrogate decision making in favor of supported decision making is a more fundamental paradigm shift than the reforms that began in the 1980s in that it does not simply improve the process for establishing guardianship in the hope of ensuring more accurate determinations of incapacity, nor does it simply insist that guardians ask for input from the individual subject to guardianship on important matters, or refrain from abusing, exploiting or neglecting them. Rather, supported decision making "aims to retain the individual as the primary decision maker but recognizes that an individual's autonomy can be expressed in multiple ways, and that autonomy itself need not be inconsistent with having individuals in one's life to provide support, guidance and assistance to a greater or lesser degree, so long as it is at the individual's choosing."[128] One interviewee described supported decision making as "what really good family and friends do. It's having conversations with each other about needs and wants and coming to a decision with their help when needed."

This paradigm shift toward supported decision making was demonstrated in 2014 at the 3rd World Congress on adult guardianship, which was held in Washington, D.C. More than 360 participants from 22 countries on six continents presented on a variety of topics, but one consistent theme was how countries were attempting to align their guardianship statutes and practices with the Article 12 mandate. Many of the delegations that presented at the conference demonstrated how their countries have begun to conceptualize and, in some cases, implement supported decision making as a legal alternative to guardianship. Among others, the governments of Canada, Great Britain, Ireland, parts of Australia, parts of New Zealand, parts of Germany, Bulgaria, Israel, the Czech Republic, Norway, Sweden, and India have either adopted or are exploring adopting supported decision making.[129]

> *[T]he governments of Canada, Great Britain, Ireland, parts of Australia, parts of New Zealand, parts of Germany, Bulgaria, Israel, the Czech Republic, Norway, Sweden, and India have either adopted or are exploring adopting supported decision making.*

Supported decision making has become a very important part of the conversation around guardianship reform in the United States as well. Supported decision making is not only a concept driven by the CRPD, but it is also seen as a way to answer a fundamental challenge raised by Professor Leslie Salzman, who argued in a 2010 law review article that substituted decision making (i.e., guardianship) is antithetical to the integration mandate outlined in the Supreme Court's *Olmstead* decision and subsequent case law. She argues ". . . that by limiting an individual's right to make his or her own decisions, guardianship marginalizes the individual and often imposes a form of segregation that is not only bad policy, but also violates the [ADA's] mandate to provide services in the most integrated and least restrictive manner."[130] An extensive examination of supported decision making follows in Chapter 8.

> *" . . . [B]y limiting an individual's right to make his or her own decisions, guardianship marginalizes the individual and often imposes a form of segregation that is not only bad policy, but also violates the [ADA's] mandate to provide services in the most integrated and least restrictive manner."*

Revising the UGPPA

The UGPPA was approved by the Uniform Law Commission in 1982, amended in 1989, and revised in 1997. Nearly 20 states have adopted some version of the UGPPA.[131] However, even where it has not been enacted, the UGPPA has had a profound influence on the development of U.S. guardianship law.[132] In 2014, the Uniform Law Commission began the process of revising the UGPPA in order to implement the standards and recommendations of the Third National Guardianship Summit. The Uniform Law Commission approved the revised version of the model law, now called the UGCOPAA, on July 19, 2017. New Mexico is the first state to move to adopt the model legislation, which has passed in the state Senate.

While the UGCOPAA includes a number of important changes, perhaps the most crucial reform is that it

> recognizes the role of, and encourages the use of, less restrictive alternatives, including supported decision-making and single-issue court orders instead of guardianship and conservatorship. To this end, the revised Act provides that neither guardianship nor conservatorship are appropriate where the person's needs could be met with technological assistance or decision-making support.[133]

The UGCOPAA focuses on the need to limit the use of guardianship and create alternatives that maximize the self-determination of those who may need decision making assistance . . .

The UGCOPAA makes several other changes to the model guardianship statute, including:

- replaces the terms *incapacitated person* and *ward* with *individual subject to* either guardianship or conservatorship;
- strengthens notice requirement and prohibits waivers of notice;
- raises the standard for excusing the absence of the individual who is allegedly incapacitated from "good cause" to "clear and convincing" evidence of limited circumstances that excuse the individual from attending;
- requires capacity determinations to be based more on a functional rather than medical model;
- increases use of "visitors" and professional evaluators to make capacity determinations;
- requires a court to state why a full guardianship is imposed rather than a limited guardianship;
- requires the court order to state whether rights to marry and vote are retained;
- requires individuals subject to guardianship and other interested parties to receive a statement of rights when the guardianship is established;
- imposes additional requirements before a guardian may alter living situations
- requires the guardian to frequently visit the person;
- specifies when the court is required to hold a hearing to determine if a modification of the guardianship is needed, particularly upon receipt of communication by the individual or another interested party, such as a family member;
- requires courts to terminate guardianships if the petitioner establishes a prima facie case for termination, unless the legal basis for guardianship is met; and
- creates a process for a time-limited protective arrangement (e.g., to authorize a medical procedure or the sale of property) instead of guardianship.

The UGCOPAA focuses on the need to limit the use of guardianship and create alternatives that maximize the self-determination of those who may need decision making assistance, but to also create mechanisms that enable those individuals to receive the right amount of assistance when they need it. Additionally, the model statute attempts to provide clarity and accountability in some areas that the previous statute had left within the realm of judicial discretion. Like the UGGPA before it, the result of this work is a groundbreaking document with a great deal of potential to transform guardianship—but, also like the previous iteration, its influence will depend on the willingness of states to adopt it and judges and lawyers to follow it both in letter and spirit.

Jenny Hatch: The Face of the Third Wave of Reform

Jenny Hatch

Model statutes can change laws, but it often takes a personal story to change hearts and minds. Few guardianship cases have received as much national attention as the Jenny Hatch case, even before the four-page glossy feature on her case in the February 17, 2014, edition of *People Magazine*, as well as coverage on CBS News and in the *Washington Post*.[134]

Jenny Hatch is an adult woman with Down syndrome living in Virginia who, before an unfortunate bike accident in 2012, lived a happy, productive, and independent life; was active in her community; and got by with minimal supports. After having surgery on her spine following the accident, Ms. Hatch moved in with her employers from the thrift store where she worked. Her parents filed a guardianship action, and she was placed under temporary guardianship and forced to move into a group home pending the outcome. Ms. Hatch hated the group home, saying that she felt like a prisoner.[135] Ms. Hatch's lawyers presented evidence that permanent guardianship was not necessary, as she was capable of managing her own life with supported decision making support from people she chose.[136] The judge agreed in part, ruling that Ms. Hatch's guardianship would be limited in scope ("medical and safety decisions") and in time (one year), and that it would be with the

(continued)

Jenny Hatch: The Face of the Third Wave of Reform, *continued*

guardians of her choice. The judge also recognized the role of supported decision making, both within the one-year guardianship and after it terminated. The judge's order also freed Ms. Hatch from the group home, allowing her to live in the community with her friends.

Since the ruling, Ms. Hatch has returned to live with her friends who own the thrift store where she worked and has traveled across the country, speaking at conferences and events about her experiences and the value of supported decision making.[137] She has become an eloquent spokesperson on both the danger of overly restrictive guardianship and the need for alternatives such as supported decision making. From a legal standpoint, her case is significant because it, along with *In Re Guardianship of Dameris L,* is one of the earliest cases to recognize supported decision making as a viable alternative to guardianship, and her advocacy has provided attorneys for similarly situated clients with a powerful example of the value of this alternative. As Professor Jasmine Harris of the UC Davis School of Law wrote, "[t]he Hatch victory also resonates more broadly as a common rally point and mirror of the lived experiences of many other people with disabilities who are subject to the same presumptions of incompetence and incapacity."[138]

In conclusion, this "third wave" of guardianship reform has been fundamentally different than the earlier reform efforts, not only because it represents a fundamental shift from the surrogate decision making framework of guardianship—which previous efforts sought to limit but not fundamentally question—but also because supported decision making has more of the earmarks of a popular movement than some of the previous reform efforts. Not only are activists, scholars, lawyers, advocates, and others advocating to bring about systemic change to the guardianship system, but individuals like Ms. Hatch are also advocating for their right to self-determined lives and demanding that the legal system develop and recognize alternatives to guardianship, such as supported decision making. It is the experiences of Ms. Hatch, litigants who come after her, and participants in programs such as supported decision making pilot projects in Massachusetts,[139] Texas,[140] and New York[141] that will shape guardianship reform in the future. Texas recently became the first state to recognize supported decision making in statute and to require courts to consider it before guardianship.[142] Hopefully, this grassroots involvement will help circumvent some of the pitfalls of earlier reforms, which were often exciting in theory but disappointing in practice.

Chapter 4: The Current Guardianship System in America

Although there is some disagreement about why, there is a general consensus that the guardianship system is not in much better shape than it was in 1987, despite decades of reform efforts. Chapter 4 will describe the current state of guardianship in broad strokes and will identify issues for more detailed examination in later chapters.

The Current System Lacks Data

The lack of data on who is under guardianship or what happens to adults under guardianship is a constant source of frustration for anyone attempting to understand guardianship, much less those urging policymakers that there is an immediate need for resources to address problems arising from it. Erica Wood and Sally Balch Hurme, both of whom have studied guardianship for decades and worked tirelessly to improve it, note in their introduction to the special symposium issue of the Utah Law Review reporting out the results from the 3rd National Guardianship Summit that:

> [w]e as a nation are essentially working in the dark when describing adult guardianship practice. Data and research are scant to nonexistent. Many courts and states do not know the number of adults under guardianship in their jurisdiction, let alone the demographics.[143]

"Data and research are scant to nonexistent. Many courts and states do not know the number of adults under guardianship in their jurisdiction, let alone the demographics."

Data on the Number of People Subject to Guardianship

Brenda Uekert, Principal Court Research Consultant for the National Center for State Courts (NCSC), has probably spent more time "crunching the numbers" to develop a statistical picture of guardianship than any other researcher. After decades of studying guardianship, she estimates that there are 1.3 million active adult guardianship or conservatorship cases and that courts oversee at least $50 billion of assets under adult conservatorships nationally.[144] This estimate is based on the handful of states that do track and report reasonably reliable data on guardianships; however, Dr. Uekert notes that there is wide variation among the states and it is difficult to extrapolate what we know from a few states to the country as a whole. Additionally, most states do not adequately sort data in a way that allows researchers to draw accurate conclusions from the available data. Dr. Uekert observes:

> . . . few states are able to report complete statewide adult-guardianship caseload data, because these cases are counted in a generic probate case type or otherwise blended into civil caseload statistics. A number of states cannot distinguish adult guardianships from adult conservatorships as distinct case types. Other states include both juvenile and adult guardianships in a single "guardianship" case type.[145]

It goes without saying that if we do not know how many guardianships there are, we also cannot say for sure whether guardianship is a growing trend or if its popularity is waning, making it difficult to urge policymakers to address the problems in guardianship, since it is difficult to prove that the problems are, in fact, growing.

. . . [F]ew states are able to report complete statewide adult-guardianship caseload data, because these cases are counted in a generic probate case type or otherwise blended into civil caseload statistics.

Data on the Number of Filings

Despite the lack of reliable data, there is some evidence that suggests that the number of adults subject to guardianship has been rising. In 2009, the National Center for State Courts asked 187 respondents to respond to a survey distributed through association listservs such as the National College of Probate Judges, the National Association for Court Management, and the American Judges Association. The goal of the study was to ascertain how guardianship filings had changed over the previous three years. Most respondents said that filings had stayed the same; however, 37 percent noted an increase in petitioners seeking guardianship over a person who allegedly lacked capacity and only 4.28 percent noted a decrease. This means that the number of new petitions for guardianship is either staying the same or rising, but almost certainly not decreasing. Similarly, a significant minority of 43 percent noted an increase in the number of open, ongoing guardianships over the past three years, another indication that the number of guardianships may be on the rise.[146]

However great or small the increase may have been in recent years, looking to the future, it is very likely that the need for decision making assistance will grow in the years to come:

> The need for guardianship and other surrogates will grow as the population ages, and as the prevalence of Alzheimer's disease, the number of "old old," and the number of [people] with intellectual disabilities, mental illness, and traumatic brain injury all increase.[147]

After all, the anticipated rise in the senior population is well-documented and fueling concerns about demands on the already overstretched direct-care workforce.[148] It is also possible that, even though their numbers are likely to be more stable over time, more young adults with disabilities are being made subject to guardianship as states rebalance their systems in favor of community options. It's possible that guardianship among this population is more prevalent now because parents of adults with disabilities see guardianship as a way to continue to manage care and services in the community, whereas a generation ago those services would have been provided in the closed system of an institution. However, without better data that could track the number of guardianships over time and describe at least the basic characteristics of individuals subject to guardianship, there is no way to say definitively what the trends in guardianship are. This is problematic because "[t]he starting point of any major reform is an accurate picture of the policy in need of reform; in this case, that means at a minimum that states are able to count the number of incoming and outgoing adult guardianships in the state courts."[149] Unfortunately, in the case of guardianship, that is something we cannot currently do. Despite the recent interest in the topic that has given rise to a number of the studies reported here, a comprehensive picture of guardianship trends is unlikely to become clear unless states begin regularly gathering and reporting accurate and comparable data.

"The starting point of any major reform is an accurate picture of the policy in need of reform; in this case, that means at a minimum that states are able to count the number of incoming and outgoing adult guardianships in the state courts."

What Is Known from Limited Data

Without reliable data, it's difficult to describe the extent of the problems in guardianship or to quantify the number of good or bad outcomes. However, continual and pervasive anecdotal data and what limited quantifiable data does exist strongly suggest there are very serious problems. Several notable studies have been done that attempt to ascertain whether guardianships are working as intended and to identify problem areas. Additionally, state task forces, including those funded as "WINGS" projects, have examined state guardianship programs, and national and local press reports continue to highlight some of the ongoing problems in guardianship. Generally speaking, these sources all point to problems that involve a lack of information about alternatives, insufficient due process when a guardianship arises, a failure of courts to monitor guardianships and abuse, neglect or exploitation by guardians and conservators, and a lack of an appropriate response to the concerns of families or individuals subject to guardianship. Although each of these issues will be addressed in greater depth later in the report, a brief review of available information will help characterize and summarize the current state of guardianships today.

2014 SSA Representative Payee Report

In 2014, the Social Security Administration (SSA) conducted research in response to repeated calls to do a better job coordinating its "representative payee" program with state guardianship systems. In order to do that, SSA asked the Administrative Conference of the United States (ACUS), which then worked with NCSC, to study current guardianship laws and practices. ACUS researched state guardianship laws and court practices, conducted a survey regarding court practices in guardianship, and interviewed nine state organizations or entities related to adult protective services or foster care to evaluate their practices with respect to guardianship. The findings of the study were interesting and informative, although the authors caution that it is not based on a representative sample, making it difficult to say with certainty whether these findings reflect guardianship nationally. The major findings of the study include the following:

- Approximately 75 percent of guardians were friends, family, or acquaintances as opposed to professional or public guardians.
- 60 percent of court respondents in the survey do not review the credit histories of potential guardians, and about 4 in 10 do not conduct criminal background checks.
- 47 percent of the courts in the survey inquired about a potential guardian's representative payee status with respect to the individual for whom they are guardian.
- 75 percent of the courts in the survey required inventory filings at or near the time of the appointment of guardians of the property in all cases, and about two-thirds of respondents indicated annual accounts are required as well.
- 75 percent of all respondents indicated that at least some of the financial accounting forms are subject to audits or a similar type of evaluation, usually conducted by court staff or judges themselves. It's unclear how thorough these audits are.
- Approximately 66 percent of respondents indicated that they currently use some kind of electronic case management database for guardianship cases, and a small additional number of respondents said they expected to be using one by 2017.
- Approximately 66 percent of court respondents indicated that the court had sanctioned a guardian for failure to fulfill their obligations, misconduct, or serious malfeasance within the past three years. In these cases, the court removed the guardian or issued an order requiring the guardian to show cause why they had failed in their duty or cited the guardian for contempt for failing to comply with the statute or with a court order. However, in most cases, the action taken was only noted within the guardianship file.[150]

> *[T]he fact that courts are not able to definitively report the number of open guardianship cases . . . is indicative of what is widely acknowledged to be incredibly lax monitoring . . ., despite statutory reforms requiring guardians to provide courts with annual reports regarding the welfare of the individual and accountings detailing how their resources are being spent.*

2010 Study of the National Center for State Courts' Center for Elders and the Courts

A 2010 study conducted by the National Center for State Courts' Center for Elders and the Courts (CEC) on behalf of the Conference of Chief Justices/Conference of State Court Administrators (CCJ/COSC) Joint Task Force on

Elders and the Courts, examined the availability and correctness of adult guardianship data; the adequacy and training of guardians; and promising practices for guardian recruitment, retention, and training.[151] The study's authors again warned that results are not nationally representative. In addition to noting the lack of reliable data and that the number of guardianships seemed to be on the rise as noted previously, their major findings included the following:

- Securing and retaining family and friends to act in the capacity of guardian is problematic for half of the reporting jurisdictions.
- There is considerable need for additional public and private professional guardians. The greatest need for training is for family and friends serving as guardians.
- Guardianship monitoring efforts by the courts are generally inadequate.[152]

State Data

Nationwide studies are one way to try to capture the current state of guardianships. Another way is to look at available data from selected states. Since each guardianship system is unique, it can be difficult to compare state systems. However, the WINGS effort has led to a number of states taking a close look at their guardianship systems to identify areas for improvement.

Some brief examples of findings from several of these studies follow:

New York

A recent study by the Brookdale Center for Healthy Aging at Hunter College reviewed 2,414 Article 81 cases files across New York State. Because New York has a separate guardianship statute for people with ID/DD, cases involving people with ID/DD were not included in this data. Of the cases opened, they found that the court appointed a guardian 68 percent of the time, or 1,636 cases. Further, they found that 68 percent of the individuals subject to guardianship were female; 59 percent were over age 65; and dementia was the reason for incapacity in 41 percent of cases, with psychiatric disability as the reason in 20 percent of cases.[153] In 43 percent of cases, a family member or friend petitioned to be guardian, and in those cases, a family member or friend was appointed in 86 percent of cases.

Texas

The Texas State Office of Court Administration reviewed a total of 165 guardianship cases filed in 2013 in 14 selected counties that were a mix of semiurban and rural jurisdictions. Of the individuals subject to guardianship, they found a fairly even division between male and female, with 55 percent being male. Seventy-four percent lived at home either in their own home or, in some cases, the family home, in the community when the petition for guardianship was filed, with 21 percent living in a long-term facility such as a nursing home. Fifty-one percent of the cases filed involved an individual who was turning 18. In terms of the characteristics of the guardian, 85 percent were family members, 10 percent were public guardians or Department of Aging and Disability Services (DADS) cases, and 6 percent involved the appointment of a private professional guardian.[154]

Indiana

The Indiana Adult Guardianship State Task Force is a multidisciplinary workgroup convened to examine the adult guardianship system in

Indiana. In a comprehensive 2012 report, they found that there are approximately 7,000 people who are subject to guardianship in Indiana. Of the new guardianship cases filed in a selected sample of 14 counties, 25.8 percent involved an allegation that the AIP had dementia; 22 percent involved a person who had cognitive or intellectual disabilities; 10.5 percent involved a person with severe mental illness; 5.4 percent were stroke related; 5 percent were related to an acquired head injury; 1.4 percent involved chronic intoxication; and 1.4 percent involved other conditions associated with old age. An additional 15.1 percent of the cases were classified as "other" and in the remaining 13.4 percent of the cases no reason for the incapacity was specified in the file.[155]

What the Lack of Data Means

Not only is the lack of robust data in guardianships troubling because it leaves us without an accurate picture we can use to craft effective policy, it is actually indicative of a larger problem. Courts are supposed to be monitoring guardianships in order to protect individuals subject to guardianship from abuse, neglect, and exploitation at the hands of their guardians and to make sure that guardians continue only as are necessary. However, the fact that courts are not able to definitively report the number of open guardianship cases at a given point in time is indicative of what is widely acknowledged to be incredibly lax monitoring on their part, despite statutory reforms requiring guardians to provide courts with annual reports regarding the welfare of the individual and accountings detailing how their resources are being spent.

The National Center for State Courts' (NCSC) Conservatorship Accountability Project is working with several grantee states on developing accounting and tracking processes and safeguards that will not only protect vulnerable adults from financial exploitation, but also provide a template for streamlined and compatible case management platforms that would make it relatively easy to collect and compare data on a statewide and even nationwide basis.[156] We will examine the deficiencies in monitoring practices that leave individuals subject to guardianship vulnerable to abuse, neglect, and exploitation in more depth in Chapter 7, as well as highlight some promising practices.

Does Guardianship Prevent Abuse or Lead to It?

U.S. Government Accountability Office (GAO) Reports on Guardianship

Particularly in the past decade, there is renewed concern regarding elder abuse and whether guardianship is an effective tool against potential abusers or a tool that gives potential abusers carte blanche to commit acts of abuse. GAO has twice been asked to review whether abusive practices by guardians are widespread, releasing reports in 2010 and another in 2016. The 2016 report noted, "[t]he extent of elder abuse by guardians nationally is unknown due to limited data on the numbers of guardians serving older adults, older adults in guardianships, and cases of elder abuse by a guardian."[157] However, the 2010 GAO report ". . . identified hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010."[158] These included cases ranging from financial neglect where bills simply went unpaid, leading to foreclosure; cars being repossessed; electricity being shut off; and credit being destroyed; to cases where guardians were able to siphon millions from individuals subject to guardianship (both senior and young adults); to at least one case where the guardian falsely claimed the individual subject to guardianship had terminal cancer and moved her into hospice care where she later died from the effects of morphine.[159]

Notably, both GAO reports are careful to assert that these are nongeneralizable examples. Nonetheless, while the examples of abuse GAO uncovered are only illustrative, it is apparent from the totality of available evidence regarding guardianship practices, that courts are not currently able to safeguard individuals against abuse, neglect, and exploitation committed by guardians. While it cannot be said that the findings of the GAO report demonstrate that abuse is occurring in the majority of guardianship cases, it would also be a mistake to assume that GAO only found and reported on the outliers. The GAO reports raised significant red flags for Congress, which passed the Elder Abuse Prevention and Prosecution Act of 2017.[160] The Act addresses elder abuse beyond guardianships, but specifically authorizes grants issued under the Elder Justice Act to assess guardianship and conservatorship proceedings and to implement changes deemed necessary based on these assessments, including mandating background checks for guardians, implementing systems to enable more consistent filing of annual accountings, and reports as well as regular auditing of this information.

> *[T]he 2010 GAO report ". . . identified hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010."*

Those who find the status quo of guardianship acceptable often view the existing system as one which provides needed protection to people who are vulnerable to abuse or exploitation. One professional guardian interviewed for this report explained, "[F]or somebody who is financially exploited, oftentimes the guardianship is the only way to protect them." While this concern is valid, so is the concern that guardianship itself may lead to negative or abusive outcomes. The Elder Abuse Prevention and Prosecution Act is an important step toward getting a handle on this problem, once deemed local, that has the potential to become a national crisis as the population ages.

> *[W]hile the examples of abuse . . . are illustrative and not generalizable, it is apparent . . . that courts are not currently able to safeguard individuals against abuse, neglect, and exploitation committed by guardians.*

Investigative Reporting

Investigative reporters have also taken up this question, and the results have been disconcerting. In July 2016, the *Texas Observer* reported on the Texas guardianship system in a report entitled, *Who Guards the Guardians,* very much painting a picture of a system in crisis. The report details the case of a professional guardian who was accused of charging individuals for whom he served as guardian large percentages of their income, failing to visit them in their nursing homes and selling off their homes and possessions, often without their knowledge, and pocketing a share of the proceeds for himself. According to the report, this went on for years before he lost his license to be a professional guardian. The judge who oversaw all 1,425 guardianship cases in the county finally appointed the wife of the discredited professional guardian to many of his former cases. She was later fined $25,000 total for 51 additional legal violations.[161]

Another recent case in Nevada has garnered considerable media attention. In March 2017, a professional guardian was indicted as the alleged ring-leader of a criminal syndicate. She and three associates were charged with more than 200 felony counts in a scheme to bilk clients with disabilities and senior clients out of their life savings.[162]

Finally, a compelling article appeared in the *New Yorker* in October 2017 that reviewed several cases where a professional guardian had seemed to take over the lives of senior individuals, removed them from their homes, separated them from loved ones, and charged them what seemed to be exorbitant amounts for guardianship services they had never asked for or wanted.[163]

Although the previously mentioned accounts may lead one to conclude that it is only professional guardians who are problematic and that family guardians are less likely to abuse individuals subject to guardianship, there exists at least some data to the contrary.

A recent Minnesota study found that of 31 cases of financial exploitation, 24 involved a family member.

A recent Minnesota study found that of 31 cases of financial exploitation, 24 involved a family member. In fact, ". . . closer analysis of family relationships showed that the greatest number of victims were exploited by their own children, followed by siblings and then other close relatives."[164] Professional guardians are frequently called in to manage a person's affairs when family members are either feuding with each other over the individual who is allegedly incapacitated or when the person has been abused, neglected, or exploited by a family member. We will explore these issues further in Chapter 7.

Chapter 5: Capacity and the Role of "Experts" in Guardianship Proceedings

Introduction

As explored in Chapter 1, there was a time when personal characteristics such as race, gender, and having a label of disability were enough to deny an individual the basic rights of citizenship. Historically, determining that a person needed a guardian or involuntary commitment to an asylum due to "insanity" was predicated on very amorphous standards. For example, in 1742, the Rhode Island general assembly codified "[a]n act empowering several town councils of this colony to have the care and oversight of all persons who are delirious, distracted, or non-compos mentis, and their estates."[165] In 1822, the legislature updated the law and replaced "delirious and distracted" with what at the time was considered more scientific designations of "idiot" and "lunatic."[166] Despite the sheen of science being added to state guardianship statutes across the country in the early 19th century, well into the 20th century, not even physicians' reports were deemed essential to determining capacity ("competency"), and socially inappropriate behavior, forgetfulness, or bewilderment could form the basis of a judicial label of insanity. Judges made similarly unscientific determinations of incompetence for reasons of age, intellectual disability, and even alcoholism.[167]

Today, at least in theory, every individual who is 18 or older:

> is presumed to possess the requisite level of capacity. All adult individuals are presumptively able to avail themselves of legal protections, to make legally binding decisions, and to be held responsible for their actions and decisions . . . Today, lack of capacity must be proven affirmatively, often by clear and convincing evidence.[168]

Present day determinations of incapacity are usually based on a combination of medical and functional criteria, and courts rely heavily on the input of physicians and other professionals who purportedly have expertise in determining capacity.

Present day determinations of incapacity are usually based on a combination of medical and functional criteria, and courts rely heavily on the input of physicians and other professionals who purportedly have expertise in determining capacity.[169]

The guardianship reforms of the past 30 years have largely focused on limiting who is subject to guardianship, limiting guardianship to specific areas in which the individual lacks capacity, and statutorily mandating strict due process procedures that should lead to fair and thoroughly tested outcomes that meet a high standard of proof. Accordingly, many statutes now specifically require medical documentation and often an independent evaluation by a physician who advises the court whether, in his or her professional opinion, the individual has capacity. However, some of the same reformers who had hoped to improve the quality, accuracy, and fairness of capacity evaluations to make sure that only individuals who truly lack capacity are subject to guardianship are beginning to consider the possibility that capacity is problematic and rooted more in the ideological construct of liberal autonomy and lacks a verifiable or scientific basis.[170] In this chapter, we will explore the legal and philosophical bases of "incapacity" as justification for legal interference with individual autonomy.[171] We will also examine how incapacity determinations are made and discuss whether fair and consistent determinations are possible, either under the current systems or after further reform.

Moving Away from the "Reasonable Man" Standard of Capacity

Philosophical Origins

As discussed briefly earlier in this report, individual autonomy is a cornerstone of western philosophy and is particularly important in the American constitutional system. Influential German philosopher Immanuel Kant developed this philosophy, which was later expanded upon by English philosopher John Stuart Mill. While a deep investigation of the ideas of these influential philosophers is well beyond the scope of this report, it is worth noting that the basis for our cultural and legal assumptions about autonomy and liberty, which ultimately give rise to the legal concept of "capacity," are as much philosophical as they are medical. In Kant's view, the ability to decide how to live one's life is the most basic autonomy right.[172] These ideas heavily influenced the founding fathers, as indicated by the Declaration of Independence assertion that "all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the Pursuit of Happiness."[173]

In the justice system, when something bad happens as a result of an individual's actions, their legal responsibility often depends whether and to what extent they engaged in a rational thought process leading to the consequences. Specifically, they may be described as having acted intentionally, recklessly, or negligently.

In particular, in determining whether a particular action was negligent, courts try to determine what the "reasonable man" would have done under the circumstances. The reasonable man has been described as someone whose every behavior commands admiration:

> . . . He is one who invariably looks where he is going, and is careful to examine the immediate foreground before he executes a leap or a bound; . . . who believes no gossip, nor repeats it, without firm basis for believing it to be true; . . . who in the way of business looks only for that narrow margin of profit which twelve men such as himself would reckon to be 'fair' . . . ; who

> uses nothing except in moderation, and . . . is meditating only on the golden mean. Devoid, in short, of any human weakness, with not one single saving vice, sans prejudice, procrastination, ill-nature, avarice, and absence of mind, . . . this excellent but odious character stands like a monument in our Courts of Justice, vainly appealing to his fellow citizens to order their lives after his own example.[174]

The reasonable man, when he is being an economic actor, is often fancifully referred to as *homo economicus*, in that he is consistently rational and narrowly self-interested. Mill described the "economic man" as "an arbitrary definition of man, as a being who inevitably does that by which he may obtain the greatest amount of necessaries, conveniences, and luxuries, with the smallest quantity of labour and physical self-denial with which they can be obtained."[175] These concepts of who we are as human beings, how we make decisions, and why we are possessed of the right to make decisions at all are critical concepts that give rise to the very idea that a person can be accurately described as having or lacking capacity; even as our understanding of "capacity" as a concept has evolved over time and become more complex and has expanded to include people that were not always given credit as capable of rational thought.

Behavioral Economics

The work of Nobel Prize winner psychologist Daniel Kahneman, the late psychologist Amos Twersky, and 2017 Nobel Prize–winning economist Richard Thaler—known as the founders of "behavioral economics"—have revolutionized our understanding of human decision making, revealing a process that is very different from the "rational utility maximization presumed by neoclassical economics."[176] The field of behavioral economics has largely proved that the majority of our decisions are not the result of careful consideration. In fact, when Dr. Thaler was asked how he intended to spend his Nobel prize money, he quipped, "I will try to spend it as irrationally as possible."[177] Behavioral economics shows that an individual's behavior in making choices departs from exclusive rational choice behavior because of instances of failures to act in one's own interests, which can be said to be irrational behavior.

Behavioral economics not only calls into question whether humans act rationally with respect to economics, but it undermines the fundamental belief that our decisions are based in reason. Yet, the guardianship paradigm assumes that people are entitled to rights in proportion to their ability to exercise the reason necessary to make autonomous decisions. It seems basically unjust to take away the right of a person with disabilities to make their own decisions when there is growing evidence that no one—including a court-appointed guardian—makes decisions on a rational basis.

Behavioral economics . . . undermines the fundamental belief that our decisions are based in reason. Yet, the guardianship paradigm assumes that people are entitled to rights in proportion to their ability to exercise the reason necessary to make autonomous decisions.

Capacity Determinations

Who Decides Capacity?

Because there is a legal presumption that individuals who have reached the "age of majority" have capacity, it is generally not until a judge determines that one lacks capacity that a person can be said to be incapacitated. Although a person may have a particular diagnosis and seem to those around him to lack the ability to make or communicate a decision, he is still entitled to exercise his fundamental rights in a variety of ways. However, doctors, landlords, bankers, and others may nonetheless refuse to treat, rent to, or conduct business with a person they perceive to lack capacity, for fear that the person is not able to understand what is happening, which could ultimately expose them to liability. This is especially true of doctors and some other professions that require gaining one's "informed consent" before acting (e.g., medical treatment). However, having a doctor refuse to treat a person based on his or her assessment that an individual is not capable of giving informed consent to a procedure has limited legal consequences for that individual; the person is free to keep looking for a doctor who will allow them to consent to the procedure.

In many states, although not all, it is only when a judge finds that there is "clear and convincing evidence" that the person lacks capacity that that determination is binding and the person will either need a guardian, or an agent using a valid "power of attorney" or health care proxy to consent to the procedure.[178]

"Expert" Evidence

While, generally speaking, only a judge can take away the right of an adult to act on his or her own behalf and appoint a guardian to make and carry out decisions for him or her, this decision is determined by the evidence presented to the judge. The overwhelming majority of state guardianship statutes require the submission of evidence by a medical expert.[179] This evidence is often submitted in the form of a written report that is rarely subjected to rules of evidence, although in contested hearings even a report that is required by statute may be considered hearsay—and therefore excluded from consideration by the judge—if the expert is not present in court to explain his or her findings.[180]

> *[I]n many states, it is enough that the professional have the required degree, such as a medical degree, regardless of whether he or she has any specialized knowledge that would aid in making a capacity determination.*

> *Anecdotally, physicians with expertise in cancer or gerontology may be appointed to evaluate the capacity of a young person with cerebral palsy, and individuals have been determined incapacitated after failing a math quiz administered first thing in the morning or being unable to count backward from 100 by multiples of seven.*

Some state statutes contain specific requirements regarding the level of expertise and professional training of physicians and others appointed as "experts" who advise the court regarding an individual's capacity. However, in many states, it is enough that the professional have the required degree, such as a medical degree, regardless of whether he or she has any specialized knowledge that would aid in making a capacity determination.[181] Some view this as indicative of a lack of due process given that courts are usually required to make a finding that the testimony offered by an "expert" is relevant and reliable before it will be considered in civil cases that are not in the probate court.[182] Additionally, even in instances in which the court has made such a finding, in many cases so-called *expert testimony* is not subject to the level of scrutiny and cross-examination necessary to assist the fact-finder in weighing the evidence.[183] If behavioral economics undermines the philosophical and legal basis for guardianship, it also raises questions about the decision making processes that physicians, psychiatrists, judges, and others use who contribute to determining an individual's capacity. In practice, the way capacity determinations are made is deeply problematic. Many states rely heavily on physicians and psychiatrists, who provide opinions that are based largely on generalities of a person's

Limited vs. Plenary Guardianships

Limited Guardianship—Instances in which a judge decides that a person can exercise some rights but not others on their own.

Plenary/General Guardianship—Instances in which a judge determines that an individual lacks capacity to exercise *any* of the rights earlier mentioned; the plenary guardian is a guardian of both person and property.

diagnosis rather than on any observable trait of the particular individual. Although statutes that require a physician or psychiatrist to report to the court regarding the capacity of the individual are based on the assumption that these scientists will submit to the court an unbiased and scientifically based opinion, physicians and psychiatrists are often not trained in administering the kinds of tests that may provide the most insight into an individual's ability to make decisions and might not have the requisite skills and experience with the particular disability to render a valid judgment. Anecdotally, physicians with expertise in cancer or gerontology may be appointed to evaluate the capacity of a young person with cerebral palsy, and individuals have been determined incapacitated after failing a math quiz administered first thing in the morning or being unable to count backward from 100 by multiples of seven. Clearly, such "tests" that many people without disabilities would also fail hardly seem sufficient bases for determinations of incapacity leading to the deprivation of one's rights. Often, tests simply confirm what the physician or psychiatrist had already assumed, which is that an individual lacked capacity based on their diagnosis.

Finally, even if they have a clinical basis for determining what a person can or cannot do, the experts that make these determinations may not have sufficient legal context to determine whether the individual is incapacitated as the law defines it. In one study, only 30 percent of doctors were able to correctly apply the definition of legal competence (capacity) in a fact-pattern drawn from an actual legal case. Additionally, although psychiatrists were better able to answer theoretical questions about the standards for legal capacity, they were often wrong when applying those standards to facts. In addition, only a small minority of doctors were able to understand that a person could be diagnosed with dementia or depression and still be legally "competent."[184] Determining legal capacity is a process requiring a medical diagnosis, analysis of functional abilities, and the application of legal principles. Medical doctors simply are not trained in the legal, functional, and medical assessments that could lead to a reliable determination regarding an individual's "capacity."

The job of determining legal capacity becomes even more complex in light of the modern trend toward limited guardianship, which is encouraged in many state statutes, even though studies have shown that plenary guardianships are still vastly more common than limited guardianships.[185] Nonetheless, in order to determine if a limited rather than plenary guardianship might be appropriate, physicians not only have to make a medical diagnosis, assess the person's functional abilities, and determine capacity in light of a legal standard they might not fully understand, they have to repeat this process with respect to each individual right that may be removed from the person.

Despite the tremendous complexity of the task and the probability that an examining physician or psychiatrist is not well-equipped to make a meaningful recommendation regarding capacity, their opinion regarding capacity is usually given tremendous weight by the court and rarely subject to the crucible of rigorous cross examination or fundamental due process.

Who Are the Experts?

Varies by State

States use a variety of strategies to make capacity determinations. The ABA "Guardianship Law Practice" website contains numerous resources and charts regarding guardianship and alternatives, including a chart detailing the "Representation and Investigation in Guardianship Proceedings." This chart, which is regularly updated to reflect changes to state statutes, shows how capacity is determined in all 50 states and the District of Columbia. The website is well worth looking at for state-specific information as well as a wide variety of resources: https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html#statelawsandpolicy. According to the ABA, a few states, including Kentucky and Florida, require the appointment of a panel of three experts to independently evaluate the person's capacity.[186] In Maryland, two physicians or a physician and a psychologist must be appointed.[187] In many states, the court is required to appoint a physician, and in still others, they can appoint a physician or "other qualified person," such as a psychologist, gerontologist, licensed social worker, or licensed counselor to conduct an evaluation and report their findings to the court.[188] In some states, such as Colorado, a "visitor" is appointed to interview the person who is allegedly incapacitated, and in some cases, a physician or other relevant professional is appointed to make a recommendation to the court regarding that person's incapacity.[189] Finally, in some states, a guardian ad litem (GAL) may be appointed to ensure that the person's best interests are adequately represented.

In one case, an attorney who contributed to this report noted having to object when a judge appointed an orthopedic surgeon to evaluate the capacity of a woman with intellectual disabilities.

Guardianship Resource

For state-specific information and a variety of resources on guardianship, visit the American Bar Association's website at https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html#statelawsandpolicy.

Shortcoming of Physicians as "Experts"

Although it may seem that requiring a physician to examine the individual provides some assurance that an accurate capacity determination will be made, this may not be the case at all. Even where a physician is required to perform an independent evaluation, physicians with appropriate expertise and experience may be unavailable or unwilling to perform this type of evaluation. This can lead to physicians being appointed and treated as experts when in fact they have little or no experience with the person's disability. In one case, an attorney who contributed to this report noted having to object when a judge appointed an orthopedic surgeon to evaluate the capacity of a woman with intellectual disabilities. Furthermore, experts in guardianship proceedings may or may not appear in court and even when they do, they are usually permitted to testify as experts merely on the basis of having a medical license and are not required to justify their conclusions by describing methods they used to reach them.[190]

Even in the best-case scenario in which a physician with relevant expertise is appointed, the medical profession's relationship to disability has historically been a paternalistic one.

Even in the best-case scenario in which a physician with relevant expertise is appointed, the medical profession's relationship to disability has historically been a paternalistic one. In medical terms, a *patient* benefits from anything that reverses or ameliorates any disease or disability ". . . that threatens to shorten the life or limit the functional capacity of the patient. Harm is characterized as anything that impedes or compromises the efficacy of those diagnostic or therapeutic measures."[191] This weighs heavily in favor of restricting autonomy in an attempt to ensure safety and may inevitably lead to overly restrictive guardianships. Another anecdotal example we heard from an attorney who practiced guardianship law was a determination by a court-appointed physician that the individual who had sought restoration of her rights continued to need a guardian because, as a person with an intellectual disability and diabetes, she might not be able to follow a diet that would ensure her continued health. This was in spite of her on-the-record testimony that she understood the risks associated with behavior such as eating sweets.

The questions on the MMSE include things like spelling world *backward, stating the year, naming the President, and counting backward by sevens.*

Tools the Experts Use

Tests and Questionnaires

In order to make the extremely difficult job of determining capacity easier, court-appointed physicians and other "experts" appointed to advise the court have numerous tools at their disposal, such as the Mini-Mental State Examination (MMSE), the Short Portable Status Questionnaire, the MacArthur Competency Assessment Test for Clinical Treatment (MacCAT-T), and the Semi-Structured Clinical Interview for Financial Capacity (SCIFC) to name just a few.[192] Of these, the most well-known and most often used is the MMSE, which is a 30-point questionnaire that tests cognitive abilities including orientation to time, place, and verbal recall ability.[193] The MMSE has been used so frequently since its introduction in 1975 that it has ". . . become the source for cartoons and dark humor."[194] The questions on the MMSE include things like spelling *world* backward, stating the year, naming the President, and counting backward by sevens.[195] Although the test is widely used and has been found to be reliable for assessing the likelihood that a patient has dementia, "[it] has been found in several studies to be less than a sensitive indicator of cognitive abilities relating to decision making."[196] Additionally, the MMSE relies in part on the person's ability to write, making it less reliable when used to assess individuals who are not well educated, who are illiterate, or whose disabilities make it difficult to complete these tasks without proper accommodation.[197] Finally, the test is often administered by individuals who are neither trained in its use nor qualified to interpret the results. For example, some jurisdictions appoint a court "visitor" who is charged with meeting with the AIP and—despite having no medical training or background in clinical assessments—will administer some portion of the MMSE and determine based on the results that the AIP should lose some or all of his or her rights.

Another very common test that is often used with the aging population to screen for dementia is the clock drawing test, which simply requires the individual to draw a clock with the hands pointing to a particular time. An abnormal, inaccurate clock drawing can indicate impairments in cognitive function even when the MMSE score is normal.[198]

Although these tests may be helpful in assessing cognitive decline in the aging, their ability to aid in the determination of whether an individual can exercise a particular right is doubtful. Certainly, no test has put an end to "[the] quest for an objective, uniformly dependable, consistently accurate, and easily administered tool for measuring the mental decision-making capacity of individuals . . .," which has been likened to the quest for the "holy grail."[199]

ABA/APA Framework for Evaluators

Six core elements for clinicians to address in providing capacity evaluations to courts in guardianship proceedings:

1. The specific medical condition causing diminished capacity;
2. Its effect on cognition;
3. Its effect on the person's everyday functioning;
4. The person's values and preferences;
5. Past or imminent risks; and
6. Means to enhance capacity, such as assistive technology or medication.

ABA/APA Framework for Evaluations

Recognizing that accurate capacity determinations are a fundamental requisite to a fair guardianship process and that a single test that can accurately determine capacity is likely to remain elusive, the ABA and the American Psychological Association (APA) collaborated on a series of manuals designed to help lawyers, judges, and psychologists make capacity determinations for older individuals.[200] Although they were somewhat limited in terms of scope, these manuals suggest ways to use direct observation, functional assessments, and structured interviews to determine capacity. The ABA/APA manual for psychologists sets out core elements for clinicians to address in providing capacity evaluations to courts in guardianship proceedings. These six elements are:

1. The specific medical condition causing diminished capacity;
2. Its effect on cognition;
3. Its effect on the person's everyday functioning;
4. The person's values and preferences;
5. Past or imminent risks; and
6. Means to enhance capacity, such as assistive technology or medication.[201]

For implementation of such an approach, training and collaboration between legal and health communities is warranted, as are consultations between physicians and behaviorists or psychologists. Fair assessments must also include consideration of available alternatives to guardianships in a way that "balances personal autonomy with protection."[202]

While the ABA/APA framework describes the elements of a well-done capacity evaluation, it also emphasizes the importance of finding a professional who has experience in the assessment of capacity of clients with the same type of disability as the individual who is alleged to be incapacitated.[203] As previously discussed, we know that there is extreme variability across the nation as to the nature and quality of assessments and the clinicians appointed to conduct them.[204]

Court Discretion and Due Process

The courts enjoy wide discretion in absence of both consistent criteria and methods for "experts" to use to make capacity determinations and widespread agreement regarding how to balance autonomy and protection.[205] Additionally, guardianship cases are often viewed as objectively benevolent processes that ultimately result in the protection of a vulnerable individual, and this "therapeutic" model of justice ". . . replaces the rigors of adversarialism with the judge's freestyle improvisations."[206] The disconnect between the level of due process that is required in statute and that which is actually practiced in guardianship cases throughout the country is examined in Chapters 4 and 6; however, it suffices to state here that appeals from capacity determinations are rare, and judges are not often overturned unless they are found to have abused their discretion.[207]

> *[J]udges are not often overturned unless they are found to have abused their discretion.*

Limited Guardianship and the Functional Model of Capacity

The move toward a functional, cognitive understanding of capacity that favors an outcome of a limited guardianship as a means of protection may be an improvement over the days when guardianships were always plenary and could be imposed merely because the individual was deemed an idiot, an imbecile, or insane. However, this evolution may have only succeeded in revealing how impossible it is to determine with any accuracy an individual's ability to make decisions in a particular area. Given that, it is worth considering that the whole notion of "capacity" is "a [legal] fiction determined by prevailing values, knowledge, and even the economic and political spirit of the time."[208] This is the very paradigm shift that led the drafters of the CRPD to recognize the legal capacity of people with disabilities ". . . on an equal basis with others in all aspects of life."[209] This worldwide paradigm shift based in international human rights:

> . . . sees incapacity as socially constructed, insists on the full legal capacity of every person with intellectual disabilities, and does away with substituted decision-making in favor of society's obligation to provide appropriate supports to permit everyone to make his or her own decisions. Like every emerging paradigm, this challenges our perceptions and our understanding of when, how, and even if the state may intervene in a person's life, and it has the potential to be deeply unsettling. And, unsurprisingly, it takes time.[210]

Indeed, a close look at how capacity determinations are made reveals that we may well be tilting at windmills in our noble quest to make refined capacity determinations that only remove those rights that the person is truly incapable of exercising. As Chapter 6 will examine, it also seems unlikely that the due process being provided in guardianship cases is sufficiently robust to yield such refined and accurate outcomes.

Chapter 6: Concerns About When and How Guardians Are Appointed

Guardianship—Greatest Areas of Concern

As we discussed in Chapter 4, existing data on guardianship is limited; however, there is significant evidence that guardianship is a system in continual crisis. Some of the greatest areas of concern include:

- due process protections afforded to individuals subject to guardianship and, in some cases, their families, including making sure alternatives are considered and guardianships are not overbroad;
- inadequacy of capacity assessments, as discussed in Chapter 5;
- the steps the court takes to ensure that an appropriate, qualified, and well-meaning guardian is appointed and that the individual subject to guardianship is not exploited, abused, or neglected by the guardian;
- the ability of courts to adequately track and monitor existing guardianships to ensure that abuse, neglect, and exploitation are not occurring; and
- the ability of the individual to have his or her rights restored at the earliest possible opportunity, including through the use of less restrictive alternatives to guardianship.

While some of these issues have already been discussed in preceding chapters, Chapter 6 will attempt to drill down into these issues and examine them more closely.

Due Process Concerns

Back in 1994, the Center for Social Gerontology conducted a national study that examined the guardianship process in 10 states. The study found that only about one-third of respondents were represented by an attorney during the guardianship hearing(s). While medical evidence was in the court file in most cases, medical testimony was rarely presented at the hearing. The majority of hearings lasted no more than 15 minutes and 25 percent of hearings lasted less than 5 minutes, thus raising questions as to whether there was opportunity for meaningful due process. Ninety-four percent of guardianship petitions were granted, and only 13 percent of the orders placed limits on the guardian's authority.[211]

Fifteen years later, a Utah ad hoc court committee made similar findings, concluding that:

> [t]he appointment of a guardian or a conservator removes from a person a large part of what it means to be an adult: the ability to make decisions for oneself . . . We terminate this fundamental and basic right with all the procedural rigor of processing a traffic ticket.[212]

[I]n 1994, the Center for Social Gerontology conducted a national study that examined the guardianship process in 10 states . . . [and] found that only about one-third of respondents were represented by an attorney during the guardianship hearing(s).

Near the time of this report, a local news agency had reported on its impressions after witnessing Utah's court guardianship proceedings in action: "[I]t was startling how quickly someone could be stripped of all decision-making rights. Once the paperwork is in order, 'hearings' average seconds, not minutes."[213] It is worth noting that in many jurisdictions magistrate judges hear guardianship cases, which tends to support the notion that these cases are seen as ministerial when in fact they impact fundamental rights.

"[I]t was startling how quickly someone could be stripped of all decision-making rights. Once the paperwork is in order, 'hearings' average seconds, not minutes."

In its report, the court committee went on to list findings that directly impacted the procedural and substantive due process rights of people at risk of or facing guardianship in the state:

- The person subject to the guardianship proceeding was sometimes either not represented or represented by a lawyer recruited by the petitioner's lawyer.
- The lawyer for the person subject to the guardianship proceeding sometimes acted as a *guardian ad litem*, acting in the perceived best interest of the AIP rather than as an advocate for the person's wishes.
- There was no-to-minimal procedure for the person subject to the guardianship petition to elicit and challenge evidence, and the evidence of incapacity itself was cursory.
- Once appointed, guardians were often given the authority of a conservator regardless of whether that authority was warranted by the respondent's circumstances.
- While statutes claimed to prefer limited authority for guardians and conservators, they failed to describe less restrictive alternatives.
- Plenary appointments were common with little evidence to support the need.
- There was no planning to help the person live life as independently as possible.

- There was no regulation of professional guardians.
- There was little education or assistance for family guardians.
- There was little training for judges and clerks.[214]

Based on reports in other jurisdictions[215] and recent scholarship, Utah's court committee is not alone in making these kinds of findings. Guardianship hearings are often brief, relying on incomplete or illegible information, and resulting in plenary appointments.[216] When courts do limit the guardian's authority, individuals are still often treated by those around them as incompetent or incapacitated in every aspect of their lives. Moreover, the person subject to guardianship might not be seen as having an "enforceable right" to participate in decision making in his or her own life even though the statute indicates that that the guardian should consult with the individual; the court proceeding itself can be stigmatizing; and courts frequently do not actively consider alternatives to guardianship prior to appointment.[217]

Guardianship hearings are often brief, relying on incomplete or illegible information, and resulting in plenary appointments.

In July 2017, the American Civil Liberties Union (ACLU) challenged a Utah law that eliminated a requirement that an attorney be appointed to represents adults with disabilities whose biological or adoptive parents petition courts to become their legal guardians.

One can imagine that such violations of due process would have gained the attention of the federal courts. However, for reasons beyond the scope of this report, federal courts generally will not hear challenges to ongoing guardianship cases because of a variety of legal doctrines that are designed to protect the sovereignty of state courts and the ability of judges to make decisions without fear of liability for violating the rights of litigants. Despite this guardianship statutes can be challenged as unconstitutional as written.

Interestingly, the latest example of such a challenge is a challenge to Utah's guardianship statute. In July 2017, the American Civil Liberties Union (ACLU) challenged a Utah law that eliminated a requirement that an attorney be appointed to represents adults with disabilities whose biological or adoptive parents petition courts to become their legal guardians.[218] While advocates for the law say that it helps alleviate the financial burden of seeking guardianship for parents with adult sons or daughters with ID/DD, advocates for people with disabilities are concerned that it means that these individuals will not have a voice in the process or anyone to advocate for them not to lose their civil rights.

Based on the findings of this report, people at risk of or subject to guardianship face many barriers to fair treatment by the legal system. These barriers include problems accessing zealous representation, the overuse of plenary guardianship, disability-specific guardianship processes that raise due process concerns, the inadequacy of capacity

Barriers to Fair Treatment in the Legal System for People at Risk of or Subject to Guardianship

- Problems accessing zealous representation;
- Overuse of plenary guardianship;
- Disability-specific guardianship processes (due process concerns);
- Inadequacy of capacity assessments used to remove rights;
- Lack of court oversight of guardians;
- Burgeoning caseloads; and
- Poor data collection and management

assessments used to remove rights, the lack of court oversight of guardians, caseloads spiraling upward, and poor data collection and management.[219]

Difficulty Accessing Zealous Representation

As in the Utah analysis, some commentators have raised concerns that people facing guardianship or those already subject to it cannot access independent counsel. This is confirmed by a review of information available from the American Bar Association Commission on Law and Aging.[220] The table in Appendix D of this report describes each state's approach to the appointment of counsel. States generally recognize some form of a right to counsel for alleged incapacitated people in preappointment guardianship proceedings. However, depending on the state, that right to counsel may be qualified—for example, by requiring appointment only when the person requests or wants to contest the guardianship; by allowing the court discretion to appoint an attorney; by requiring the person to bear the burden of the legal and expert fees; by limiting a person's choice of attorney; and/or by prescribing the role the attorney plays in the proceeding (i.e., *attorney ad litem* to advocate for what the lawyer believes is in the person's best interest rather than the expressed wishes of the person). This means, in practice, that the appointment of an attorney to advocate for the person's wishes in preappointment proceedings might not always occur. In some cases, lawyers might view themselves in more of a "guardian ad litem" role, meaning they advise the court as to the best outcome for the person. In other words, lawyers might actually provide evidence to the court supporting the appointment of a guardian, even when that is against their client's expressed wishes.

> *[T]he appointment of an attorney to advocate for the person's wishes in preappointment proceedings might not always occur.*

The question of the role of the lawyer in representing the person in preappointment proceedings has been much debated, with most commentators arguing that without a competent and zealous advocate, the person could face unnecessary restrictions on liberty and autonomy without due process.

Overuse of Plenary Guardianship

Empirical studies indicate that courts do not take advantage of the limited guardianship option and rarely limit a guardian's authority.[221] Most guardianship orders are not time-limited and so last until the subject's death or a court modification or termination of the order, even though an individual's capacity can change over time. For example, psychosocial conditions are often temporary or episodic, and people may experience improvement or fully recover their decision making capabilities within a relatively short time period. These kinds of condition fluctuations are often not appropriately accounted for in either the initial decision to appoint a guardian or in the duration of the guardianship order.[222]

As one scholar postulated, "[a]s long as the law permits plenary guardianship, courts will prefer to use it," even though such guardianships are only appropriate in a sub-set of cases.[223] Courts may make more global assessments of incapacity than are actually justified, based on stereotypes that lead them to undervalue the competencies and/or credibility of people with certain conditions, such as psychosocial conditions or ID/DD. Courts also may not make the proper distinction between what they perceive as the rationality of a person's decision and what that person's actual ability to make a decision is. Additional factors may be a court wanting to err on the side of protection, experiencing difficulties in determining the exact areas of decision making in need of assistance, desiring to avoid confusion about the scope of the guardian's authority, and wishing to promote judicial economy by avoiding future proceedings to expand the scope.[224]

Empirical studies indicate that courts do not take advantage of the limited guardianship option and rarely limit a guardian's authority. Most guardianship orders are not time-limited . . . even though an individual's capacity can change over time.

Unequal Treatment Under the Law for People with ID/DD

There are an estimated 4.7 people with developmental disabilities in the United States, including those with intellectual disabilities, and guardianship disparately impacts this population in a number of ways.[225] In many states, it is easier to obtain guardianship of people with intellectual and developmental disabilities than of others because the process they are subject to is distinct from individuals whose lack of capacity stems from disabilities that arise after one has become an adult, such as dementia, head injury, and psychiatric disabilities. The table in Appendix B lists the states that have distinct guardianship statutes for adults with ID/DD. These statutes are invariably designed to make it easier for parents to get guardianship of children with intellectual and developmental disabilities when they reach the age of majority. Often, they provide for:

> . . . an abbreviated proceeding for individuals with mental retardation when they reached the age of eighteen. The underlying assumption was that [people with intellectual disabilities] were perpetual children, such that the legal powers all parents had over persons under eighteen should simply be extended indefinitely for the parents of [people with intellectual disabilities] . . .[226]

Ryan King

Sometimes, these alternative guardianship processes are viewed and described as "less restrictive alternatives to guardianship." However, although the process used to establish the guardianship may be less expensive and less onerous for parents and others seeking guardianship over an adult with intellectual and developmental disabilities, it is not clear that these types of guardianship are any less restrictive than other forms of guardianship. While some of these alternative guardianship processes, such as Florida's "Guardian Advocacy" statute, F.S. 393.12, are more recent developments, some have been on the books for a long time.

One such example is New York's Article 17-A, which has remained largely unchanged since 1969, other than amendments in 1989 that broadened the types of "developmental disabilities" covered by the statute. While these statutes vary in significant ways, one common factor is that it is less burdensome to "prove" that a person with a developmental disability lacks capacity and/or needs a guardian than it typically is when other disabilities are present. To this point, New York's Article 17-A has been criticized in the following ways: 1) as diagnosis driven rather than based on a functional assessment of capacity; 2) as lacking due process as there is no requirement of a hearing and the person with developmental disabilities is not required to attend if one does occur; 3) as lacking a process for periodic review of the continued need for guardianship; 4) as lacking reporting requirements that make the guardian accountable to the court for the health and welfare of the person subject to guardianship; and 5) that guardianships under Article 17-A are plenary.[227]

In a few states, the statute specifically avoids the question of capacity by providing that a guardian can be appointed for a person with developmental disabilities who needs decision making assistance without an adjudication of incapacity. For example, in Florida a "guardian advocate" can be appointed for a person with developmental disabilities ". . . if the person lacks the decision-making ability to do some, but not all, of the decision-making tasks necessary to care for his or her person or property or if the person has voluntarily petitioned for the appointment of a guardian advocate."[228] A guardian advocate appointed under this statute has generally the same rights and responsibilities under Florida's more general guardianship statute. The main difference is that, since the individual is not technically considered "incapacitated," the rights that can be removed from the person but not transferred to the guardian—such as the right to vote or seek employment—are not taken away from the individual. However, if the right to contract has been transferred to the guardian advocate, the individual who is the subject of a guardian advocacy is not entitled to marry without court approval as that is legally a contractual arrangement. Although Florida's guardian advocacy is considered by some to be a less restrictive alternative to guardianship, it is essentially a limited guardianship with fewer due process protections afforded to the person with a developmental disability under this statute.

Many families are grateful for less onerous paths to establish guardianship in instances in which the family and the individual's interests are aligned and where the lack of capacity or need for decision making assistance is readily apparent. However, the short shrift given to due process, the cursory nature of the capacity determination, and the lack of focus on viable alternatives to guardianship make these statutes problematic against the backdrop of overall policy aims of promoting self-determination and less restrictive alternatives to guardianship whenever possible. Additionally, families who seek guardianship under these processes may feel pressured into a less-than informed decision without fully understanding the implications of guardianship or the possible alternatives.

The suggestion of guardianship usually first arises at an individualized education program (IEP) meeting when a child with a disability nears the age of majority.

Rights are not easily restored once they've been removed by a guardianship. In fact, there have been examples of families who later regretted seeking guardianship for their grown children with ID/DD, only to encounter a difficult time convincing the courts to allow them to use alternatives that would meet the individual's needs. In September 2015, the *Washington Post* chronicled the story of Ryan King, an adult with ID/DD who was subject to guardianship. When Ryan turned 18, his parents were told they had to become his guardians in order for him to receive adult services. In 2007, Ryan's parents asked the Court to remove them as his guardians, saying that he did not need or want to be under guardianship. By that time, King had worked at a grocery story and used supported decision-making with his parents for years. However, the court denied their request. It was not until nearly 10 years later that the court eventually terminated Ryan's guardianship, after he found new attorneys to represent him and present expert evidence supporting his functional capacity and effective use of supported decision making."[229]

School-to-Guardianship Pipeline for Youth with ID/DD

The Pipeline Problem

The suggestion of guardianship usually first arises at IEP meeting when a child with a disability nears the age of majority. Children who have IEPs under the IDEA are entitled to receive services until they graduate from high school or they reach age 22. Children with disabilities may have a difficult time graduating at the expected pace for a variety of reasons. However, these delays should not undermine the presumption of capacity for those that have reached the age of majority, which is 18 for most purposes with the exception of the drinking age. Be that as it may, parents are often informed by teachers or administrators that the rights that parents have under IDEA, for example to participate in IEP meetings and to due process if there is a dispute over the content of the IEP, will transfer to the child when they turn 18. In theory, this takes place in the context of a fulsome transition plan designed to help the child take on the adult responsibilities of employment or higher education and vocational training. However, too often this notice is issued as a warning to parents alongside a suggestion that they need to obtain guardianship over their children with ID/DD in order to continue to participate in their education and to protect youth who are often seen as incompetent and potentially vulnerable to abuse or exploitation due to their disabilities. While such concerns should not be taken lightly, it is worth noting that *all* parents have fears about whether their teenager will be ready for the responsibilities of adulthood when they turn 18, but it is only the parents of teenagers with disabilities who are regularly advised that they have the option of preventing the child from becoming legally an adult in the eyes of the world.

> *[A]ll parents have fears about whether their teenager will be ready for the responsibilities of adulthood when they turn 18, but it is only the parents of teenagers with disabilities who are regularly advised that they have the option of preventing the child from becoming legally an adult in the eyes of the world.*

In 2008, researchers found that in one school for children with developmental disabilities, faculty encouraged all parents to obtain guardianship when their children turned 18. Furthermore, faculty had few reservations or second thoughts about concluding that their students needed guardianship, as they were largely motivated by a perceived need to protect the young adults and believed the way to do this was by pursuing guardianship. Frighteningly, researchers found that the faculty lacked knowledge regarding the guardianship process and about alternatives to guardianship.[230]

Evidence suggests that parents of young adults with disabilities are often seeking guardianship when their children turn 18 and are still in school. One study examined 221 guardianship files across nine jurisdictions in Michigan that were filed under Chapter 6 of the Michigan Mental Health Code, which governs guardianships for people with developmental disabilities. They found that more than 50 percent of the individuals in the sample were 18 when the guardianship petition was filed and more than 90 percent were still in public schools when the petition was filed. Interestingly, for approximately half the individuals in the study, the sole income was SSI.[231] While it is not altogether surprising that parents are seeking guardianship over young adults with intellectual disabilities at a relatively young age, it does suggest that guardianship in these cases is being filed proactively (prior to these young adults attempting greater independence first) and perhaps without a full consideration of the alternatives, since the young adult had a guardian as a child (as do all children) and continues to have one as an adult. In fact, numerous alternatives exist that could alleviate the main concerns that parents have at this important juncture in their children's lives. These alternatives are explored more fully in Chapter 9, but it's important to note that in many cases these alternatives already exist without any need for statutory changes.

For instance, a young adult who has not completed high school by the time they're 18 can voluntarily elect to continue to include their parent in their IEP meetings, or in some states there is a process for the school to recognize the parent as the representative of an adult child with a disability for IDEA purposes upon a determination that the individual is unable to participate meaningfully in the process. With respect to medical decisions, there is usually a provision that provides for the next of kin to consent to medical treatment on behalf of a person 18 years of age or older, who "lacks capacity to understand appropriate disclosures regarding proposed professional medical treatment . . ."[232] In such cases, capacity is determined in reference to medical personnel determining that the person cannot provide informed consent to medical procedures rather than a judicial proceeding. Finally, a person who receives SSI due to an intellectual disability will often have a representative payee appointed to manage their benefits, alleviating the need for a conservator or guardian of property if the monthly benefit is the individual's only source of income. With these three alternatives in place, the need for guardianship is greatly reduced.

If guardianship is a family's first choice rather than the last resort after other alternatives have been tried (or at least seriously considered and rejected), the negative impact may not be limited to the young person with a disability who finds his or her rights curtailed more than necessary. Obtaining guardianship can be an expensive and arduous process for families, too, and the ongoing reporting requirements may prove too much for some. These may be acceptable trade-offs where guardianship fulfills the perceived need to protect the individual; however, there are reasons to ask whether guardianship is actually helpful in many cases, even where the individual's lack of capacity seems readily apparent.

There is a great deal of evidence that special education teachers regularly encourage or even pressure parents into seeking guardianship of their transition-age children with disabilities. For example, a 2015 study supported by the TASH

Human Rights Committee and the Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS) tends to support this conclusion. The study analyzed 1,225 responses to an online survey regarding their experiences with guardianship and alternatives. Eighty-seven percent of respondents were parents of people with disabilities. Thirty-seven percent of respondents indicated that they or the person about whom they were answering questions had a guardian, and 63 percent did not, although of the latter group, 37 percent indicated that guardianship had been recommended. When asked, "Who first suggested guardianship?" the most common response was "school personnel." Strikingly, the survey results indicated that regardless of who first made the recommendation, plenary guardianship and "power of attorney" were the most often recommended option for decision making assistance across every IDEA disability category except deafness, recommended with equal frequency.[233]

There is a great deal of evidence that special education teachers regularly encourage or even pressure parents into seeking guardianship of their transition-age children with disabilities.

Alternatives to the Pipeline

While clearly some parents are receiving encouragement to pursue guardianships over their children with disabilities, there are also signs pointing to some families increasingly learning of alternatives to guardianship and getting better advice to help them weigh their options. These changes are likely due in part to changing attitudes toward disability generally, a growing awareness and recognition of alternatives such as supported decision making and changing expectations regarding employment for young adults with disabilities such as seen in the 2014 Workforce Innovation and Opportunity Act (WIOA).[234]

Workforce Innovation and Opportunity Act (WIOA)

Section 511 of WIOA limits the ability of employers who hold 14(c) certificates from the U.S. Department of Labor (which allow them to pay people with disabilities under minimum wage) to pay subminimum wages to any person with a disability age 24 or under, unless they are already employed by such an employer, in which case they are "grandfathered in." Under the new law, holders of these certificates cannot pay subminimum wages to any youth without first documenting that the youth has received transition services under IDEA; has applied for Vocational Rehabilitation (VR) services and either been found ineligible or had their case closed after working toward an individual plan for employment (IPE) goal for a reasonable period of time; and has received career counseling. These limitations are intended to make it less likely that youth will be inappropriately routed into segregated, subminimum wage employment without exploring all the alternatives for meaningful work and post-secondary education and training. WIOA has the potential to be transformative in terms of societal expectations of young people with intellectual and developmental disabilities, and it may be that these raised expectations will make guardianship less of a foregone conclusion as well.

State Efforts to Promote Alternatives to Guardianship

Some state education agencies are making a genuine effort to make sure that parents' desire to continue to be involved in their children's education is not a reason for guardianship. For example, the D.C. Office of the State Superintendent of Education website specifically encourages the use of supported decision making for students who may need assistance to ". . . make his or her own decisions, by using adult friends, family members, professionals, and other people he or she trusts to help understand the issues and choices, ask questions, receive explanations in language he or she understands, and communicate his or her own decisions to others." Additionally, the site provides a form ". . . to provide assistance to local education agencies (LEAs) and adult students to document supported decision-making decisions. . . ."[235]

Some state education agencies are making a genuine effort to make sure that parents' desire to continue to be involved in their children's education is not a reason for guardianship.

Another example is the "I'm Determined" project funded by the Virginia Department of Education, which focuses on providing direct instruction, models, and opportunities for students to practice skills associated with self-determined behavior, including effectively participating in their IEP.[236]

Many family-based groups not affiliated with a state education agency are also trying to improve on the information that is available to families at this critical juncture. "Family Voices" of Wisconsin has a fact sheet on "Supported Decision Making for Transition Age Youth" that provides valuable information about alternatives to guardianship and how to use supported decision making effectively in this context.[237]

Finally, state DD Councils have also launched initiatives designed to encourage the full consideration of alternatives to guardianship and make sure people with ID/DD and their families have complete information when deciding whether they need to resort to guardianship. One such initiative is "Lighting the Way to Guardianship and Alternatives," funded by the Florida Developmental Disabilities Council, which provided trainings across Florida for individuals and families as well as legal professionals interested in knowing more about guardianship and alternatives.[238]

[S]tate DD Councils have also launched initiatives designed to encourage the full consideration of alternatives to guardianship and make sure people with ID/DD and their families have complete information . . .

Financial Costs of Guardianship

Throughout this report, we have made the case that the adjudication of incapacity and the imposition of guardianship is a serious deprivation of constitutional rights. To the extent that the traditional parens patriae authority can be used to subject an individual to guardianship, the decision to do so must be reached through due process. However, to put it bluntly—due process is not cheap. Even where every person in the guardianship system is working with the interests of the person with a disability in mind, the person can emerge from the process much poorer than they entered it. Where an individual subject to guardianship is indigent, the costs often fall on the state, and given the relative stinginess of state budgets in the last 10 years, there are real gaps in funding that make it impossible for the system to work for the people it is supposed to be supporting and protecting.

As often noted, simply describing guardianship can be difficult because of tremendous differences in statutes from state-to-state, as well as differences in practice from court-to-court; differences in the dynamics with family guardians, professional guardians, and public guardians; differences that stem from the reason for guardianship, whether it's ID/DD, dementia, mental health, head-injury, or another cause; and whether the guardianship is "contested" or not. Similarly, each of these factors can alter the financial aspects of guardianship. Additionally, the local economy can impact the cost of guardianship a great deal; simply put, professional guardians, lawyers, and other actors may charge vastly more for their services in Miami than they would in Pella, Iowa. However, there are some fundamental issues related to the costs associated with guardianship that we can explore. Please note that this may be related to the conversations around financial exploitation, but here we are really focusing on costs that occur even in the absence of any intent on the part of the guardian or any other actor to unjustly enrich themselves.

Cost of Justice

Even the most straightforward, uncontested guardianship case can be quite expensive. Estimates of the average cost of obtaining guardianship range from as low as $1,500 to as high as $5,000 and even higher. Contested guardianships where the individual does not agree that they need a guardian or where there is disagreement over who should be appointed as guardian can be even more costly. These estimates may include initial filing fees, paying an attorney to represent both the individual subject to guardianship and the putative guardian, and fees associated with the determination of incapacity, such as paying a psychiatrist to examine the alleged incapacitated individual and report their findings to the court. Once the guardianship is established, the guardian is generally entitled to receive a reasonable fee for their services out of the estate of the person subject to guardianship. In addition, the guardian will often—and in some states is required to—retain an attorney to represent the guardianship, that attorney is also paid out of the estate of the person subject to guardianship. When guardians are required to file documents that facilitate the court's ability to monitor the guardianship, such as annual accountings and

Estimates of the average cost of obtaining guardianship range from as low as $1,500 to as high as $5,000 and even higher.

reports, they are usually entitled to be paid for the time it takes to prepare the documents, and the attorney for the guardianship can collect a "reasonable fee" for the time it takes to review the documents and file them with the court.

A majority of states' statutes establish "reasonable fees" as the standard for how much a guardian can be paid for the work that they do. In 2013, the Florida State Guardianship Association (FSGA) conducted a survey about the fees charged by the 400 professional guardians who were members of the organization at that time. Of those, 130 responded. The range of fees was quite broad, with the lowest fee coming in at $15 per hour and the highest fee being $125 per hour; it's worth noting that the range of experience of the professionals was also quite broad, with some of the guardians reporting that they were just starting out and others reporting that they had more than 20 years of experience as professional guardians. The most common rates reported were between $45 and $85 per hour. Additionally, the survey found that most guardians set their rates in accordance with local court rules or customs. Twenty-five percent of respondents reported that their fee varied based on the activity and almost 13 percent reported that the courts set limits on the amount of time that particular activities should take and limit fees assessed accordingly.[239]

In 2013, the Florida State Guardianship Association (FSGA) conducted a survey about the fees charged by . . . 400 professional guardians. . . . The range of fees was quite broad, with the lowest fee coming in at $15 per hour and the highest fee being $125 per hour . . .

In Florida as well as other states, significant questions can arise regarding the nature of the work performed. For example, the reasonable fee that an attorney can charge for their legal services may be different than what they can charge when they are acting as the guardian for an individual, as lawyers often do. Another facet of this issue is how much guardians can charge for performing tasks that do not require the experience and training that a professional guardian might be expected to have. For example, if a guardian visits a person subject to guardianship and, while they're there, spends two hours helping the individual clean up their living space they are probably not entitled to charge $125—which might be considered a reasonable fee for a guardianship service, but probably not for housekeeping services. The National Guardianship Association (NGA) standards address this issue and provide guidance on time records. At a minimum, accountings filed by a guardian should include a detailed description of the task performed to allow the court to determine whether the activity justifies the professional guardian's hourly rate or a lesser rate that is commensurate with the activity. However, many courts lack the personnel, expertise, and resources to closely review these reports or confirm their accuracy.

Finally, while most of this discussion concerns the ability of professional guardians to charge for their services, the UGGPA and the updated version, the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act, provides that guardians can be paid out of the guardianship estate for their services irrespective of whether they are professionals or family members. However, family members are not necessarily able to claim the kinds of hourly rates professional guardians are able to based on training and experience. Additionally, family members are not generally entitled to compensation for services that are the kind family members usually perform for each other but only for services that fall within the scope of the guardianship (e.g., paying bills).

Public Funding of Guardianship

In addition to the critique of guardianship that it potentially drains the person's resources under the guise of preserving them, there are issues related to public funding of guardianship. In most states, public guardianship is a mechanism to provide decision making services for an individual who has been determined to need a guardian, but for whom no qualified individual has stepped forward to serve as guardian. Additionally, in some states, public guardianship is specifically for individuals who are indigent or of limited means while in few others public guardianship is limited to people with specific types of disabilities. A national study of public guardianship in 2007 found that public guardianship essentially falls into four categories: 1) the public guardian is an official of the court and is appointed by the chief judge of the court; 2) a statewide public guardianship office that is part of the executive branch of state government; 3) the public guardian is an arm of a preexisting social service agency; and 4) the public guardian is a county agency. Within these three models of public guardianship, funding streams may vary dramatically, but across the board, public guardianship systems are under-funded. There are significant unmet needs for public guardianship across the country as well as for other decision making services for individuals who do not have close family or friends willing or able to provide assistance. The 2007 study found that funding for public guardianship comes from a patchwork of sources, but that none are sufficient. This can lead to incredibly heavy caseloads for public guardians, raising concerns about the quality of the services provided. Additionally, the report points out that individuals who are in institutions but may be able to transition to the community may need a public guardian to advocate for such a move and to make the necessary arrangements, but not be able to access one because the public guardianship system is chronically under-funded.[240]

[I]ndividuals who are in institutions but may be able to transition to the community may need a public guardian to advocate for such a move . . . but not be able to access one because the public guardianship system is chronically under-funded.

Additionally, some of the ways that public guardianship systems operate are inherently problematic. For example, the study found that in 2007, 32 states used a social services agency model for public guardianship. In this scenario, the authors claim, if the public guardian program is ". . . housed in an entity also providing social services, then the public guardian cannot advocate for or objectively assess services, or bring law suits against the agency on behalf of incapacitated persons."[241] There is clearly a need for more robust and independent sources of funding for public guardianship.

More public dollars—including federal dollars—must be invested in alternatives to guardianship, which are widely recognized as being not only less restrictive, but also less expensive than guardianship. ACL has funded a number of pilot programs exploring the effectiveness of supported decision making. These projects are discussed in Chapter 8.

Professional Guardianship in the Absence of Sufficient Public Funding

One last interesting finding from the FSGA survey discussed was that "[m]ultiple respondents reported the hourly rate of the guardian being affected by the percentage of pro bono work carried by the guardian."[242] In other words, the estate of one individual subject to guardianship was charged more to compensate the guardian for work performed for an indigent individual. FSGA is careful to note that this practice is inequitable and unfair to the person who is paying more to make up for the unmet need for public guardianship in the community, but anecdotally this practice persists in Florida and other states. Although a discussion of financial exploitation by guardians is offered elsewhere in the report, it's worth noting that practices can lead to the perception, whether accurate or not, that professional guardians are "fleecing" their clients. Families of individuals subject to guardianship, who may have their own stake in preserving assets they anticipate inheriting one day, often perceive guardianship as ". . . a closed system in which attorneys, fiduciaries and other professionals have associations with one another and loyalty to each other that may potentially override their professional responsibilities."[243] This perception may or may not be correct, but given previously identified significant shortcomings regarding the court's ability to monitor guardianships or to subject accountings to any kind of close examination, it is easy to understand why some would jump to the conclusion that judges, lawyers, and professional guardians are engaged in a conspiracy to defraud their loved one. Ironically, their loved one may be being overcharged in part because the professional guardian has a large pro-bono caseload. This may be compounded by the fact that professional guardians and the attorneys who represent them may have to respond to actions taken by the family members of an individual subject to guardianship, and they are usually entitled to their hourly rate to do so. With hourly rates for probate attorneys reaching as high as $350 an hour and even higher in some regions of the country, this can very quickly make the costs associated with guardianship at least appear excessive. This can spiral into a scenario where everyone is pointing the finger of blame at each other while the assets that are supposed to be preserved and used to meet the individual's needs are rapidly depleted, even though no one involved intended any harm to the "protected" individual.

Several states have created oversight mechanisms outside of the judicial apparatus that are intended to regulate public and professional guardians, while those efforts are mostly aimed at addressing issues of fraud, they may have the impact of preventing the type of spiraling fees scenario previously described. The Office of Public and Professional Guardians (OPPG) in Florida, for example, created a mechanism for reporting complaints regarding a professional guardian and the ability to sanction guardians, including suspension or revocation of their certification as professional guardians, without filing the complaint with the court. This may help detect and address situations where the guardian is actually committing abuse or failing to discharge their duties, but it also may prevent unnecessary and expensive judicial procedures in some cases. Additionally, OPPG can assess whether multiple complaints have been registered against a particular guardian and respond accordingly, whereas a court might not know that several people have issues with the same guardian's actions.[244]

Chapter 7: Concerns Once Guardianships Are in Place

Overview of Concerns

Many of the individuals interviewed for this report told NCD that, in their experience, guardianship is an extremely dysfunctional system. Not only are there serious deficiencies in terms of the due process that is afforded to individuals facing losing their rights in a guardianship proceeding, there are significant problems once a guardianship has been established. National advocacy organizations and the media have highlighted the abuse of guardianships and conservatorships as a means to exploit people with disabilities and older Americans. Unfortunately, the ability of courts, advocates, and others to address this issue has been impeded by a number of factors, including the absence of accurate national information regarding the numbers of people affected by guardianships, the conditions under which a guardianship is imposed, the services and alternatives being offered, the frequency and nature of misfeasance by guardians, and the possible warning signs of abuse. However, several states are taking steps to increase their efforts to effectively monitor guardianships to ensure that individuals who find themselves subject to guardianship are protected from abuse, neglect, and exploitation by their guardians. Additionally, as previously noted, the President signed legislation in 2017 that attempts to assist states in their efforts to ensure that older people, including those subject to guardianship, are protected from abuse.[245]

Guardianship has been referred to as a double-edged sword*—an instrument designed to protect vulnerable people in society from abuse or neglect, while simultaneously removing fundamental rights that may increase opportunities for such abuse.*

Guardianship: A Double-Edged Sword?

Guardianship has been referred to as a *double-edged sword*—an instrument designed to protect vulnerable people in society from abuse or neglect, while simultaneously removing fundamental rights, which may increase opportunities for such abuse.[246] As Professor Michael Perlin stated, "At best, the guardianship will provide the personal care and property management that the [person with a disability] alone cannot handle. At worst, guardianship will deprive the individual of decision-making authority that he or she has the capacity to handle, and create the opportunity for personal or financial abuse."[247]

Guardianship affects a person's legal right to make some or all of the decisions in their lives, including those about finances, health care, voting, marriage, socializing, and working, among others. Guardianship can easily go beyond protecting rights and seriously interfere with self-determination, especially if guardians exercise control in areas where persons could make their own decisions either with or without support.[248] Another legal scholar expressed concerns that "the total power which the law gives to guardians creates the possibilities for isolation and vulnerability that leads to, or at least permits, abuse."[249]

While there are certainly many cases where families have made guardianship work for them, as well as many professional guardians who have taken the National Guardianship Association "standards of practice" and ethical guidelines to heart to promote the well-being and self-determination of people subject to guardianship, there are also many examples of overly restrictive guardianships and of financial, physical, and emotional abuse perpetrated by unscrupulous guardians. This chapter will explore some of the consequences of guardianship and propose recommendations for change.

Guardianship's Impact on Life Outcomes

In a survey of 22 projects, studies, and conferences from 1961 to 1996, elder law scholar A. Frank Johns was unable to identify any findings that clearly showed that guardianship leads to positive life outcomes for people who are subject to it.

The Impact on Life Outcomes

The justification for guardianship is that it is a means of protecting vulnerable individuals. However, when A. Frank Johns, an elder law scholar who often writes about guardianship, surveyed 22 projects, studies and conferences from 1961 to 1996, he was not able to identify any findings that clearly showed that guardianship leads to positive life outcomes for people who are subject to it. Even if they can show that guardianship preserves property, those prior investigations ". . . have also uncovered evils in guardianship: removing all rights; denying access, connections, and voice to those lost in guardianship's gulag; and still continuing a process rooted in systemic perversities."[250]

Johns wrote that the more recent studies of guardianship monitoring and public guardians "acknowledge that guardianship still limits the autonomy, individuality, self-esteem, and self-determination" of those subject to guardianship, and he expressed continued concerns that the legal system surrounding guardianship focused more on the interest in protecting a person's property than the person him/herself.[251]

Guardianship orders impact the very decisions that define people as human beings, and thus have significant impact on the daily lives of people subject to them. Studies have found that, when a person loses the right to make his or her own decisions, there will likely be a negative impact on the person's functional abilities, physical and mental health, and general well-being. One scholar talks about the "constructive isolation of guardianship" and its impact on people.[252] People subject to guardianship can "feel helpless, hopeless, and self-critical" and experience "low self-esteem, passivity, and feelings of inadequacy and incompetency," as well as significantly decreased "physical and mental health, longevity, ability to function, and reports of subjective well-being."[253] Some scholars also argue that, because guardianship is sought based on a finding that a person lacks capacity, it can be demeaning and socially stigmatizing.[254]

Studies have found that, when a person loses the right to make his or her own decisions, there will likely be a negative impact on the person's functional abilities, physical and mental health, and general well-being.

Financial Abuse by Guardians

Although guardians are often appointed to protect an individual's assets from waste or to prevent a "bad actor" from obtaining access through undue influence, fraud, or misrepresentation, ironically this often places guardians in the best possible position to financially exploit vulnerable individuals themselves. Two recent GAO reports attempt to ascertain the scope of this problem. Both reports focused on financial abuse of only seniors but, as noted previously, individuals are only subject to guardianship if they are "incapacitated," which clearly means that, while the reports may not examine younger people with disabilities subject to guardianship, the senior individuals described in these reports are people with disabilities. In both reports, GAO noted that a lack of accurate data on guardianships made it impossible to determine whether guardianship abuse is widespread.[255] However, the 2010 report detailed the cases of 20 guardians who improperly obtained $5.4 million in assets from 158 incapacitated victims.[256] In addition to the theft or improper obtainment of assets, in some instances, guardians also physically neglected and abused their victims. The guardians in these 20 cases came from diverse professional backgrounds and were overseen by local courts in 15 states and the District of Columbia.

[T]he 2010 [GAO] report detailed the cases of 20 guardians who improperly obtained $5.4 million in assets from 158 incapacitated victims.

GAO found several common themes across the 20 cases. In 6 of 20 cases, the courts failed to adequately screen potential guardians, appointing individuals with criminal convictions or significant financial problems to manage high-dollar estates. In 12 of 20 cases, the courts failed to oversee guardians once they were appointed, allowing the abuse of vulnerable seniors and their assets to continue. Lastly, in 11 of 20 cases, courts and federal agencies did not communicate effectively or at all with each other about abusive guardians, allowing the guardian to continue the abuse of the victim and/or others.[257]

In a more recent report published near the end of 2016, GAO found that while these problems persisted, states and federal agencies had begun to take steps to at least collect better data that can not only guide policymakers but also can

catch malfeasance earlier. One such positive step that GAO identified in their report is the development of the National Adult Maltreatment Reporting System (NAMRS), a national reporting system based on standardized data submitted by state adult protective services (APS) agency information systems.[258] In a hearing before the Senate Special Committee on Aging addressing the 2016 GAO reports findings, Cate Boyko, manager of the Conservator Account Auditing Program for the Minnesota Judicial Branch testified about the state's "Conservator Account Monitoring Preparation and Electronic Reporting" system, better known as "CAMPER." This electronic records system allows guardianship records to be monitored continuously for red flags that might indicate that exploitation is occurring. Additionally, it provides accurate and easily accessible data that can be audited on a regular basis to ensure that guardians of the property are managing money prudently and not engaging in exploitation. In order to encourage adaptation of this system to meet the needs of other states, CAMPER's source code has been made available to other states who may want to replicate the system.[259]

Overbroad Guardianship

As discussed in Chapter 3, limited guardianships were an important innovation in the second wave of guardianship reform, but its use remains inconsistent across the United States. In some cases, judges and professionals may draft overly broad guardianship orders to prevent parties having to return to court to expand the guardians authority as a disease such as Alzheimer's progresses. Indeed, having to return to court in a guardianship case can have the effect of depleting the resources of the individual subject to guardianship, because unless indigent, he or she is ultimately on the hook for paying all the costs associated with guardianship. In several states there is a requirement that the individual be represented by counsel whenever they are faced with losing rights under guardianship. This means that, at a minimum, their estate will have to pay for two lawyers—one representing the person who is already under a limited guardianship but who allegedly lacks capacity in an additional area, as well as the guardian's lawyer, who would normally be urging the court to expand the guardian's authority—and for the fees assessed for the examination that would be required to determine the individual lacked capacity in an additional area. It is easy to see how this can quickly become a costly endeavor. However, a guardianship that removes more rights from the individual than necessary is legally and morally impossible to justify, even if there is a financial argument for it.

As discussed elsewhere in this report, restoration cases can be similarly costly, and it may be that establishing guardianships that are overly broad may lead to an increase in petitions for restoration. As discussed further in Chapter 8, there are numerous alternatives that can be used instead of guardianship; these tools should also be used when possible to limit the scope of guardianship. However, given the difficulty identifying discreet areas of incapacity described in Chapter 5 and the financial and judicial economy arguments previously outlined, it seems unlikely that courts are going to truly embrace limited guardianships in the way we might have hoped.

Implications for Voting

> *I think that one of the ways that you can really silence someone and make them feel not a part of society is by taking away something that's as fundamental as the right to vote.*
>
> —NCD Interview Participant

As NCD noted in its 2013 report, *Experience of Voters with Disabilities in the 2012 Election Cycle*, federal laws such as the Help America Vote Act (HAVA) have tended to focus on physical access to the polls by people with disabilities, "yet competency requirements imposed by state laws or by election officials or service providers also present challenges for voters with disabilities." Thirty-nine states have laws that restrict the right to vote based on competency: 25 states require a court to specifically determine that the individual lacks the capacity to vote in order for incapacity to justify disenfranchisement; 10 states provide that a person "under guardianship" is barred from voting outright; 4 states bar those who have been deemed "non-compos mentis" from voting (defined differently in each state); and 7 states prohibit "idiots," "insane persons," or those of "unsound mind" from voting.[260] Along with other aspects of guardianship law described in Chapter 2:

> the rationale for disenfranchisement changed from one of dependency as a marker of who was or wasn't a full political citizen, to perceived lack of mental competency in the mechanics of voting. All the while, the legal system maintained that lunatics and idiots did not possess the requisite minds for voting.[261]

This issue rose to national prominence in the 2016 election. As widely reported at the time, a former National Public Radio producer named David Rector was placed under conservatorship following a brain injury. He went to court to ask for restoration of his right to vote under California law,[262] which changed in 2016. Under the new law, the court could only remove the right to vote after making a specific finding that the individual was unable to express a desire to vote. Mr. Rector was successful in getting his right to vote restored, and his story raised awareness of this important voting rights issue.[263] Sadly, in most states, individuals who are subject to guardianship may not realize that they could lose their right to vote even if the subject of voting is never raised at the guardianship hearing. These determinations that an individual is incapable of voting can be challenged as discriminatory if they remove the right to vote from individuals due to disability or supposed "mental incompetence" despite there being no specific finding that the person lacks the ability to make decisions specific to voting. On the other hand, where courts do seek to explore whether an individual subject to guardianship should be allowed to vote, "[p]robate courts . . . sometimes ask individuals who are the subject of guardianship proceedings to demonstrate an understanding of elections and politics that goes far beyond what is expected of the general public before they are permitted to vote."[264] As previously noted, California is one of four states to have adopted the standard urged by the American Bar Association's House of Delegates, which is that the right to vote should only be removed based on incapacity if the individual cannot express "a specific desire to participate in the voting process."[265] Although Maryland, Nevada, and New Mexico are the only other states that use this standard, the standard is nonetheless consistent with the Voting Rights Act, which prohibits states from applying restrictive and unequal tests to determine who is qualified to vote.[266]

Sadly in most states, individuals who are subject to guardianship may not realize that they could lose their right to vote even if the subject of voting is never raised at the guardianship hearing.

Some express concerns that allowing people with significant cognitive disabilities to vote could lead to widespread voter fraud. There is some evidence that voters in long-term care facilities who utilize absentee voting are vulnerable to this kind of fraud.[267] However, it is not clear whether individuals who are subject to guardianship would, as a group, be more likely to have their franchise abused than other people with disabilities and older individuals.

Sexuality and Guardianship

Sexuality is an incredibly broad and incredibly fraught topic for people with disabilities that raises issues not only about consent and mental capacity, but also "the forced sterilization of [people with disabilities], the rights of [people with disabilities] in institutions to have sex and be free from sexual abuse, and the rights of lesbian, gay, bisexual, and transgender (LGBT) [people with disabilities]."[268] Against this complex backdrop, NCD recognizes that "the desire to enter into intimate personal relationships, including sexual relationships, is one of the most personal rights there is" and that ". . . desire is no less important for the many adults with disabilities who are under some form of guardianship."[269]

Although disability and sexuality has long been a taboo subject, and there are still pervasive and destructive myths surrounding disability and sexuality, disability organizations such as The Arc of the United States and the American Association on Intellectual and Developmental Disabilities have long recognized that people with intellectual disabilities must have their sexual rights "affirmed, defended, and respected."[270] Similarly, in the context of guardianship, the National Guardianship Association Standards of Practice provide:

> [t]he guardian shall acknowledge the person's right to interpersonal relationships

> and sexual expression. The guardian shall take steps to ensure that a person's sexual expression is consensual, that the person is not victimized, and that an environment conducive to this expression in privacy is provided.[271]

Particularly for people with intellectual disabilities, who many in society frequently describe as having a mentality that correlates with a child's age, society is uncomfortable with the idea of these individuals having sexual feelings, and in some cases justifiably concerned about an individual's ability to make an informed decision about sexual relationships. Concerns about the very real possibility of sexual abuse are too often justified. According to the Bureau of Justice Statistics, between 2011 and 2015, people with all types of disabilities are more than three times as likely to be victims of rape or sexual assault as their peers without disabilities, and people with cognitive disabilities were the most likely to be victims of all types of violent crimes among the disability types measured.[272] National Public Radio reports that, according to unpublished Justice Department data, the risk of sexual abuse faced by people with intellectual and developmental disabilities may be seven times higher than for the general population.[273] NCD has long recognized that "rights protection programs must be established to reflect the fact that women and girls with disabilities are subject to double discrimination in society and require protections against physical and sexual abuse in the family and in the very social programs created by society to serve them . . ."[274] It's worth noting that guardianships can also sometimes arise out of a family's desire to protect an adult child or older loved one who might be vulnerable to sexual abuse and might not be able to offer informed consent to enter into a sexual relationship.

[G]uardians are uniquely positioned to police with whom the individual subject to guardianship can associate, creating a situation where the individual is only allowed intimate contact with partners of whom the guardian approves.

As discussed earlier in this report, all adults are presumed capable of making decisions for themselves. This presumption is true of sexual relationships, as well as expressed by states' age of consent for sexual activity, which is most often between 16 and 18 years old. Additionally, states also define the circumstances of sexual incapacity in which circumstances negate consent, such as intoxication, age, being asleep, being in the custody of the state, or mental disorders.

While no one wants to see predatory or exploitive behavior against individuals who may not be able to consent, or who may have limited ability to express that they are even being victimized, these laws do create confusion regarding the circumstances under which a person who is subject to guardianship, or whose ability to offer informed consent is questionable, could ever have consensual sex. Additionally, guardians are uniquely positioned to police with whom the individual subject to guardianship can associate, creating a situation where the individual is only allowed intimate contact with partners of whom the guardian approves.

In some cases, the guardian might have the person's best interests at heart, but this scenario can also become deeply problematic.

As an example of the problems that can arise, in the case of *In re Guardianship of Atkins*, a gay man suffered an aneurysm and his parents subsequently became his legal guardians, immediately preventing his long-time boyfriend, with whom he had lived prior to his hospitalization, from visiting him because they disapproved of the relationship. The court upheld the right of the parents to prevent the men from even seeing each other, saying that "Patrick's parents had the ultimate and sole responsibility . . . to determine and control visitation with and access of visitors to Patrick Atkins in his best interest."[275]

Similarly, a lawyer who was interviewed for this project recalled several cases in which guardianship was sought for the expressed purpose of preventing the individual subject to guardianship from having an intimate relationship of which the guardian did not approve. In one case, a mother had sought and obtained guardianship over her 19-year-old daughter who was deaf and had some emotional problems in order to prevent her from seeing her somewhat older girlfriend. In another case, a father sought guardianship over his young adult daughter with a mild cognitive impairment because she had created a profile on a dating website. In his order, the judge specifically noted that this behavior on her part opened the door to sexual exploitation and a guardianship was necessary to protect her. The father's motives in this case might be understandable, but in an era when 27 percent of adults ages 18 to 24 use online dating websites, the conclusion that seeking companionship through an online dating profile opened the door to exploitation should be questionable at best, especially as legal grounds for guardianship.[276]

One can clearly recognize and understand the consequences of failing to protect an individual subject to guardianship from sexual exploitation or abuse. However, there is also harm in preventing individuals who are subject to guardianship from having an outlet for sexual expression, which the Supreme Court has recognized as being "[a]t the heart of liberty . . . ."[277] This right is as important to individuals subject to guardianship as it is to everyone else, even if it makes some uncomfortable or uneasy.[278] Although "the degree to which [the right] extends to people who have cognitive impairments remains unexplored,"[279] there can be no doubt that exercising control over another human being's opportunities for sexual expression implicates an important liberty interest.

> *[T]here is also harm in preventing individuals who are subject to guardianship from having an outlet for sexual expression, which the Supreme Court has recognized as being "[a]t the heart of liberty . . . ."*

The National Guardianship Association (NGA) has taken an important step in asserting that guardians should recognize the right of individuals subject to guardianship to engage in sexual expression and take steps to ensure that such sexual expression is consensual. Additionally, NGA has made information available to professional and family guardians at its annual conferences and on its website that can help guide these discussions and help guardians make good decisions with respect to these issues.[280] However, taking these steps alone may still prove insufficient to protect an individual from having his or her sexual autonomy essentially revoked while subject to guardianship. As discussed in Chapter 8, the process of supported decision making might be a more effective way of ensuring that people subject to guardianship or who need decision making assistance are not completely deprived of a right to sexual expression.

Jurisdictional Issues

Because guardianships are created under state law, a host of vexing problems can arise that have to do with which state has jurisdiction over an individual who is alleged to be incapacitated or who is subject to guardianship. For example, what state has jurisdiction over an individual subject to guardianship who is receiving treatment in a specialized facility in another state? Can a state such as Florida impose a guardianship on an individual who is a snowbird and only lives in the state during the winter months? Is a relative who lives in a different state than an individual subject to guardianship a more appropriate choice as a guardian than a professional or public guardian within the state? As Sally Balch Hurme, a prolific author on issues related to guardianship and aging, has pointed out, “guardianship has been traditionally ‘strictly local.’ But in today’s mobile society, it is difficult to contain guardianship issues within one state’s boundaries.”[281]

“[G]uardianship has been traditionally ‘strictly local.’ But in today’s mobile society, it is difficult to contain guardianship issues within one state’s boundaries.”

The Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA) is a uniform law that has been adopted in all but three states (Florida, Texas, and Kansas) and helps clarify which state’s laws govern particular situations within guardianship cases.[282] The UAGPPJA provides a number of advantages:

- Provides a clear process for identifying which state may appoint a guardian for an adult who has homes in multiple states
- Facilitates the transfer of guardianships when a guardian and person subject to guardianship move from one state to another
- Enhances interstate recognition and enforcement of out-of-state guardianship orders, enabling a guardian to act in multiple states if necessary (e.g., to sell property in state B even though the person subject to guardianship lives in state A)
- Provides a simplified process for courts to communicate and cooperate with each other, making it easier for courts and parties to communicate, maintain records, and respond to requests
- Provides for emergency appointment of a guardian when a person subject to guardianship is or who is allegedly incapacitated is in a state but does not live there

The act clarifies the rights and responsibilities of states and parties in guardianship cases that cross state lines, which can help ensure greater due process for individuals subject to guardianship and save resources for families. Additionally, the law puts in place procedures that allow courts to take jurisdiction over individuals who were brought to a state through "unjustifiable conduct" or for the purposes of exploitation. The ABA collected stories of multistate guardianship issues from 2008 through 2009 that vividly detail how the UAGPPJA improves the way guardianships function across state lines. However, there may still be situations where the UAGPPJA does not provide all the answers. The goal of the UAGPPJA is in large part to allow for the easy transfer of cases from one state to another when a person with a disability moves across state lines. However, there have been well-documented problems with specialty care facilities that advertise their services across state lines to guardians who then send individuals to the facility for treatment. In some cases, there have been allegations that the facilities are not providing the best care, but the out-of-state guardian is not readily able to ascertain the problems or visit the individual regularly, and the individual may not have access to the courts in their home state or in the state where the facility is located. In that case, transferring the guardianship to the state where the facility is located could jeopardize the person's eligibility for important sources of financial support such as Medicaid waiver, state-based trust funds (e.g., for people with head injury), and worker's compensation. Additionally, a local court taking over the case of an individual who ultimately wants to and should return to their home state where they may have better natural supports may actually make it harder for the person to achieve that goal.[283] These issues were examined in a Congressional hearing in 1992.[284] However, according to a series of reports from the Center for Investigative Reporting, the problem continues unabated.[285]

> *[T]ransferring the guardianship to the state where the facility is located could jeopardize the person's eligibility for important sources of financial support such as Medicaid waiver, state-based trust funds . . ., and worker's compensation.*

Restoration of Rights

As outlined throughout the report, there are three instances in which a review for the possible restoration of rights is in order:

- When guardianship is imposed and the individual did not meet the legal standard of incapacity
- When the individual did meet the definition of incapacity but a less restrictive alternative than guardianship would have provided sufficient assistance and protection
- When an individual subject to guardianship regains capacity either due to a medical recovery or because he or she has acquired the necessary knowledge and skills to make and implement decisions

When any of these situations occur, there must be a way to restore the rights of a person subject to guardianship. Perhaps not surprisingly, although each state provides for means to terminate a guardianship and restore one's rights, there is little data on the frequency of or circumstances under which such restorations

Circumstances Warranting a Review and Possible Restoration of Rights

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- When the individual did meet the definition of incapacity but a less restrictive alternative than guardianship would have provided sufficient assistance and protection
- When an individual subject to guardianship regains capacity either due to a medical recovery or because he or she has acquired the necessary knowledge and skills to make and implement decisions

occur. One of the individuals subject to guardianship who was interviewed for this report summarized the difficulty she encountered in terminating guardianship: "I had to prove myself over and over, and over again for like six months straight that I can budget my money and all that stuff and they finally gave me my rights back. . . . it took three years to get my rights back."

ABA Commission on Law and Aging/ Virginia Tech Center for Gerontology Study

Although the lack of reliable data limits analysis, a 2017 study conducted by the ABA Commission on Law and Aging in conjunction with the Virginia Tech Center for Gerontology sheds some light.[286] Since this is the only report of its kind, this section will rely heavily on this report and its findings. Therefore, throughout this section, it will simply be referred to as the *ABA Restoration Report* or *study* for clarity.

The authors of the *ABA Restoration Report* identified and examined each state's statutes and procedures governing restoration, and analyzed reported cases going back to 1845, with a particular focus on 57 cases since 1984. An interdisciplinary roundtable of experts in guardianship, aging, and disability—including NCD staff—was convened to develop the findings and recommendations in the report. Even though the report's findings are interesting, many questions are left unanswered due to limitations in available data.

Only four states could provide data on restoration cases at the probate court level, for a total of 275 restoration cases:

- Of those 275 cases, 80 percent involved individuals who were age 17 to 59; more than 65 percent lived in their own home or the home of their family; and 70 percent had estates of less than $50,000.
- In approximately 33 percent of the cases, the reason for guardianship was mental illness, in approximately twenty percent of the cases the individual had an intellectual disability, and only a small number of cases involved people with dementia.
- In almost 75 percent of the cases, the guardianship was over both person and property.

Eighty-four of the cases were pulled from public guardianship files, and were therefore excluded from data calculations because these cases all involved guardianships with common characteristics (e.g., minimal assets and income, nonfamily guardian) that would throw off the analysis of variables the study was attempting to understand. However, from the remaining court files, family guardians were appointed 68 percent of the time, and private professional guardians or private for-profit guardianship agencies were guardians 24 percent of the time.

It's encouraging that in 40 percent of the cases, the petitioner who was seeking to have the individual's rights restored was the guardian, and often a family member. In almost as many cases, the petitioner was the individual subject to guardianship. The report also notes that the vast majority of these cases are "uncontested," meaning that no one opposes the assertion that the person should get his or her rights back—at least not as an official matter of record with the court. Additionally, in approximately 42 percent of the cases, the individual subject to guardianship was not represented by a lawyer, but since most were uncontested cases, it is perhaps not surprising that they were nonetheless successful. It's difficult to draw many conclusions from the data because it did not include cases where restoration petitions were filed but not granted. North Carolina did, however, provide the dispositions of 223 cases from 2010 through 2015. Still, among the North Carolina cases about three-quarters were successful.

The authors of the study note that:

> . . . the court file research produced a snapshot of a "successful restoration case" across states. In this typical case, the individual is about 40 years old, lives at home, has an estate under $50,000, and has a mental illness or perhaps a dual diagnosis with other conditions. The guardian is most likely a family member. After two to five years, the individual is restored, and his or her rights are returned. Either the family guardian or the individual himself or herself petitions for the restoration, and it is the first attempt. The case is not contested. The individual has no legal representation—or may have a court-appointed attorney or guardian ad litem. The case is built on a combination of clinical and lay evidence. The court restores all rights without any particular terms.[287]

The authors conclude that these cases show that the restoration process can work, but that there might be many cases in which a petition is never filed because the person, his or her guardian, or his or her family does not know that the person is entitled to seek restoration. Additionally, it was noted by some at the roundtable that there might be many cases in which the person indicates to the court that he or she would like his or her rights back but receives no response; or in which the persons asks his or her guardian for help with the process and is denied. Finally, there might be many more cases in which rights are not restored because the guardian or another person contests the petition for restoration, essentially operating as the opposing party. Far less is known about these cases and their disposition.

State Laws Vary on Restoration

The statutes in each state vary widely in key aspects of the restoration process, and as in other areas of guardianship, vary in practice from the process prescribed in statute. In the roundtable discussions, participants identified potential issues that impact the likelihood that a person subject to guardianship will have their rights restored to include the following:

- Awareness of restoration as an option
- Access to the courts

Issues Impacting the Likelihood of Restoration of Rights

- Awareness of restoration as an option
- Access to the courts
- Periodic court review of the continuing need for guardianship
- The right to counsel (and the role of appointed counsel as zealous advocate and not guardian ad litem)
- The role of the guardian in restoration cases
- The focus on supports and alternatives to guardianship
- Evidentiary standards

- Periodic court review of the continuing need for guardianship
- The right to counsel (and the role of appointed counsel as zealous advocate and not guardian ad litem)
- The role of the guardian in restoration cases
- The focus on supports and alternatives to guardianship
- Evidentiary standards

Some of these issues are addressed in the revised Uniform Act (UGCOPAA), which provides that within 14 days of appointment of a guardian, the individual and other named parties (generally family and the guardian) must receive notice of their right to seek restoration. In addition, four states already have a "bill of rights" for individuals subject to guardianship that specifically enumerate the right to seek restoration. The revised act also requires guardians to submit annual reports that, among other things, include recommendations regarding the continued need for guardianship and whether any of the individual's rights should be restored. For example, Tex. Estates Code § 1101.103 requires a physician's certificate to state whether improved functioning is possible and to state the time-frame for reevaluation.

In recognition of the fact that individuals subject to guardianship might not have the means or know-how to file a petition to have their rights restored, 20 state statutes and the revised act permit informal requests such as handwritten notes or verbal requests by an individual asking to have their rights restored. However, there is no way to know how effective these communications are, and some roundtable participants expressed concern that such requests sometimes are ignored and do not lead to formal restoration proceedings. The study does note that there were several examples of this approach being successful in the case files.

> *20 state statutes and the revised act permit informal requests such as handwritten notes or verbal requests by an individual asking to have their rights restored.*

The Role of Guardians in Restoration Cases

The role of the guardian in restoration cases can also be problematic. The report notes that ". . . it appears that the guardian's opposition may have negatively affected the disposition, as only 33 percent of petitions were successful when the guardian opposed the petition, but 50 percent were successful when the guardian was in support."[288] Some view guardian opposition to restoration petitions as a conflict of interest, especially since the estate of the individual subject to guardianship will pay for any of the activities taken in opposition to the petition. The cost of seeking restoration can be prohibitive, although some states are in the processes of amending their statutes and practices to make it less expensive. After an appellate court in Colorado concluded that a guardian can oppose a motion by the person subject to guardianship and can charge the estate of the person for doing so, the Colorado legislature revised the guardianship statute and prevented guardians from opposing or interfering with a petition for restoration sought by the individual. However, the situation highlighted by the Colorado case continues to be a problem in other states. The case law review of the report identified several cases in which the court ordered the payment of the attorney's fees of the guardian out of the estate of the person subject to guardianship, leading the authors of the report to conclude, "it appears that an individual subject to guardianship may need to not only battle the fiduciary who is appointed to act on the person's behalf, but also pay steeply for it."[289] However, some at the roundtable felt that there were circumstances under which a guardian may reasonably have a good faith belief that the person continues to benefit from guardianship, ". . . and continuing protection is needed against exploitation or undue influence."[290]

Attorneys in Restoration Cases

Another related issue is the individual's right to an attorney in restoration cases and the role of the attorney. The revised Uniform Act and 18 states require the same procedural safeguards that apply when guardianship is first sought. Twelve state statutes require the appointment of counsel when an individual subject to guardianship seeks restoration of rights. However, as with representation on the "front-end" of guardianship, the role of counsel in these cases is not always clear. As noted earlier in this report, the ABA Model Rules of Professional Conduct Rule 1.14 call for the lawyer to act in the traditional advocacy role of an attorney for his or her client even when the client has diminished capacity, unless the lawyer feels that there is a substantial risk of harm to the client. This leaves open the possibility that the attorney will independently determine that the individual continues to need a guardian and fail to advocate for his or her client's wish to have rights restored. This may spring from misguided paternalism or a genuine concern for the health and safety of the client. Regardless of the reason, the result is that the individual does not have effective counsel advocating for the individual's desired outcome. Furthermore, in the experience of some of the individuals at the roundtable, the attorney who represented the client in the original guardianship proceeding is often appointed to represent the individual when seeking to restore rights. That attorney may or may not have advocated against the guardianship in the first place and is certainly unlikely to raise arguments that are based on evidence that his or her client was erroneously determined to lack capacity in the first place.

The Restoration Report raises the question of whether legal services or Protection and Advocacy Attorneys are representing individuals seeking to have their rights restored. The report's case file research revealed that legal services attorneys represented individuals in only a couple of cases, and Protection and Advocacy (P&A) attorneys did not play a role in any of the cases examined. This result was somewhat discouraging given that the P&As are federally funded to provide legal and advocacy services for people with a variety of disabilities, so you might expect them to play a role in the restoration of the civil rights of individuals subject to guardianship. However, "A 2017 report by the National Disability Rights Network (NDRN) found that 84 percent of the 50 P&A agencies responding to a survey currently represent or could represent [people] with disabilities in guardianship issues."[291] The NDRN report goes on to note that when P&As get involved in guardianship cases, it is usually to help an individual with full or partial restoration of rights. One attorney with experience working as a P&A attorney in restoration cases who participated in the roundtable reported that, in order to get the court to allow her to represent clients for whom she had filed a restoration of capacity instead of the court-appointed attorney, she would regularly file an affidavit indicating that her client would not be charged for her services regardless of the outcome. Ironically, in several cases she reported that the guardian and his or her attorney were regularly paid out of the estate to oppose the petition for restoration. Additionally, in one case, the court effectively made the original attorney co-counsel, although he subsequently appeared as a witness and testified that the individual subject to guardianship continued to need a guardian. The individual's rights were fully restored after several hearings, but not before the attorney who testified against the petition was paid out of the estate of the individual.

While it is a positive development that P&A attorneys are getting involved in guardianship cases in recognition of guardianship as a critical civil rights issue for people with disabilities, the payment mechanisms are problematic when a publicly funded attorney is put in the position of representing a client whose money will be used to pay their opposing counsel. Given the limited availability of funding for P&As and legal services, it's common practice for attorneys in those organizations to try to recoup attorney fees from the opposing party (often the state) when they are successful. However, in guardianship cases, the only person paying for anything is often the person who is subject to guardianship, although in a few instances when the individual is indigent and the state, county, court, or other mechanism is used to pay the court costs and other fees. In most cases, unless there is proof that the guardianship was filed in bad faith or some other malfeasance occurred in the course of the guardianship, there is no one to recover from other than the individual subject to guardianship. Since P&As do not charge their clients for the services they provide, they would not be able to recoup fees and costs from the individual. Restoration cases can be very complex and time consuming, and the costs can be considerable—especially if they have to hire, and pay for, an independent expert to refute the testimony of the court-appointed expert. Under the circumstances, it's actually surprising

> *[T]he payment mechanisms are problematic when a publicly funded attorney is put in the position of representing a client whose money will be used to pay their opposing counsel.*

that P&As and legal services are willing to take these cases at all, but according to the NDRN report, many of them are. Finally, many P&As provide information to people with disabilities and their families regarding guardianship, including their right to have the need for guardianship reviewed and about the availability of alternatives. For example, the Kentucky P&A makes these resources available on their website.[292]

Evidentiary Standard/Burden of Proof

The evidentiary standard and burden of proof could also impact the success of restoration cases. According to the report, 34 jurisdictions fail to outline an evidentiary standard in statute, "leaving wide discretion for courts and uncertainty for litigants."[293] Only two states, the UGPPA, and the revised Act make it clear that all the petitioner has to establish is a prima facie case for restoration unless the opposing party submits clear and convincing evidence that the guardianship should continue. Eight states require the petitioner to prove that there is clear and convincing evidence that the person should have their rights restored, and in seven states the petitioner must meet a preponderance of the evidence standard. Mississippi leaves the decision entirely up to the judge, requiring "such proof as the chancellor may deem sufficient."[294] This lack of clear standards creates a very difficult environment for attorneys who rely on evidentiary standards not only to plan and build their case, but also to make decisions about their likelihood of success. This uncertainty unfairly prejudices the rights of individuals subject to guardianship.

The evidentiary standard and burden of proof could also impact the success of restoration cases. According to the report, 34 jurisdictions fail to outline an evidentiary standard in statute . . .

Many state standards also remain unclear whether restoration is appropriate only when an individual's capacity has been established legally, or if restoration might also be appropriate in instances in which, although the individual still meets the legal definition of *incapacitated*, a less restrictive alternative such as supported decision making is either in place or could be if the guardianship is dissolved. The recent *Ross v. Hatch* case in Virginia and *In the Matter of the Guardianship of Dameris L.* in New York, and in the 1995 case *Hedin v. Gonzalez* from Iowa stand for the proposition that guardianship may be removed if sufficient supports are in place, even if the person still meets the definition of *incapacitated* according to the state statute.

Restrictions on Restoration Efforts

Because guardianship represents a very serious curtailment of a person's liberty, it is of the utmost importance that individuals subject to guardianship be given a real opportunity to seek to have their rights restored when that becomes appropriate. However, as noted earlier, the burden of paying for restoration or even attempts at restoration generally fall on the person seeking to have his or her rights restored. Since preserving the individual's assets is one of the primary purposes of guardianship, it's perhaps not surprising that a few states curtail the ability of petitioners to file petitions for restoration of capacity. In all, 17 states either require or allow courts to specify that a petition for restoration may not be filed within a given time-frame, not to exceed one year. In a few additional states, the statute provides that a petition for restoration cannot be filed within six months after an attempt at restoration has failed.[295]

While, regrettably, these restrictions have a chilling effect on individuals attempting to file for restoration of rights, they could be necessary to protect the resources of individuals who may file numerous futile and ill-conceived petitions for restoration, sometimes influenced to do so by individuals seeking to exploit them. However, within these limitations, individuals who are subject to guardianship must have access to the courts so that the guardianship can be removed and rights restored at the earliest possible opportunity, whether it's because the decision to impose a guardianship in the first place is called into question, the individual's condition has improved, the person's functional abilities developed or have been regained, or supports and services have been identified that alleviate the need for guardianship. The authors of the restoration report note that data on the frequency of restoration is almost nonexistent, but it seems to be a rare occurrence. This raises the very real possibility that a large number of people continue to be subject to guardianship even though they have developed skills and alternatives that might allow them greater independence.

As we have noted throughout this report, continuation of the deprivation of one's self-determination through the vehicle of guardianship is a violation of one's basic civil rights and liberties unless no less restrictive alternative can be found. When an individual subject to guardianship is willing to reach out and ask the court to restore their rights, that, in and of itself, is a clear indication that the individual is keenly aware that he or she has lost something important that is worthy of pursuing restoration of, and the court systems and state laws should work in such a way as to welcome ready review of whether a guardianship remains justifiable and appropriate.

Chapter 8: Less-Restrictive Alternatives to Guardianship

Throughout this report, NCD has noted that guardianship law has evolved significantly over the past three decades. However, guardianship law, despite its reforms, has not kept pace with advances in civil rights over the past 40 years and remains a system that would be recognizable to the ancient Greeks. With that in mind, guardianship is not the only way to address some of the difficult issues that arise when a person's disability or age raises questions about his or her ability to make decisions concerning health and welfare or to manage his or her property.

Olmstead Necessitates Finding Alternatives to Guardianship

In 1999, in the *Olmstead* decision, the U.S. Supreme Court interpreted the ADA to give rise to an obligation to provide services to people with disabilities in the least restrictive environment that will meet their needs.[296] Such rights do not disappear when an individual becomes subject to guardianship. As one guardianship professional interviewed for this report concluded, "It is the responsibility of the guardian to make sure that those rights of the individual are honored and respected." Both within and outside of the guardianship context, many advocates, scholars, and legal experts are considering ways to better integrate people with disabilities into the decision making process. Leslie Salzman, a law professor who is perhaps best known for advancing the proposition that guardianship can constitute a violation of the ADA's integration mandate, has called for society to radically rethink guardianship and the whole idea of surrogate decision making:

> Rather than focusing on how to improve the guardianship process, we will consider innovative ways to integrate [people] with diminished mental capabilities to the greatest extent possible into the management of their personal and property affairs. With the appropriate level of decision-making support, [people] with disabilities will be further integrated into the "theater" of human activity and guardianship will rarely be needed and will be utilized in only the most extreme circumstances.[297]

Introduction to Alternatives

Guardianship statutes, for the most part, already require courts to look to less-restrictive alternatives before imposing a guardianship. These alternatives may be informal or formal and may themselves be restrictive. NCD's research found that guardianship can be at odds with the goals of promoting the self-determination of people with disabilities, is fraught with constitutional issues, and potentially exposes people with disabilities to exploitation; this necessitates an analysis of alternatives to guardianship. This report is not intended to describe all of the alternatives in detail, but these alternatives are important steps in the path forward for people with disabilities who need or want decision making assistance and the people who care about them.

Each of the following alternatives offers slightly different solutions that can be modified to fit the circumstances of the individual and the people in their lives. What is more important than the particular method of decision making assistance is one's commitment to understanding and incorporating the wishes and needs of the person into the decision making process, rather than focusing solely on protection. The primary alternative to guardianship should always be self-directed decision making—sometimes called *supported decision making*—which encourages individuals to access whatever advice and counsel they're comfortable with from family, friends, and professionals with whom they are in relationships of trust. However, some individuals may want or need more formal arrangements in order to implement the types of daily decisions that we all make in our lives. The circumstances of the individual, including their wishes, needs, resources, and availability of trustworthy support networks should be considered when considering alternatives to guardianship.

NCD's research found that guardianship can be at odds with the goals of promoting . . . self-determination . . ., is fraught with constitutional issues, and potentially exposes people with disabilities to exploitation; this necessitates an analysis of alternatives to guardianship.

As has been pointed out again and again throughout this report, people make bad, ill-informed decisions all the time—and some of those people have disabilities and others do not. What is clear is that some individuals need or want assistance with decision making, and they should be able to readily access effective and meaningful alternatives to guardianship that enhance, rather than undermine, their self-determination.

Although supported decision making has received a great deal of recent attention as an alternative, there are many other alternatives that have been used in lieu of guardianship for a long time, and many of them are also used in conjunction with supported decision making. Determining when an alternative to guardianship is appropriate and which one to use for which kind of circumstance or decision is no more of an exact science than determining when an individual lacks capacity and needs a guardian. As discussed in the following section, each of these alternatives carries with it the potential for misuse. However, if this report has shown anything it is that guardianship does not always offer the level of protection against abuse and exploitation that it is intended to, and the protection that it offers comes at a high price to the freedom of the individual subject to guardianship. As we move away from relying on guardianship and focus on assisting individuals with decision making rather than supplanting it, policymakers will need to explore innovative ways to prevent abuse while advancing self-determination.

This chapter will first discuss a model that has been developed by the ABA to help decide what decision making assistance a person may need. This is followed by a brief exploration of the most commonly used alternatives to guardianship and by a more extensive examination of supported decision making, which is emerging as the most promising and comprehensive alternative to guardianship.

A Practical Tool for Considering Alternatives

Four sections of the ABA, with the assistance of the National Resource Center for Supported Decision-Making, designed the "PRACTICAL" tool to assist lawyers in identifying less restrictive alternatives to guardianships. The name of this tool is an acronym that comes from the nine-step process described following this paragraph. The tool is useful for attorneys advocating on behalf of a client facing guardianship, representing families who are thinking about seeking guardianship, serving as guardians ad litem, and serving as guardians or representing guardians who are considering whether rights restoration may be appropriate given the availability of existing alternatives.

The PRACTICAL tool holds a great deal of promise for changing the way that lawyers think about their obligation to protect people with diminished capacity. Such a no-nonsense approach has the potential to operationalize finding alternatives to guardianship and to divert some would-be guardianships into less-restrictive alternatives. At the very least, using this tool provides a layer of assurance that alternatives to guardianship have been thoroughly considered and decreases the likelihood that an individual will end up in an unnecessary guardianship that unnecessarily curtails their liberty to make decisions for themselves.

PRACTICAL Steps to Identify Less Restrictive Alternatives to Guardianships

The steps in the PRACTICAL process are as follows:[298]

1. **Presume** guardianship is unnecessary. This step encourages the lawyer to assume at the outset that there may be less restrictive alternatives that can address the individual's need.
2. **Reason.** This step encourages the lawyer to consider the reason that there are concerns about the individual's ability to make decisions.
3. **Ask** whether the concern may be caused by a temporary or reversible condition. This step encourages lawyers to screen for conditions or environmental factors that may be affecting decision making ability, but which could be mitigated or reversed, alleviating the need for guardianship.

(continued)

PRACTICAL Steps to Identify Less Restrictive Alternatives to Guardianships, *continued*

4. **Community.** This step encourages the lawyer to determine whether the concerns can be addressed by connecting the individual to family or community resources that can provide support and alleviate the need for guardianship.
5. **Team.** This step encourages the lawyer to ask whether there is or could be a "team" in place that could assist with decision making and helps them identify potential supporters.
6. **Identify** abilities. This step encourages the lawyer to recognize that the person may need assistance in some areas but have strengths in others areas. This step may include getting an evaluation by a professional or using the existing capacity handbook for lawyers discussed in Chapter 5.
7. **Challenges.** This step encourages the lawyer to screen for potential challenges with the identified supports and supporters. Avoiding guardianship is not helpful if the alternative is not viable on a long-term basis or exposes the individual to potential abuse, neglect, or exploitation by putative supporters.
8. **Appoint.** This step encourages the lawyer to examine whether the person is able to appoint a legal surrogate. In such cases, the lawyer should explore ways to establish powers of attorney and health care surrogates and identify other documents that can help supporters implement decisions consistent with the individual's values and preferences.
9. **Limit.** If there are areas where no less restrictive alternatives to guardianship can meet the individual's needs, it may be necessary to move forward with a guardianship petition. This step encourages the lawyer to work to make sure the resulting order is as limited in scope as it can be.

Alternatives by Context

Financial Decisions

A recurring concern expressed in the interviews conducted for this report was the ability of some individuals to manage money and use their available and often limited resources effectively to make sure that they are able to take care of their basic necessities such as food, clothing, and shelter. The complexity of these issues varies considerably based on the type and amount of available resources an individual has. A young person with intellectual disabilities whose only monthly income comes from SSI benefits administered by the SSA will have different needs for assistance with money management than a retired person with dementia who has a sizable retirement account or pension—even though their cognitive functioning and comprehension of money management may be equally impaired. Accordingly, the options that are available may vary as well. Additionally, the source of the income will impact which alternative to guardianship is available and most appropriate.

Banking Options

One possibility that would likely be available in a broad range of circumstances falls under the general rubric of "banking options." Online banking has flourished in the past decade or so and has fundamentally changed how we all use and manage money. According to the 2016 U.S. Consumer Payment Study, only 11 percent of Americans prefer cash over debit or credit cards for most purchases, with 40 percent of Americans preferring to use credit and 35 percent preferring to use debit cards.[299] According to the study, more and more Americans are paying bills online and through automatic payments and the majority of consumers use a debit or credit card to pay recurring bills while only 14 percent write monthly checks to pay recurring bills such as rent, gas, electricity, and cable. Along these same lines, the way we interact with banks has changed. In 2016, the majority of respondents indicated that they used a mobile banking app. This shift has impacted our economy on a macro level, but it also means that—on a micro level—fewer and fewer of us regularly go into a bank to make transactions. In fact, on March 1, 2013, the treasury department stopped issuing paper Social Security checks in favor of direct deposit. From a practical standpoint, this means that many of the same people from the disability and aging populations who may be seen as lacking capacity and needing a guardian currently or will have bank accounts or prepaid debit card accounts into which their checks can be deposited. These individuals could potentially get assistance from someone they trust to help them with their banking and bill paying using a computer or mobile device. That being said, it is also true that the Federal Deposit Insurance Corporation (FDIC) found in a nationwide survey conducted with the National Disability Institute (NDI) that people with disabilities were far more likely to be considered "unbanked" because no one in their household had either a checking or savings account. Since the definition of disability that NDI used in their survey includes many individuals who would not meet the strict definition of disability used by the SSA, it's not clear what, if any, impact the 2013 law has had on the number of "unbanked" people with disabilities.[300]

Online banking and bill paying using a mobile app make it easier to get assistance with managing money, and, although they may create the potential for exploitation, the Federal Government is taking steps to address this possibility. In 2013, the Federal Reserve, the Consumer Financial Protection Bureau, the Securities and Exchange Commission, and five other Federal Government oversight bodies issued interagency guidance for banks on reporting financial abuse of older adults.[301]

This guidance clarifies the important role banks can play in curbing financial abuse and highlights previously published guidance describing suspicious activity such as unusually large withdrawals, closing of certificates of deposit and accounts without regard to penalties, and debit transactions that are out of character or inconsistent with prior transactions.[302]

Other alternatives for managing money and property for people with disabilities who may need assistance in doing so include powers of attorney, special needs trusts, and appointment of a representative payee for Social Security benefits, which will be discussed in the pages that follow. Each should be considered carefully as they restrict the person's access to their own resources and, while less restrictive than guardianship, may suffer from some of the same infirmities.

The primary advantage of powers of attorney is that they are low cost and easy to create, change, and revoke.

Powers of Attorney

A power of attorney is a written document executed under state law that allows a person or persons to represent or act on the behalf of another person (called the *principal*) in personal or business affairs or other legal matters. We often think of a power of attorney in terms of financial or health care decision making, but it can be a useful legal instrument in a variety of contexts. A power of attorney is "durable" when the document indicates that the agent's authority does not end if the person becomes incapacitated. A "springing" power of attorney only becomes effective once a certain event occurs, such as the principal becoming incapacitated, but is a type of power of attorney that is not legally recognized in some states. Although forms are often available online, powers of attorney are powerful documents that require careful consideration by the principal, who may benefit from a lawyer's advice and drafting experience, particularly in the area of finances. To be valid, powers of attorney must conform to state law requirements, some of which include notarization and witnessing.

The primary advantage of powers of attorney is that they are low cost and easy to create, change, and revoke. Powers of attorney have been used as an alternative to guardianship for older adults for a very long time; these legal instruments give people the opportunity to decide who they want to assist them as they grow older and to have meaningful conversations about important life decisions, such as long-term care and management of their property as their needs change. As one professional working in elder law who was interviewed for this report noted, powers of attorney can—assuming they are drafted well and a trustworthy agent is appointed—completely take the place of guardianship of the property.

Despite misconceptions to the contrary, many people with cognitive or intellectual disabilities also can execute powers of attorney and advance directives for health care. [303] More public education, particularly of the legal and judiciary communities, needs to be done to ensure that this legal tool—an important civil right under state law—is equally available to people with cognitive or intellectual disabilities who can knowingly and voluntarily use it. As one professional NCD interviewee stated, "We have to create education with the public [and] with judges, so that the signatures of people with disabilities will be [honored]. I think that third party [recognition] remains . . . an issue."

As is the case with guardianship, alternatives to guardianship, including powers of attorney, can be used exploitatively. The concerns include whether or not the appointed agent will follow the wishes of the person and act ethically and diligently and whether or not the lack of court supervision may put the person's safety or financial well-being at risk. These concerns are not unjustified, examples of physical, emotional, and financial abuse by agents, including family members, are not difficult to find. Some have even characterized the durable power of attorney for property is "a license to steal."[304] As a result, financial institutions can be very cautious about honoring powers of attorney, which can result in them being less effective. Powers of attorney are only as protective as the agent is trustworthy, only as effective as the willingness of third parties to accept it, and—like guardianship—do not prevent things like family power struggles over the person or his or her assets.[305]

Many debate what statutory reforms are needed to add safeguards to the use of powers of attorneys. Recent suggestions have included requiring 1) all durable powers to follow a standard statutory form with protective language (e.g., such as that within the Uniform Power of Attorney Act); 2) all durable powers to be registered with an oversight agency to be effective; 3) notice to be given to family members of such registration; and 4) increased court or governmental oversight that allows investigations if suspected abuse is reported.[306] Although these reforms are worthy of consideration, the historical unwillingness to devote greater resources to monitor and prevent abuses in guardianship suggests that there may be a similar unwillingness to devote public resources to monitor and enforce the terms of what are essentially private agreements among parties. In the end, powers of attorney are an important alternative to guardianship that gives the individual greater ability to decide who should help them make and carry out decisions and to revoke that decision if they so choose. Although there is risk of abuse with powers of attorney, guardianships also carry these risks, despite their intention to prevent it.

Trusts and Special Needs Trusts

A trust is a legal relationship wherein a person has a legal obligation to manage property—such as money, real property (land), personal property (such as jewelry), or anything else of value—for the benefit of another person.[307] A special needs trust is a particular kind of trust that can be established for the benefit of a person with a disability.[308] The assets in this kind of trust can only be used in restricted ways, but they allow the person with a disability to have access to funds that might otherwise disqualify them from a variety of benefits programs. The money or property in a trust is managed by a trustee, who determines how to manage the trust for the beneficiary or beneficiaries in accordance with the terms of the trust. Although the trustee and the beneficiary can be the same person, in situations where the goal of the trust is to manage money for a beneficiary who may need assistance, the trustee would usually be a trusted family member, friend, or professional.[309]

A trust can offer some of the same benefits of guardianship in the sense that the beneficiary cannot directly access the resources, which are therefore protected from waste and third party influence or exploitation. Additionally, trustees are obligated to comply with rules that govern fiduciary responsibility and can be legally responsible for mismanagement, which provides a layer of accountability and formality that may work well as an alternative to guardianship for some.[310] On the other hand, a beneficiary of a trust has limited recourse if he or she disagrees with the way the trustee is spending the money. For example, a beneficiary might want the money in a trust used to buy something that seems objectively reasonable, such as a new television. However, if the trustee disagrees and refuses to buy that item, there is little the beneficiary can do, provided that trustee is otherwise spending or saving the money in a prudent manner for the beneficiary's benefit. In that sense, a trust can limit the individual's self-determination as much as a guardianship of the property.

> *[A] beneficiary of a trust has limited recourse if he or she disagrees with the way the trustee is spending the money.*

Representative Payee

In the Social Security benefits context, a representative payee is a person or an organization appointed by the SSA to manage benefits for a Social Security beneficiary who is unable to manage or direct the management of those benefits. The representative payee must use the benefits to pay for the needs of the beneficiary and save any benefits not needed to meet current needs. The representative payee is also accountable to SSA for how the money is spent and must be able to report this information to SSA.

A representative payee can play an important role in ensuring that benefits are spent wisely and that they are used to support the beneficiary's needs. However, SSA has faced criticism for failing to appropriately screen and monitor representative payees and for failing to recruit suitable payees for individuals who do not have family or friends available to assist them.[311] Additionally, the determination of who needs a representative payee has been called ". . . less than scientific . . ." by former SSA Inspector General Patrick O'Carroll.[312] In other words, the representative payee program may be an alternative to guardianship that suffers from many of the same problems that are prevalent in guardianship systems.

> *[T]he representative payee program may be an alternative to guardianship that suffers from many of the same problems that are prevalent in guardianship systems.*

Health Care Decisions

Guardianship is sometimes sought because an individual is thought to be unable to make medical decisions for themselves. Often, this is because a physician or other medical professional does not feel that they can obtain "informed consent" from the person to proceed with a medical treatment, procedure, or even examination. The medical provider must be sure the patient understands the purpose, benefits, and risks of a procedure, as well as the range of treatment options, and voluntarily consents to the procedure. If the medical provider does not do so, any therapy or treatment ". . . may amount to a tort—a common law battery—by the physician."[313] If the provider does not believe the patient is capable of providing informed and voluntary consent, they may require the appointment of a substitute health care decision maker, which may in turn raise various issues depending on the age of the patient, his or her health condition (particularly if it involves reproduction or a terminal condition), and his or her relationship to the people who might naturally be available to assist with medical decisions. Parents of young adults with intellectual and developmental disabilities are often counseled to obtain guardianship lest they be shut out of their child's medical decision making or—worse—their child be unable to access medical care. However, these fears are frequently unfounded, given the number of viable alternatives usually available in the health care context.

HIPAA

Under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), a patient can voluntarily authorize disclosure of otherwise protected and confidential health information to whomever they choose, including his or her parents and other family members. If the patient is not present or is incapacitated, a health care provider can disclose information if it is in the best interest of a patient to do so. HIPAA does allow a person, including adults with disabilities, to specifically prevent disclosure of their private information, as long as they have capacity.[314] However, this should not necessarily be viewed as problematic. While we may care about loved ones and want the best for them, the purpose of HIPAA is to give individuals the autonomy to decide whom they trust to assist with health care decisions.[315]

Advance Directives

Even if a doctor does not believe that the individual has capacity to make health care decisions and therefore cannot provide informed consent, with appropriate planning, guardianship can still be unnecessary. Advance planning tools, such as advance directives, can be used to memorialize the individual's health care preferences. Advance directives detail the person's preferences with respect to certain medical interventions should they become unable to communicate them to a doctor. Most states also allow individuals to designate someone as their surrogate to make decisions for them in the event they become incapacitated and cannot make medical decisions for themselves. These tools are often most useful in the context of end-of-life decisions and are dependent on the person having capacity when they sign the document. There has been debate around exactly what level of capacity is required in order for an individual to legally execute an advance directive or health care proxy, and the answer will depend on state law and legal precedent.[316]

Advance directives detail the person's preferences with respect to certain medical interventions should they become unable to communicate them to a doctor.

Surrogate Health Care Decision Making Laws

Even in circumstances in which individuals have not had opportunity to memorialize their wishes in an advance directive, or had the requisite capacity to understand and sign such a legal document, there are ways that their families can continue to help with medical decisions. As summarized by the ABA Commission on Law and Aging, when an individual cannot make health care decisions and has not designated a surrogate to make decisions on his or her behalf, ". . . in 38 states the statute prescribes that the highest person available and willing to make health care decisions becomes the surrogate."[317] These statutes typically list natural relatives in order of priority, such as spouse, adult children, parents, siblings, ". . . and so on through the family tree."[318] When these statutes come into play, it is usually not following a judicial determination that the patient lacks capacity. Rather, it is based on the determination of the attending physician, sometimes in consultation with another physician in order to ensure that the individual is not unnecessarily being deprived of the right to make these important decisions on their own.

Florida seems to be unique in that it specifically notes that when a patient is "incapacitated *or [has a developmental disability]* . . ." his or her physician can look to next of kin to make health care decisions for the patient [emphasis added].[319] While this law seems to have been passed at the urging of parents of adults with developmental disabilities in order to facilitate their ongoing involvement in the individual's health care, it remains problematic because it presumes the incapacity of adults with developmental disabilities—disabilities which may or may not involve any cognitive impairment whatsoever—who may be perfectly capable of making their own health care decisions.

Although these statutes may alleviate the need for guardianship, they are often not taken into consideration when alternatives to guardianship are being considered. It is vital that they be understood and considered in order for guardianship to remain the last resort. Additionally, doctors and other medical professionals need to be trained to work with patients with disabilities—including intellectual disabilities, cognitive impairments, and psychiatric disabilities—and their families as appropriate to maximize the patients' ability to make their own medical decisions. There is a strong argument to be made that the ADA requires providers to accommodate people with disabilities in the decision making phase of medical treatment in the same way they are required to provide an accessible exam table, American Sign Language interpreters, or allowing a patient to bring a service animal to an appointment.

Educational Decisions

As discussed earlier, when an individual reaches the age of majority (generally 18 years of age), they are entitled to make decisions for themselves, and their parents no longer have any legal right to make decisions on their behalf or obtain confidential information unless the adult child has given permission. However, this does not mean that parents who are told by school staff that they need to seek guardianship as soon as their son or daughter with disabilities turns 18 are getting sound advice. There are several alternatives that enable parents to continue to stay involved in the education of their son or daughter after they've turned 18.

Powers of Attorney

As discussed in Chapter 6, many parents of youth with developmental disabilities are advised by school personnel that they need to obtain guardianship when their son or daughter turns 18 or face being denied a say in their adult child's education. This advice often raises concerns for parents of students who remain eligible for IDEA services through age 21. However, according to guidance from the Office of Special Education Services (OSERS):

> . . . if State law permits parental rights under the IDEA to transfer to a student who has reached the age of majority, that student can become the educational rights holder who invites family members to participate in the IEP meeting. If the adult student does not want to have that role, he or she can execute a power of attorney authorizing a family member to be the educational decision-maker.[320] The OSERS guidance goes on to suggest that supported-decision making—discussed further in the next section—is likely to be a good option in these situations as well.

". . . if State law permits parental rights under the IDEA to transfer to a student who has reached the age of majority, that student can become the educational rights holder who invites family members to participate in the IEP meeting."

Educational Representatives

In addition to the option of a power of attorney, in some states, there is a procedure for the involuntary appointment of an educational representative for an adult student who, through a process recognized in state law, is deemed unable to make educational decisions but who has not been adjudicated incapacitated. For example, in Connecticut, an educational representative can be appointed for an adult student when two professionals (e.g., physicians, psychologists, nurse practitioners) have certified in writing that the individual cannot make educational decisions.[321] While this process may make it less likely that a parent will seek guardianship in order to continue to play a role in their adult son or daughter's education, it still acts as a revocation of an adult's rights to make decisions for his or herself and with virtually no due process, which is highly problematic.

International Best Practices

Many interpret the CRPD to categorically reject guardianship. Article 12 requires Parties to the convention to "recognize that [people] with disabilities enjoy legal capacity on an equal basis to others in all aspects of life" and to "take appropriate measure to provide access by a person with disabilities to the support they require in exercising their legal capacity."[322] Countries that have signed the treaty have responded to this mandate in a variety of ways, and in many cases it is not clear how successful these evolving legal frameworks have been or whether they will have the staying power to permanently supplant guardianship. However, because the CRPD requires states to file reports describing how they are meeting their obligations, including the requirements of Article 12, advocates and policymakers in the United States will be able to track the evolution of these initiatives over time.[323] Since the federalist system in America that gives individual states the responsibility for developing and maintaining their own guardianship system is relatively unique in the world, there may be some innovations that other countries adopt that may prove more difficult for the United States to implement on a nationwide basis. However, it remains useful to examine the efforts of countries that have responded to the Article 12 mandate with effective reforms across decision making areas.

The Trend Toward the Alternative of Supported Decision Making

Supported decision making (SDM) is an emerging, less-restrictive alternative to guardianship that is currently used both within the United States and abroad. Scholars have recognized it as having the strong potential for resulting in favorable outcomes in the lives of people with disabilities,[324] and studies are underway to further verify such outcomes.

> *"[N]o one is ever truly independent. We're interdependent on one another and that's true for people with all kinds of disabilities and people without disabilities."*

Definition of Supported Decision Making

Supported decision making (SDM) generally occurs when people with disabilities use friends, family members, and professionals to help them understand the everyday situations they face and choices they must make, allowing them to make their own decisions without the need for a substitute decision maker, such as a guardian.

Definition of Supported Decision Making

Many view the CRPD as the impetus for current reform efforts to advance SDM. Article 12 of the CRPD requires signatory nations to both recognize and assist in helping people with disabilities exercise legal capacity on an equal basis to others.[325] Used by the CRPD Committee, the term *supported decision making* describes one of the ways a person can be assisted in exercising legal capacity.[326]

There is no singular definition or model of SDM.[327] However, it generally occurs when people with disabilities use friends, family members, and professionals to help them understand the everyday situations they face and choices they must make, allowing them to make their own decisions without the need for a substitute decision maker, such as a guardian.[328] SDM works in the same way that most adults make daily decisions—by seeking advice, input, and information from others who are knowledgeable and whom the adult trusts. As one interview participant explained:

> no one is ever truly independent. We're interdependent on one another and that's true for people with all kinds of disabilities and people without disabilities.

All forms of SDM operate on three core elements:

- A person's autonomy, presumption of capacity, and right to make decisions on an equal basis with others

- A person’s involvement in a decision making process that does not remove his or her decision making rights
- The recognition that people will often need assistance in decision making through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language[329]

Benefits of Supported Decision Making

SDM has the potential to provide people with disabilities the support needed to understand their options while ensuring that they still retain ultimate legal decision making authority, unlike guardianship.[330] In discussing potential outcomes of that approach, many point to studies that have found the following:

> *People with intellectual and developmental disabilities who exercise greater self-determination . . . have better life outcomes and quality of life . . .*

- People with intellectual and developmental disabilities who exercise greater self-determination—who are “causal agents” with more control over their lives[331]—have better life outcomes and quality of life,[332] including being more independent, more integrated into their communities, better problem-solvers, better employed, healthier, and better able to recognize and resist abuse. People with intellectual and developmental disabilities learn through the process of making decisions, and self-determination, if taught, can also be learned.[333] As one interviewee explained, “It’s not about protecting someone. It’s about teaching them how to best protect themselves.”
- Older adults with more self-determination have improved psychological health, including better adjustment to increased care needs.[334] Older adults with progressive dementia are more likely to retain cognitive function when they use their cognitive skills.[335]
- Self-determination has been linked to better life outcomes for youth with disabilities in foster care.[336] Additionally, outcomes for other students with disabilities are better when they are empowered to exercise self-determination.[337] Those with self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes.
- In absence of an approach like SDM, when denied self-determination, people can “feel helpless, hopeless, and self-critical,”[338] and experience “low self-esteem, passivity, and feelings of inadequacy and incompetency” and a “decrease in their ability to function.”[339]
- Although not generalizable given limited number and size, professionally evaluated pilot programs have found that SDM led to positive outcomes for participants, including greater community inclusion, improved decision making skills, increased social and support networks, and increased self-confidence, happiness, and willingness to try new experiences.[340]

Some of those interviewed for this project put the reason for using SDM into human terms. Said one interviewee, "He's a human being. He has likes and dislikes; we all do. And why do we not respect that?" Another focused on the adage that "to err is human" when the interviewee said, "We have to acknowledge that everyone, whether they have a cognitive disability [or not], make[s] bad decision[s] so we frequently have to acknowledge and respect the right for [a] person to make a 'wrong' decision."

Areas for Greater Study with SDM Models

While many studies extol the benefits of SDM models, as is the case with any alternative, there still exists the potential for unintended consequences or experiential disparities based on type of disability, which warrant further study:

- **Substituted Decisions:** Supporters in a SDM model may misunderstand their role and substitute their decisions for the person with a disability, or unintentionally lead the person to a predetermined outcome "through issue-framing, inaccurate assessment of [the person's] preferences, or simple conversations" in which the person gives deference to supporters.[345] One must ensure people with disabilities are not, in fact, disempowered through undue influence by so-called supporters.[346] Some interviewees expressed concern about the potential for abuse under a supported decision making model: "[C]ertainly using support decision-making would offer a real opportunity . . . if one or more people were inclined to take advantage or exploit an individual. And it's unclear to me what the

Supported Decision Making Furthers the Goals of U.S. Federal Policy

SDM furthers the goals of U.S. federal policy, including those under:

- The Americans with Disabilities Act, which secures the basic civil rights of people with disabilities, including the right to self-determination, community integration, and the right to receive accommodations in order to participate in a governmental programs and employment and access the services of businesses that are generally open to the public, such as doctor's offices and banks.[341]
- The Individuals with Disabilities Education Act, which mandates transition planning that should empower young adults with disabilities to make choices as they enter adulthood.[342]
- The Rehabilitation Act because individuals who are active participants in an individualized plan for employment and decisions regarding their employment generally are more likely to achieve positive employment outcomes.[343]
- Medicaid and Home and Community Based Services, which are developed with an emphasis on person-centered planning.[344]

ramifications would be beyond just general criminal laws.”

- **Court Oversight:** If an adopted SDM model requires agency or court oversight, it might have the effect of operating very similarly to guardianship (e.g., people could be subjected to continuous monitoring).[347]
- **Unwanted Assistance:** SDM may conflict with a person’s right to make his or her own decisions without support, should the model be promoted or enforced even when an adult does not want that kind of assistance at all.[348]
- **Disability-Specific Emphasis:** So far, SDM has gained more headway as an alternative to guardianship for people with intellectual and developmental disabilities, and most SDM pilot projects in the United States have targeted people with intellectual disabilities. However, SDM has not yet been embraced to the same degree as a viable option for older adults with cognitive impairments[349] or people with psychiatric disabilities.[350]
- **Application for Those with Severe Disabilities:** Likewise, further exploration is warranted regarding how SDM could work for people with severe intellectual and other disabilities.[351] As one interviewee said of her brother, “He does not use words in any form, so he does not type, he does not speak in words, he does not sign his name as a signature, and he does not use an alternative communication device. From a legal perspective, it would be very difficult for him to create alternative detailed support plans.” However, one interviewee with a different significant disability explained how SDM worked for her, using the voting context as an example: “My Mama [and I] have a system where I slap her left hand or right hand to make my choice. If I don’t slap either one, it means I don’t like either choice. So anyway, I voted three times now for president and governor.”

Under SDM, it is the person with a disability who is the decision maker. The supporter(s) solely explain(s) the issues, and may interpret the signs and preferences of the person to others based on their prior knowledge of and relationship to the individual.

How Supported Decision Making Works

When it comes to SDM, one size does not fit all. As the CRPD Committee clarified, “Supported decision-making can take many forms.”[352] Supporters may help the person understand the choices at hand, communicate that person’s decisions to others, or even “help others realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity.”[353] As the U.S. Health and Human Services’ Administration on Community Living stated regarding SDM:

> solutions . . . are different for each person. Some people need one-to-one support and discussion about the issue at hand. For others, a team approach works best.

> Some people may benefit from situations being explained pictorially. With supported decision-making the possibilities are endless.[354]

Under SDM, it is the person with a disability who is the decision maker. The supporter(s) solely explain(s) the issues, and may interpret the signs and preferences of the person to others based on their prior knowledge of and relationship to the individual. "Even when [a person] with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to [his or her] wishes."[355]

SDM arrangements need not be documented in a formal written agreement, although some are in order to encourage third parties to rely on the decision that is made.[356] The capacity to enter into an SDM agreement has been contrasted with the capacity to contract; an SDM agreement is seen not as a contract, but rather as a way in which an adult with a disability authorizes (an) other person(s) to advise and consult in that adult's decision making.[357]

In its purist form, SDM is an *alternative* to guardianship. However, the National Guardianship Association has recognized the best practice of using SDM principles *within* guardianship as well, stating that if guardianship is "necessary," "the supported decision-making process should be incorporated as a part of the guardianship."[358] Some guardians interviewed as part of this project linked guardianship with promoting SDM or restoration of legal decision making rights:

> Guardianship to me is being able to explain the situation and help the person make the decision but helping them make the most educated decision and just being there if they need somebody.
>
> Our job as guardian was to keep him safe, and to help him grow to where he could make decisions on his own with support.

Past reforms represented "tinkering with the existing guardianship system" to provide guardians with education and training on implementing person-centered decision making, enhance monitoring and accountability to ensure that goal, and assuring care and life planning for older persons and people with disabilities.[359] However, as has been previously noted, the U.N. Committee on the Rights of Person with Disabilities represents more of a departure, taking the position that any form of guardianship is inconsistent with Article 12 of the CRPD and with the spirit of SDM.[360] It remains to be seen whether SDM can coexist within guardianship or whether guardianship is anathema to SDM, but as one scholar has noted, "guardianship is here to stay, at least for now."[361] Given that fact, guardianship reform efforts, such as those by the National Conference of Commissioners on Uniform State Laws that recognize the role guardians and courts should have in "encourag[ing] the development of [a person's] maximum self-determination and independence"[362] are still worthy of promotion.

International and U.S. Support and Advancement of SDM

Internationally, SDM has gained visible momentum in academia, case law, regional courts and bodies, legislative reform, the creation of centers and institutes, nonpeer reviewed publications, conferences and symposia, and United Nations (UN) activity. At least

162 countries have ratified the CRPD, driving widespread change.[363] Among others, the governments of Canada, Great Britain, Ireland, parts of Australia, parts of New Zealand, parts of Germany, Bulgaria, Israel, the Czech Republic, Norway, Sweden, and India have either adopted or are exploring the adoption of SDM.[364] Here are a few international examples of how SDM has been adopted:

- Some Canadian providers are using a formal SDM model where a person with a disability may enter into a private legal agreement with one or more people who will provide assistance with decision making or act as formal decision making representatives for the person, with continuing and active involvement by the person.[365]
- In Sweden and some other European nations, a legal mentor or personal ombudsman can be judicially appointed to act as a decision making assistant for a person who is found incapable of making any or all their decisions alone.[366]
- In a South Australian SDM project, a person would nominate one or more people to act as a supporter and memorialize that arrangement in a non-statutory SDM agreement. An extra person (called a *monitor*) helped with the process and identified problems if they occurred.[367]

The move from substitute decision making (traditional guardianship) to SDM is a paradigm shift in how society thinks about the decision making abilities of people with disabilities,[368] and the United States has lagged behind the international community in moving that direction.[369] Not only has the United States not ratified the CRPD, but domestic guardianship reform efforts frequently "accept the predominance of a legal regime that locates decision-making in the surrogate or guardian, and not in the individual being assisted."[370] In contrast to guardianship, SDM "retains the individual [with a disability] as the primary decision maker, while recognizing [he or she] may need assistance—and perhaps a great deal of it—in making and communicating a decision."[371]

The move from substitute decision making (traditional guardianship) to SDM is a paradigm shift in how society thinks about the decision making abilities of people with disabilities, and the United States has lagged behind the international community in moving that direction.

However, as it has become increasingly clear through decades of guardianship reforms that the guardianship system has intractable problems; SDM is beginning to get a foothold in the in the United States through advocacy and discourse of constituents to legislatures and policymakers, and through the courts. For example, since 2012, court decisions favoring SDM over permanent guardianship have come out of New York, Virginia, Massachusetts, the District of Columbia, Florida, and Vermont, among others.[372] State legislatures are beginning to formally recognize SDM as well,[373] such as by enacting statutes formally recognizing SDM Agreement Forms (Texas[374] and Delaware[375]), identifying SDM as an option in special education (District of Columbia[376]) for adult students and in areas of medical decision making (Maryland[377]), and ordering SDM-related studies (Virginia[378], Maine[379], and Indiana[380]). There also exists keen interest in specifically codifying SDM as an alternative to guardianship within state laws, considering, as of August 2017, there were at least half a dozen states with pending SDM-related bills in their legislatures.[381] Moreover, SDM pilot projects have emerged in states including Massachusetts[382], Maine, North Carolina[383], South Carolina, New York,[384] and Texas,[385] among others. Vermont, for example, has convened a statewide task force of agencies working with older adults and people with disabilities designed to incorporate SDM theory and practice into its service systems.[386]

The value of promoting SDM is being recognized in federal policy, as well. In 2014, the Administration for Community Living (ACL) within the U.S. Department of Health and Human Services began funding the National Resource Center for Supported Decision-Making to conduct cutting-edge research, create educational programming, and gather and develop multidisciplinary best practices and tools to further establish SDM as a recognized and viable decision making support for people with disabilities and older adults across the United States.[387] SDM has been promoted by the American Bar Association Commission on Law and Aging[388] and the National Guardianship Association,[389] as well as a number of federal advisory bodies[390] and federal agencies, including, for example, the Department of Education.[391] SDM has also been the topic of national stakeholder summits, including those convened by the American Bar Association,[392] Quality Trust for Individuals with Disabilities, the Burton Blatt Institute, the Council on Quality and Leadership,[393] the Autistic Self Advocacy Network (ASAN), and the National Resource Center for Supported Decision-Making.[394]

This model law, known as the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA), formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship.

The American Bar Association has also formally recognized the importance of advancing SDM. In August 2017, its House of Delegates approved a resolution urging the amendment of guardianship statutes to require that SDM "be identified and fully considered as a less restrictive alternative before guardianship is imposed" and be considered a "grounds for termination of a guardianship and restoration of rights."[395]

Perhaps most exciting from an SDM reform perspective is the completion of the revisions to the UGPPA. The UGPPA was originally approved by the Uniform Law Commission in 1982, amended in 1989, and last revised in 1997. Nearly 20 states have enacted some version of the Act. A drafting committee began the process of revising the UGPPA in early 2015 and, on July 18, 2017, the Uniform Law Commission approved the resulting revisions. This model law, known as the UGCOPAA, formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship. The UGCOPAA no longer uses the term *incapacity* and requires that, in order to appoint a guardian, the court must find by clear and convincing evidence that the individual "is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive technological assistance, or supported decision-making."[396] The model law has been approved by the ABA House of Delegates and is ready for adoption by state legislatures. Given the influence that the UGPPA has had on the guardianship laws of many states and the interest in guardianship reform that seems to be developing across the country, the UGCOPAA is likely to have a strong impact on state law in the coming years.

Next Steps for Supported Decision Making as an Alternative to Guardianship

One of the greatest barriers to full adoption of SDM is the lack of reliable data specifically tying it—and not only the concept of self-determination, which has been highly studied—to improved life outcomes.[397] To better guide SDM models,[398] validated empirical evidence is needed regarding best practices in SDM, including effective and support structures and methods, and whether people who engage in SDM are more self-determined, autonomous, experience better life satisfaction, and achieve meaningful community living and participation.[399] There is also little evidence on how SDM is applied in jurisdictions in which it is used due to a lack of data collection regarding the number of SDM arrangements; of demographic data of those who use SDM and who act as a supporters;[400] and how SDM can work for people with severe intellectual disabilities and other populations, among other areas.[401] To help fill this research gap, the National Resource Center on Supported Decision-Making is currently conducting qualitative and quantitative studies to document the nature, use, barriers, and outcomes of SDM by older adults and people with intellectual and developmental disabilities,[402] the results of which are pending.

Scholars have recommended some other promising SDM-related safeguards and proposed reforms, including:

- Providing sufficient resources for widespread education on SDM to the general public, people with disabilities, third parties working with people with disabilities and supporters, and the legal and judiciary systems. There should be standards of conduct for supporters,[403] and those supporters should have access to training on what it means to support someone with decision making and how to minimize unintended undue influence. Training must help supporters understand "the total lack of any decisional power" being a supporter conveys.[404] Family members and other supporters must receive practical information to understand the fundamental philosophy behind SDM, how to use strategies of communication and conflict resolution, how to manage power differentials and the risk of undue influence, how to balance enabling rights and managing risk, and how to collaborate with other supporters.[405] Just having an SDM regime established in law is not enough.[406]
- Funding more geographically and demographically diverse projects and pilots that specifically test SDM models, and use SDM and the court systems to restore people's rights as a matter of law,[407] particularly for people who are older adults with cognitive decline, people with psychosocial disabilities, and people with severe intellectual disabilities.

- Requiring states to ensure that self-advocacy skills are included in school curricula and to support and promote self-advocacy organizations.[408] For SDM to firmly take root, it must be promoted in childhood, including within educational programming and school-to-adult transition planning.
- Placing limitations, when formal SDM agreements are used, on how or if supporters can act with regard to certain kinds of important decisions, creating legal prohibitions that would disallow supporters from acting in transactions in which they have a conflict, and ensuring the involvement of more than one supporter.[409] Using examples the New York pilot intends to apply, these safeguards could include the use of monitors, who are chosen by the person with a disability for all or some decisions, or "mentors," who can serve as the person's "constant and trusted advisor [and] a relationship with [him or her] that coincides with the progressive decline of neurodegenerative conditions."[410]
- Establishing a state or official office that has the power to investigate allegations that a supporter acted improperly and to resolve conflicts that might arise without automatically turning to more restrictive forms of intervention, like guardianship.[411]
- Funding the creation of programs that directly provide supports for people who have no one suitable to act as a supporter,[412] and writing laws and policies that facilitate access to formal and informal supports for large number of people requiring assistance with day-to-day issues.[413]

While there are numerous areas requiring future study, SDM has demonstrated promise as a comprehensive alternative to guardianship that avoids many of the widely recognized problems with guardianship's impact on people's lives.[414]

In order to achieve the promise of the ADA, we must continue to improve opportunities for people with disabilities to exercise self-determination, make choices, and take risks. While there may be steps that can be taken to improve these opportunities within guardianship, in the estimation of the Council after an extensive and thorough examination of the complex issues involved, the greatest promise lies in recognizing the legal capacity of people with disabilities on an equal basis with others in all aspects of life and in taking steps to provide access by people with disabilities to the support they may require in exercising their legal capacity.[415]

Chapter 9: Stakeholder Experiences with the Guardianship System

Overview of NCD's Qualitative Study

For this report, NCD funded an in-depth qualitative study on the use and nature of guardianship. NCD's research team worked in partnership with researchers at the Institute on Disabilities at Temple University (the Institute on Disabilities) to interview stakeholders around the country and analyze trends. The stakeholders interview included people with disabilities subject to guardianship, people with disabilities using alternatives to guardianship, family member guardians and/or supporters, and representatives chosen for their expertise in advocacy, law, court operations, and the professional services for people with disabilities. NCD's research team conducted 46 interviews that captured a wide range of life experiences and perspectives on guardianship and alternatives to inform this report. This chapter reports the analysis of those interviews, highlights salient themes, and shares some of the stories and experiences shared in the participants' own words. The full analysis can be found on NCD's website.

Methodology

From February 2017 through April 2017, the NCD research team, in partnership with the Institute on Disabilities, conducted and analyzed a total of 46 qualitative interviews. The participants were identified through extensive outreach to the members of the advisory boards established for this NCD project; the National Resource Center for Supported Decision-Making; public and private guardians; and national and local disability, self-advocacy, and aging networks. Researchers used a snowball sampling process, in which existing participants recruited future participants from among their acquaintances. The research team used of this style of sampling rather than a probability sampling process in order to reach individuals who would have otherwise been difficult to involve. Selection of participants also factored in their geographical diversity, individual characteristics, level of need for support, and individual experience.

Research Sample

The original goal was to interview a balanced sample of 10 participants from each of the four categories. However, despite widespread outreach, there were challenges in locating people subject to guardianship who were able to be interviewed. Reasons for this likely are related to complications associated with getting the approval from the guardians involved,[416] constraints related to conducting interviews outside the District of Columbia remotely by telephone or video conference, and, in some cases, the reported severity of disability experienced.

As a result, the final tally of participants included:

a. 6 people with disabilities subject to guardianship, one of which identified as being under "partial" guardianship and another that identified as having a plenary guardianship subsequently changed to a limited one;

b. 12 people with disabilities using alternatives to guardianship, including at least 3 who had previously been subject to guardianship but had subsequently had their rights restored;

c. 16 family member guardians and/or supporters; and

d. 12 representatives chosen for their expertise in advocacy, law, court operations, and professional services for people with disabilities.[417]

The participants included residents of California, Delaware, the District of Columbia, Florida, Georgia, Illinois, Kentucky, Kansas, Massachusetts, Minnesota, New York, North Carolina, Pennsylvania, Texas, Utah, Virginia, Washington, and Wisconsin. Participants included people and/or family members of people with ID/DD, acquired and/or traumatic brain injury, psychosocial disabilities, sensory and physical disabilities, and dementia. Some participants reported the presence of co-occurring disabilities. Given that the goal of 40 interviews was exceeded and there is obvious diversity of category and within each category, the interviews provide excellent data to analyze.

Interview Questions

The interview protocol that the NCD research team developed included input from the project's advisory committee members. The research team developed four sets of interview questions, one for each of the four participant categories. The interview questions address the project's previously identified research questions, which provided a general framework for the issues to be explored. The research questions NCD sought to answer were as follows:

1. Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?
2. Is supported decision making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?
3. Are people with disabilities who may need decision making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?
4. How does guardianship impact people with disabilities and their families? Does guardianship help improve outcomes of health, safety, and protection for people?
5. How does the current use of guardianship align or conflict with other U.S. national disability policy goals and initiatives, including the goals of the ADA and its community integration mandate and principles of due process under the law?

Interview Method

The interviews were semistructured in nature to allow the interviewer and participant to engage in a formal interview while simultaneously encouraging the exploration of unique issues and topics that emerged during the interview. The interviewers were trained to tailor their questions to the specific respondent and/or interview context and situation. The goal was to solicit the broadest array of information, opinions, and ideas. The protocol was designed to keep the interview length to no more than one hour, although some actual interviews exceeded that time frame or were broken into multiple interview sessions at the participant's preference. The protocol emphasized the voluntariness of the interview and the openness of the dialogue—that is, that there were no right or wrong answers, that the participant did not have to answer any questions he or she did not want to answer, and that the participant could take a break from or end the interview at any time.

Due to the geographical diversity of the participants, most of the interviews were conducted by telephone or videoconferencing, while others were conducted in person. Two participants asked to submit their responses in writing as an accommodation. The interviewers were all law students at the American University School of Law's Disability Rights Law Clinic,[418] under the supervision of NCD's research team. They were trained on how to use the interview protocol, conduct a qualitative interview, and accommodate people with disabilities. A third-party contractor recorded and transcribed the interviews and then the NCD research team redacted personally-identifiable information to protect the privacy of the participants. The research team next analyzed the electronic transcripts of each interview, the notes that the interviewer took during the course of the interview, and email communications about aspects of the interviews from interviewers to the project coordinator.

Analysis and Salient Themes

After reviewing and analyzing the interviews and other documents, NCD researchers were able to point out themes that emerged from the data from each of the four categories of participants and organized those themes based on the research questions posed by NCD. The Institute on Disabilities also analyzed the interview results within each participant category, grouping separately the interviews of people with disabilities subject to guardianship, people with disabilities who used alternatives to guardianship, family member guardians and supporters, and professional representatives.

Treatment Within the Legal System

Across participant category, NCD's research identified three salient overarching themes regarding the treatment of people with disabilities within the legal system of guardianship. These themes were that:

- Judges do not fully appreciate what guardianship is, how it limits people, and what other alternatives are available.
- There are differences between legal rights and how people experience the legal system, actors, and spaces in practice.
- People with disabilities are not adequately assessed in terms of their ability to make decisions and function.

The results of the data analysis for each participant category are discussed as follows.

People with disabilities subject to guardianship

NCD's research found that people with disabilities subject to guardianship expressed positive, negative, and neutral reactions about their treatment within the legal system with respect to guardianship.

There were people who described positive experiences with their lawyers, in court and/or with their guardians. For example:

- One person in her early 40s described being under a "partial" guardianship since she turned 18 and identified as having a developmental disability. Her parent served as her primary guardian, with other family members serving as successor guardians, if needed. She said: "[Guardianship] was my choice. [I wanted] somebody available to help with things, and [I] am glad I do. I don't think I would change it."

Other people subject to guardianship had negative experiences, which included being prohibited from accessing money and changing guardians, inattentive lawyers, and lack of an explanation of rights. For example:

- One person, who was a veteran and reportedly had psychosocial disabilities and a history of substance abuse, reported: "I had a lawyer. Someone got him [for me.] . . . He made me sign the papers. If I had known what this was about, I would never have signed the papers. He never checked up on . . . me. He just dumped me . . . I don't need no damn guardian." This participant indicated that his lawyer did not represent him in the way he wanted, that he did not get adequate opportunity to talk to his lawyer before the guardianship hearing, and that he did not know if the lawyer told the judge what he wanted because he did not go to court. However, this participant was aware that he could go back to court to ask that his guardianship be removed, and he said he planned to do that.

> *"I had a lawyer. Someone got him [for me.] . . . He made me sign the papers. If I had known what this was about, I would never have signed the papers. He never checked up on . . . me. He just dumped me . . . I don't need no damn guardian."*

People with disabilities using alternatives to guardianship

NCD research found that people with disabilities using alternatives to guardianship, including those who had had their guardians removed and their full rights restored, had no positive responses to the treatment of people with disabilities within the legal system with respect to guardianship.

In terms of negative responses, participants reported that society took for granted that every person with disabilities requires guardianship. For example:

- One person with a significant developmental disability stated: "At my IEP meetings during high school, the school told my parents they needed to get a guardianship of me, so that they could still make decisions for me . . .

Just because I do not talk doesn't mean I'm incompetent."

Additionally, some interviewees felt that the legal system, courts, lawyers, and evaluators did not spend enough time to adequately assess an individual's level of function. For example:

- One woman with a psychosocial disorder who had been under state guardianship at one point in her life reported: "I did [have an attorney] but I only spoke to him for about 10 minutes, about an hour before we went to court. . . . He just read over my reports and said, 'Oh, it doesn't look good.'"

These interviewees also noted the lack of education they received on their civil and legal rights and defined *guardianship* as the taking away of a person's rights.

> *"At my IEP meetings during high school, the school told my parents they needed to get a guardianship of me, so that they could still make decisions for me . . . Just because I do not talk doesn't mean I'm incompetent."*

Family member guardians and/or supporters

NCD's research found that family member guardians and supporters expressed positive, negative, and neutral reactions regarding how people with disabilities are treated within the legal system with respect to guardianship.

Multiple participants described the court experience as positive, stating they felt the person with disabilities was respected—although sometimes absent—and that the person's rights, including right to seek revocation of the guardianship, were reviewed. For example:

- One family guardian reported that her son was treated "very politely" in the court process. She went on to say: "He had his own representation. He did have a lawyer. They only met right before. My lawyer shared all that information with this other attorney, and they met privately before coming in, so I wasn't there. I couldn't answer questions for him or deter questions or anything like that. . . . And . . . our guardianship judge, . . . he's been great. . . . he's not pro-guardianship, he's pro-family . . . he's not someone that I can't approach."
- Another family guardian reported: "[T]he judge that did our proceedings, I thought did a marvelous job. . . . [H]e was very good in explaining to us what this meant, that it's serious—taking people's rights away—and I thought he was very good."

Many interviewees indicated that the people with disabilities did not, in fact, understand the legal proceedings, that their rights and the nature of the legal process were not adequately explained to them, and that their legal counsel had limited communication with them. For example:

- One guardian said: "[T]he judge had said to [my daughter], 'Do you want guardianship or do you not?' . . . [and] she said, 'Sure, yes, I'll have guardianship.' But I don't think [she] really understood what was happening in the court system at that particular time."
- Another guardian said: "We never had a hearing and never went to court. Because

of [my daughter's] disability, people totally ignored that . . . But she had someone represent her who was appointed by the state who came in and spent 10 minutes talking to us. [Because my daughter does not communicate verbally], the lawyer did not [know] how to communicate with her [and] then signed off on the guardianship, and we never went to court."

- One former guardian of her son, who had his rights eventually restored, reported: "[T]he lawyer that the court appointed . . . came for 2 hours, never went to his job site, never went to where he volunteered to actually see him moving about and being functional." She went on to say that the court focused on her son's diagnosis and did not "take the time to actually study who's [in front of them] and their functionality."

"[T]he lawyer that the court appointed . . . came for 2 hours, never went to his job site, never went to where he volunteered to actually see him moving about and being functional." She went on to say that the court focused on her son's diagnosis . . .

Another retired judge agreed: "[M]uch of the procedural protections that are provided in the [guardianship] statute are ignored."

Some interviewees who were family members and/or supporters described the person subject to guardianship as being seen as not a full person and not existing in the eyes of the law. Some defined *guardianship* as the "closest thing to the death sentence" and "like being in prison."

Professionals

NCD's research found that the professionals interviewed had positive, negative, and neutral reactions regarding how people with disabilities are treated within the legal system with respect to guardianship.

There were professionals that saw the legal system as designed to protect the rights, including legal representation and due process, of people with disabilities, but noted that research is needed to better understand how that system actually works in practice and how people with disabilities experience it. For example:

- One senior law attorney with decades of experience in guardianship policy concluded: "[W]e got the laws in pretty good shape. The concern is a less than vigorous recognition of those due process rights in some courts."
- Another retired judge agreed: "[M]uch of the procedural protections that are provided in the [guardianship] statute are ignored."

A few professionals noted the need to promote, where necessary, limited rather than full guardianships and/or conservatorships. For example:

- One professional stated: "I think that guardianship is much more palatable as something that we have in a country that believes in individual freedom and liberty when it's limited to actual needs as opposed to when it's general and premised on the notion that people are globally incompetent." He went on to say that it was important to look at rights not as a "bundle of sticks . . . that you either give or take away. [It's about] looking at those sticks individually in determining only which decision-making capacity [that] individual lacks and taking only those [rights] away."

Some professionals remarked that, within the legal system, people with disabilities are treated not as individuals, but as stigmatized stereotypes; receive variable due process, without adequate legal representation; and are not adequately assessed in terms of their capability to make decisions and function. For example:

"[P]eople [in guardianship proceedings] who are entitled to representation get somewhere between okay and crap . . .

- One professional concluded: "[P]eople [in guardianship proceedings] who are entitled to representation get somewhere between okay and crap . . . Pro bono programs are primarily for parents and practitioners in getting the cases into court and not for representing the people with disabilities . . . There's no provision for counsel in [my state's] statute [for people with developmental disabilities].
- One professor, who also had experience being a guardian for his adult child stated: "I worry about whether the hearings are rubber-stamped formal or whether they are genuine interrogations [and] inquiries . . . "

Some interviewees who are professionals also reported that judges and lawyers have inadequate training, understanding, and experience with the needs of people with disabilities. For example:

- One developmental disability service provider stated: "I understand there's very little teaching in law schools around disabilities and so they don't really get disabilities and they don't get guardianships and what it may mean for the person with the disability."
- One law professor further explained: "[T]he way the [guardianship] laws were established [are] based on kind of a presumption of incompetency depending on the person's label of disability . . . I don't think the legal system treats people well. In the guardianship process, I think judges may want to do the right thing, but they don't know enough about the [disability] themselves to understand that, even if someone has a label of intellectual disability . . . or can't even speak . . . [they] still may be able to make decisions for themselves so long as they can get the support that they need."
- For one professional interviewed, it came down to values: Judges may be "less likely to care about the due process issues and less likely . . . to value the individuals in front of them" because of a priority on expediency and judicial economy.

Not all professionals agreed:

- One attorney at a public guardian agency stated that she has "seen some good judges say, 'Wait a minute . . . do you ever want to drive, do you want to vote, do you want to do these things? . . . Are you okay with your mom making your decisions?'"

Additionally, in terms of guardianship, there were professionals who argued that the expectation should always be the least restrictive intervention in terms of decision making support; and a presumption of competence. Professionals also noted that education about rights should be personalized and not limited to the courtroom. For example:

- "There needs to be a special attention given to and the way that people learn information and especially in the setting that or the circumstance that needs to be individualized to some degree or as much as possible to accommodate the various ways in people and people with disabilities can understand that kind of information."
- "[I] don't think being in a stressful courtroom should be the first time that that discussion is being had, I think [it] . . . can be very intimidating for people."

One attorney at a public guardian agency stated that she has "seen some good judges say, 'Wait a minute . . . do you ever want to drive, do you want to vote, do you want to do these things? . . . Are you okay with your mom making your decisions?'"

Supported Decision Making

NCD's research identified two salient overarching themes among the interviews when it came to supported decision making:

- No support system, including guardianship and supported decision making, is free from risk of exploitation or abuse.
- For people with significant support needs, supported decision making might not be as easy to implement well.

The analysis results for each participant category are discussed as follows.

People with disabilities subject to guardianship

NCD research found that people with disabilities subject to guardianship expressed positive and neutral reactions regarding supported decision making as a viable alternative to guardianship.

Participants responded positively to the definition of supported decision making, although many were not previously familiar with the term. Some described a relationship with their guardian as akin to the supported decision making model. For example:

- "If I don't understand something all I have got to do is tell [my guardian] and she will help me understand it."

People with disabilities using alternatives to guardianship

NCD research found that people with disabilities using alternatives to guardianship expressed positive reactions regarding supported decision making as a viable alternative to guardianship.

Participants recognized that all people rely on natural supports to understand and make decisions and sometimes make poor decisions and that, in that sense, people with disabilities should be seen as no different than people without disabilities. For example:

- One person said: "I think there are people with and without disabilities who make really bad decisions and would benefit from someone helping them learn how to live healthier and safer lives. To me, supported decision-making is what really good family and friends do. It's having conversations with each other about needs and wants and coming to a decision with their help when needed. My mama still gets helps from my grandpa and grandma when she has a big decision to make. Buying a car, having surgery, taking a new job. We all need each other [and should] respect our rights to make the final decision."

> *A mother who uses supported decision making with her son said: "He's a human being. He has likes and dislikes; we all do. And why do we not respect that?"*

- Another person said: "I believe that people should be able to make their own decisions, but they also have to deal with the consequences of the decisions they make. If someone is there telling another person what they should do, . . . they're not going to be able to make their own judgments about situations and figure out their own problem-solving for certain situations."

Family member guardians and/or supporters

NCD research found that family members and/or supporters expressed positive, negative, and neutral reactions regarding supported decision making as a viable alternative to guardianship.

There were family members who described supported decision making as a form of self-determination. They reported that most people can and should have the right to make their own decisions and that people with disabilities should be involved in the decision making process. For example:

- A mother who uses supported decision making with her son said: "He's a human being. He has likes and dislikes; we all do. And why do we not respect that?"
- Another participant who supports her adult cousin with multiple sclerosis emphasized his right to make his own decisions: "[H]e had a hospitalization . . . in which . . . the hospital staff were recommending that he move from [the] hospital to . . . a residential rehab facility. And he didn't want to go. He said, 'I want to go home.' . . . I really don't think it's a good decision, but it's his decision and he's decided he wants to go home, so I will make sure that he has all the support in place."
- A guardian said: "I don't make any decisions for my son without him—without talking to him about it. . . .[I]f he doesn't have to buy in [to a decision], then it's going to be a lot harder for me to deal with that decision and getting it to be accepted and make it happen. . . . [H]e knows . . . if there's something he wants to do, he can come and . . . we can talk it through. Is it realistic? Sometimes it is, sometimes it isn't."

Additionally, family members asserted that, because supported decision making tends to rely on natural supports, the people with disabilities using it will be engaged with their community, which will in turn enable them develop skills necessary to receive the information they need to weigh the benefits and risks of potential decisions. In addition, community members will hold each other accountable for the kind of support that is provided, which will also guard against conflicts of interest. For example:

- One family member said: "I do believe that's a better way to go when there is a group of people, because the way we supported [my son] is that we do build a circle of support around him so that people know and understand what his hopes and dreams are for the future."
- Another said: "[I]f you have supported decision-making and the person could still keep their rights, . . . if there's a small group of people [supporting the person], hopefully, they would hold each other accountable [and include] some family members so that . . . people [involved] have similar values. . . . I think there's some level of safety in that."

However, there were also those who expressed concern that third-party providers, such as doctors, may be less likely to listen to people with disabilities who are using supported decision making as opposed to their guardians. One interviewee remarked that, although learning decision making through experiences with it was important, supported decision making is not ideal for people who do not use verbal communication. Another participant also noted that supported decision making only works when everyone involved is open, honest, and believes in community. For example:

- "[I]f a person cannot speak up for themselves, how do we ensure that they have equity? How do we ensure that he is not just left sitting as he is in a corner in a chair alone 24 hours a day? Supported decision making won't take care of that."
- "I really hate saying [this] because I think everyone can make decisions on some level. But [for] some of the very larger ones . . . we know that she is unable to process all of that."

"I think supported decision-making can be alternative outside of guardianship as well as a component within an appropriate . . . guardianship."

Professionals

NCD's research found that professional experts expressed positive, negative, and neutral reactions regarding supported decision making as a viable alternative to guardianship.

Positive responses considered supported decision making the "gold standard," part of what it means to become an adult, and an empowering way to maximize autonomy, self-control, and self-esteem. Some saw supported decision making as a way people can make decisions consistent with their own goals and values and lead happier and healthier lives. Others commented:

- "I think supported decision-making can be alternative outside of guardianship as well as a component within an appropriate . . . guardianship."

- "That's what we should be focused on, that no one is ever truly independent. We're interdependent on one another and that's true for people with all kinds of disabilities and people without disabilities."

Negative responses about supported decision making noted that it, as well as other alternatives to guardianship, such as powers of attorney and representative payees, still affords opportunities for abuse and exploitation. For example:

- "I'm not sure that . . . supported decision-making is going to make a difference one way or the other in terms of preventing . . . abuse. . . . We want to allow people to make mistakes and to be like everybody else but sometimes the cost to somebody with a disability is . . . being abused and taken advantage of . . ."
- "Well, frankly, I don't know that anybody knows what [supported decision-making] exactly means. . . . [Y]ou're to get . . . people around this person and then you support what their decisions are and . . . , unless the person has only the physical disability, I think that's pretty stupid. Now that doesn't mean we don't do supported decision-making all the time as a guardian, [but] we have some controls over that [to be sure about] what makes them safe and what might . . . put them at risk . . . We don't do [something] just because they say [so] because, at the end of the day, if we help facilitate somebody doing something that puts them at risk and they get hurt, guess who's liable? Me."

They also raised concerns about supporters imposing their own beliefs on the person.

- With supported decision making, "what you're supposed to do is help facilitate the person to make their own decision, but if your facilitator has very strong belief about what this person should or not be doing, it's hard to imagine how they're going to be a very effective facilitator."

Neutral reactions included calls for training on supported decision making and more safeguards against abuse and exploitation. It was also noted that parents may find it particularly difficult to transition to allowing their adult child to use supported decision making.

Access to Information About the Guardianship Process and Possible Alternatives

NCD's research identified two salient and overarching themes regarding whether people with disabilities and their families are being provided with information about the guardianship process and possible alternatives. These themes are as follows:

- People with disabilities, family members, and professionals agree there is not enough high quality and accessible information available about alternatives to guardianship, particularly supported decision making. Often, people are presented with guardianship as the only option.
- While many people are not familiar with supported decision making as a formal concept, they are engaging in it and benefiting from it.

The analysis results for each participant category are discussed as follows.

People with disabilities subject to guardianship

NCD's research found that people with disabilities subject to guardianship expressed positive and neutral reactions regarding information about guardianship and its alternatives.

There were people subject to guardianship who responded that their guardian provides them with information as needed. For example:

- One person, who was in his mid-50s, has an acquired brain injury and hearing impairment, and whose sister serves as his guardian, stated: "I like having a guardian . . . They look after me and take good care of me, make sure I'm doing nothing wrong and make sure I'm taking my medicine . . . They make sure that everything I do I go the right [way] in doing it and . . . make sure that I'll be happy. I have no complaints about the way they treated me."

So, you got a lot of parents that . . . will then rush to go get guardianship and then, once they get it, and they actually realize, 'Oh, my goodness, my son or daughter no longer has rights,' then they can't get that overturned."

Many respondents reported that they were not familiar with alternatives to guardianship or did not know whether they were ever offered or explained.

People with disabilities using alternatives to guardianship

NCD research found that people with disabilities using alternatives to guardianship expressed positive, negative, and neutral reactions regarding the receipt of information about guardianship and its alternatives. Some interviewees had received information about guardianship and its alternatives through the school system or community-based programs. Others did not specify how they learned about guardianship and its alternatives.

Negative reactions called for more personalized education and training on decision making and money management for people with disabilities, their supporters, the educational system, and the broader community. Some saw the educational system as pushing parents into becoming guardians without informing them of other options. For example:

- "[P]arents are told that when their child turns 18 and they don't have a guardian, they won't be able to make medical decisions, they . . . won't be able to support their loved ones. So, you got a lot of parents that . . . will then rush to go get guardianship and then, once they get it, and they actually realize, 'Oh, my goodness, my son or daughter no longer has rights,' then they can't get that overturned."

Family member guardians and/or supporters

NCD research found that family members and supporters received a range of information about guardianship and its alternatives. Some learned about decision making options, such as supported decision making, power of attorney, and representative payee, through case managers, community programs, and their own jobs. Others only received information about guardianship from their child's school or legal professionals and were never presented with options other than guardianship. For example:

- "[T]he information does not come to families or individuals. You have to go seek it out yourself and I think that's part of, I think there's just a lot of misinformation and no information."
- "I would love to get out of guardianship but have been unable to. . . . We received guardianship when she was 18 because we were told that was the right thing to do. . . . I was told that because [my daughter's disability] is so severe and she's also nonverbal . . . that we should assume guardianship for her at the age of 18, and this was by the school . . . I think that parents who made decisions years ago without options should now . . . be able to go back and have the opportunity that parents have now of putting one of less-restrictive options into effect."
- "[M]y husband and I questioned, 'Why do we need to get guardianship? We will always see that he's cared for properly and all of that,' but [we were told] that was the practice."

"I think that parents who made decisions years ago without options should now . . . be able to go back and have the opportunity that parents have now of putting one of less-restrictive options into effect."

Some reported that they had been engaging in supported decision making, but were not familiar with the term. Others expressed concern about the potential for there to be abuse and exploitation outside of guardianship. Others described applying supported decision making in select situations. For example:

- One guardian said: "When it's appropriate I ask what [my daughter's] choice is and go with her choice. . . . When it's over her head and she won't be able to comprehend a decision, then we make it for her in her best interest."

Professionals

NCD's research found that the professionals interviewed also had a range of positive, negative, and neutral responses regarding information about guardianship and its alternatives.

Some professionals asserted that the public is generally aware of both limited and full guardianship and that many learn about it through their peers and affiliations with organizations knowledgeable about it, so there is a need for self-advocacy. Others felt that information on decision making processes was inadequate or nonexistent, and that such information should be presented not only in legal settings, but also schools and health settings.

- One professional indicated that guardianship was the main option presented to families of people with developmental disabilities: "When your child is 18 years old, you had better be in court and getting that guardianship, bingo bango, just like that."

Other professional experts remarked that information dissemination varies from case to case and state to state.

Impact of Guardianship

NCD research identified two salient and overarching themes from the interviews with respect to the impact that guardianship has on people with disabilities and their families.

- Guardianship can be overly restrictive in its effect.
- Guardianship can improve the lives of those supporting the person with disabilities, but it does not necessarily improve the life of the person subject to guardianship.

The analysis results for each participant category are discussed as follows.

> *"[I]t was a real eye-opener when I got to ask my wife, 'Would you marry me?' I didn't have to go to my mom [to get permission] and say, 'Hey, ma, I asked that girl, will she marry me?'"*

People with disabilities subject to guardianship

NCD research found that people with disabilities subject to guardianship had positive, negative, and neutral reactions to how guardianship impacts them and their families and improves health and safety outcomes.

Some interviewees described positive experiences in which their guardians assisted them in managing their finances, answered their questions, or protected them from making poor decisions. For example:

- One person, who was in her early 60s and had a psychosocial disability, reported liking her public guardian: "They help me with my money and stuff and make sure that my bills are paid and stuff like that." She went on to say: "I said, 'I don't want nobody to take advantage of me no more.' I said, 'I'm safer with you, [Public Guardian].' I told her that she is an angel from heaven and she is." She also explained how her guardian helped her get some of her rights restored.

Others felt negatively or neutral about being subject to guardianship. One person felt that guardianship led people to underestimate their intelligence. Another did not feel any significant change to his or her life since being subject to guardianship.

People with disabilities using alternatives to guardianship

People with disabilities using alternatives to guardianship had negative and neutral reactions to how guardianship impacts people and their health and safety.

Many interviewees disliked the lack of control people have over their decisions and finances when they are subject to guardianship. For example:

- One man with a developmental disability described the self-worth that came from making his own decisions: "[I]t was a real eye-opener when I got to ask my wife, 'Would you marry me?' I didn't have to go to my mom [to get permission] and say, 'Hey, ma, I asked that girl, will she marry me?'"
- A woman in her 20s said: "I felt very uneasy over the idea of someone else having

> control of my life. . . . It makes me feel sad, and sometimes even irritated, because the guardian can always make decisions for the person, and what if the person wants something different than what the guardian wants? . . . I would feel kind of like a prisoner, knowing that all my decisions were up to someone else."

One interviewee recounted that, when she was subject to guardianship, she was psychologically, verbally, and physically abused by staff at a hospital. She went on to say that, to her, guardianship "means prison on the outside of the prison."

Another interviewee shared that she felt that being subject to guardianship has an effect on a person's development of decision making ability: "I think [my friend who is subject to guardianship] has trouble making her own decisions because she always just seems to go with what her guardian wants, and never really seems to question it."

"I have legal guardianship over my son but it's just there. It's just sitting there on a shelf. . . . [I]t's just there as a safety net . . . So, I can sleep more soundly knowing that . . . the police couldn't come to my door, take him away in handcuffs and not have to speak to me."

Neutral responses noted that the impact of guardianship varies case by case.

Family member guardians and/or supporters

Family members and/or supporters had positive, negative, and neutral reactions to how guardianship impacts people and their health and safety.

Positive reactions included assertions that that guardianship means there will be court oversight, which will provide the people subject to it some protection from exploitation. Others noted that guardianship gives the guardians themselves greater peace of mind. For example:

- "[W]e had a major incident and went to the hospital. And the hospital said that they would give all the information [about my brother] to the [residential] provider about what happened and they would not give that information to me . . . It was part of the reason I took guardianship."
- "I have legal guardianship over my son but it's just there. It's just sitting there on a shelf. . . . [I]t's just there as a safety net . . . So, I can sleep more soundly knowing that . . . the police couldn't come to my door, take him away in handcuffs and not have to speak to me."

Others saw guardianship as a way of supporting the decision making of the person subject to it, while allowing the guardian to act on the person's behalf in the event he or she is incapable of making a certain decision. For example:

- One family member guardian stated: "I first of all make sure that people speak to [my son, who has a traumatic brain injury], because often, because he doesn't speak, people assume that he's not bright enough to understand and that they address me, because I'm his guardian. And . . . as a human being, he has a right to be addressed . . . and not spoken about [but] spoken to."

Many negative responses argued that neither guardianship nor any support system can totally protect a person from exploitation, and that the lack of checks and balances within guardianship can actually foster exploitation and abuse. For example:

- "My daughter is just as safe even if I didn't have guardianship. I'm still her mother and there's still people in the community that were looking after her with or without guardianship. I don't think guardianship makes any difference on your safety. Just having that piece of paper doesn't make you safer."
- "[My daughter] says you can [try and] bubble wrap people, but that's still not going to stop them from getting into trouble. . . . Sometimes those things just happen. [Your] piece of paper that says [you have a] guardian isn't going to stop things."

"Actually, what I know now is that she's not [considered by others to be] a real person anymore, that she really doesn't exist except for what I allow her to have and what I allow her to do, . . . as a guardian."

- "Guardianship is not going to be a bubble around you that protects you completely. . . . The problem with guardianship, in general, is the extent of authority that people do have over other people and the potential for exploitation and abuse . . . [T]here have been some gosh awful stories about guardians [and others] who . . . exploit. They take . . . [people's] government benefits or whatever other money, and they lock people in . . . a closet and don't take care of them."
- "[G]uardianship can make people more vulnerable. . . [T]here's a possibility that others might find that person more vulnerable if they knew that somebody else was somewhat overseeing their decision making or their health or anything like that. I think it puts them in a more vulnerable position."

Many saw guardianship as negatively impacting people's health and happiness and forcing them to live the lives the guardians wanted for them. " For example:

- "It's going to be about what's best for the agency or the guardian and that's not necessarily the best for the person."
- "Actually, what I know now is that she's not [considered by others to be] a real person anymore, that she really doesn't exist except for what I allow her to have and what I allow her to do, . . . as a guardian."

Neutral responses reported that the pros and cons of guardianship vary on a case by case basis. For example:

- "[I]t can be good and it can be bad. It all depends on the guardian. If . . . there had been people that had been [subject to] guardianship because they're in very poor health, because they haven't been taking their medicine or whatever, and once they get the guardian in place, and when they get the health fund[ed], they can restore their lives."

Professionals

Professional experts had positive, negative, and neutral reactions to how guardianship impacts people and their health and safety.

There were professionals who asserted guardianship ensured people subject to it had their needs met; were protected from exploitation and abuse; and were served by outside providers, such as those in health care, housing, and finance arenas. For example:

- "[T]here are lots of situations where guardianship or conservatorship is absolutely wanted and I think to take that tool away would be bad for a bunch of different reasons."
- "[S]ome people are very happy to get the help. They know they can't handle things anymore and they're cooperative."

"I think guardianship can be an effective tool for some people . . . [I]t's simpler to have guardianship. It's more complicated to have conversations."

- "[W]hen a guardianship is appropriate is when a person . . . is putting themselves at serious risk or being financially exploited. For somebody who is financially exploited, oftentimes the guardianship is the only way to protect them. . . . I've gotten some self-neglect cases . . . [where] one person was almost dead by the time they were removed from the house and another had a long history of signing himself out AMA from various facilities and such. . . . [I]f we are looking at people who are putting themselves at risk and not open to any other options . . . the only choice is guardianship."
- "I can't give you case examples but I would say that most guardianships provide positive outcomes for the individual . . . We don't have the data [but] it's [likely] a miniscule percentage of the overall number of guardianship cases that are problematic."

Others saw guardianship as improving the lives of those surrounding the person with disabilities without necessarily improving his or her own life. For example:

- "[T]he threat of guardianship . . . if you have problems because of cognitive impairment, the help you're going to get is, 'We're going to take away your rights.' That causes a lot of people to absolutely deny that they have a problem to accept any help when the problem might be much more easily managed."
- "[I]f I get a guardianship, I don't have to argue with mom anymore about whether she should move or . . . whether she can still drive or whatever. I don't have to argue with her anymore. I can just tell her."
- "I think guardianship can be an effective tool for some people . . . [I]t's simpler to have guardianship. It's more complicated to have conversations."

Negative reactions stated that guardianship does not eliminate abuse, but can generate hostility, dehumanize and disempower people subject to it, and negatively impact family relationships and natural supports. For example:

- One professional with a background in long-term care and adult guardianship through a state division of aging services said: "[I]t doesn't make sense to me that you take rights away from an individual to help them." She went on to say: "I've run into quite a few people [subject to guardianship] who have said, 'I am not a person anymore.'"
- An attorney, law professor, and consultant on disability-related issues said: "[G]uardianship creates a category of people who are not considered as legal people." She went on to say: "I don't think people are going to necessarily be exploited or hurt if there is no guardianship anymore. People are exploited and hurt right now with guardianship. Let's try a different way." She noted that guardianship could also detrimentally impact decision making skills of youth with disabilities: "When guardians are appointed for someone with an intellectual disability at the age of 18, they are denied the opportunity to learn how to make decisions of the critical years of their lives."
- Another added: "I think it is a terrible affront to human dignity to take away somebody's ability to make basic life decisions and cut them out of the conversation, if they are able to participate in any way."

"[I]t doesn't make sense to me that you take rights away from an individual to help them."

Others pointed to the fact that abuses can occur within guardianship:

- One interviewee stated: "[W]ith guardianship . . . you always have the potential for somebody to abuse their powers. . . . You can have an incredibly protective parent that gets a guardianship and is convinced that [example person] can never cross the street so [example person] doesn't flourish and grow . . ."
- Another participant, who was part of a service provider for people with developmental disabilities stated: "[P]eople have sort of succumbed to the power of the guardianship that made terrible choices for people. They've ripped people off, neglected people, have isolated people, and so I've seen the worst kinds of guardianships . . . ."
- An attorney for a public guardian agency described abusive guardianship situations in which her office was asked to intervene: "[In] many other cases [we] were brought [in] where there's an existing guardian [that] either somehow failed to complete their duty [or] they misappropriated money or they didn't do what they were supposed to do and they've neglected the person or abused the person in some way."

Neutral reactions contended that any support system requires a process for ensuring there are no conflicts of interest.

National Disability Policy Goals and Initiatives

NCD's research identified two salient and overarching themes from the interviews with respect to the impact that guardianship has relating to U.S. national disability policy goals and initiatives:

- Good guardians support and advocate for people subject to guardianship in ways that align with disability policy goals.
- Guardianship can also inhibit an individual from living a full, integrated life.

The analysis results for each participant category are discussed as follows.

People with disabilities subject to guardianship

People with disabilities subject to guardianship had positive, negative, and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives.

Multiple people subject to guardianship reported that guardianship did not impact their day-to-day lives, where they lived, or their community involvement. Others disagreed. For example:

> *"I thought . . . they would just help us handle our money and everything, [but] we are in servitude to them with their workers. . . . I don't mind a little help . . . , but when they control my life every day, tell me where to go, what time, when to shave, when not to shave . . . I do not like this guardianship."*

- Guardianship is "a lot different from what I thought. I thought . . . they would just help us handle our money and everything, [but] we are in servitude to them with their workers. . . . I don't mind a little help . . . , but when they control my life every day, tell me where to go, what time, when to shave, when not to shave . . . I do not like this guardianship."

People with disabilities using alternatives to guardianship

People with disabilities using alternatives to guardianship had negative and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives. Interviewees stated that guardianship impacts where people subject to it can live, what they can do, who they can associate with, how they are treated, and how integrated into the community they are. For example:

- "Well, it's good because . . . I'm still living by myself, choose who to come and who not to come and I still being able to choose what I want to eat, when I want to eat it . . . So, my life, it's just like everyone else's right now."
- "Sometimes, when we protect people, we shelter them. So this is why I say, sometimes guardianship can be a hindrance because we never give somebody the chance to make even the small decisions from what they want to eat or what they want to wear. Then, you run the risk of them never ever being able to make a decision."

Neutral responses asserted that all forms of decision making requires varying levels of support depending on the extent of the person's disability.

Family member guardians and/or supporters

Family members and/or supporters had positive, negative, and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives.

Some expressed that guardianship supported people's civil rights and ensured they are safe and can build decision making skills. For example:

"Our job as guardian was to keep him safe, and to help him grow to where he could make decisions on his own with support."

- "Our job as guardian was to keep him safe, and to help him grow to where he could make decisions on his own with support."

Others indicated that they supported the person with disabilities to choose for themselves where they lived, what they wanted to do, whether and how they wanted to vote, and whether or not they wanted to get married.

A number of interviewees described guardianship as an invasion of civil and human rights that creates stigma, lowers expectations, and negatively impacts how others act toward people with disabilities. There were participants who asserted that people subject to guardianship are hindered from living a full life that is integrated within the community. For example:

"[T]he idea of me declaring him incompetent is kind of the opposite of everything we're striving for . . . [D]eclaring someone to be incompetent takes away their personhood and in a sense makes them a piece of property."

- "I don't think anyone should have guardianship. I think everyone deserves civil rights no matter what your level of understanding is. I assumed because my daughter is nonverbal, I have to assume that she understands everything and I think that's how we should think of everyone."
- "[T]he idea of me declaring him incompetent is kind of the opposite of everything we're striving for . . . [D]eclaring someone to be incompetent takes away their personhood and in a sense makes them a piece of property."
- "[G]enerally speaking, the public is still paternalistic and maternalistic towards people [subject to] guardianship. 'Oh, you poor little person, you've got [a disability], you can't do this and you can't do that, and yadda, yadda, yadda.'"

Neutral responses recognized that the experiences of people subject to guardianship can vary—some can be empowered and others can be disempowered by it.

Professionals

Professional experts had positive, negative, and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives.

Some interviewees argued that guardianship aligns with disability policy goals in that good guardians support and advocate for the person in a way that helps him or her be integrated. For example:

- "The good guardian is going to ensure that there is integration into the community[,] . . . that they receive the socialization, the community interaction, the community respect that they are do and that's what a good guardian does."

Other interviewees asserted that guardianship impinges on a person's civil rights, correlates with social isolation, and as a result conflicts with disability policy goals, such as the ADA. For example:

- "By definition, if you are not the person making decisions, your ability to be a real member of the community [is] smaller . . . [I]n most instances, guardianship violates the inclusion mandate of the ADA and the *Olmstead* principle."
- "[Guardianship is] never going to allow that person [subject to it] to really become integrated to community because [others are] going to have to be always checking" with the guardian, not the person.

A neutral reaction noted that focusing on the dignity and autonomy of people with disabilities can fix the problems of guardianship and inequality faced by that population.

Chapter 10: Findings and Recommendations

Throughout this report NCD has noted that while guardianship exists to protect individuals who may need assistance managing their affairs or who may need protection from abuse, neglect, or exploitation, it also undermines the ability of people with disabilities to exercise self-determination often without sufficient due-process to say definitively that the individual lacked the capacity to make decisions for themselves. Additionally, in some cases, guardianship may create conditions that lead to exploitation rather than protecting vulnerable individuals from it. As NCD examined the ongoing efforts of the past several decades to rectify some of the well-recognized problems in guardianship, it became clear there are no easy answers or perfect solutions to these complex issues. However, the Council makes the following findings regarding the current state of guardianship and offers recommendations that we believe would improve the lives of people with disabilities who may need decision making assistance and prevent them from being placed into unnecessary or overly restrictive guardianships as well as improving court oversight of existing guardianships to prevent abuse, neglect, and exploitation.

Finding 1: There is a lack of data on existing guardianships and newly filed guardianships.

Most states do not track on a statewide basis how many individuals are subject to guardianship, much less describe those guardianships in terms of basic demographic information, whether the guardian is a professional or family guardian, the extent of the guardian's authority, the assets involved, and other basic questions that would help policymakers and stakeholders make determinations about what reforms may be needed in guardianships or where resources should be directed to improve guardianship outcomes for people with disabilities.

(continued)

Recommendations:

NCD recommends that Congress and the Administration develop initiatives to produce effective and comprehensive data on guardianship. There are two ways production of this data should be approached:

- Federal agencies such as the SSA, the CMS, the VA, SAMHSA, and other relevant agencies should collect data on whether or not individuals they serve are subject to guardianship.
- States should be offered incentives and technical assistance with developing electronic filing and reporting systems that collect basic information about guardianships from the moment a petition is filed. A searchable, computerized system for aggregating information on adult guardianship cases would not only yield better usable data on guardianships, but would also improve that ability of courts to monitor and audit individual guardianships. Systems such as the "My Minnesota Conservator" reporting and data project are already in use in a few states and could be adopted across the country. Data collected must be detailed enough to allow for drawing conclusions and should include demographics, type of guardianship (limited vs. plenary, guardian over property vs. person, etc.), type of guardian (public guardians, private professional guardian, family guardian), age at which the person was subject to guardianship, court audits, timeliness of reports, amount of funds/property in the estate, and the involvement of the person in federal programs (Social Security benefits, SSI, Medicaid, Medicare, VA benefits, etc.). The data should also include whether the initial petition was contested, whether there is any time limitation to the guardianship, and whether there is any periodic review of the continued need for guardianship.

Finding 2: People with disabilities are widely (and erroneously) seen as less capable of making autonomous decisions than other adults regardless of the actual impact of their disability on their cognitive or decision making abilities. This can lead to guardianship petitions being filed when it is not appropriate and to guardianship being imposed when it is not warranted by the facts and circumstances.

Recommendations:

- The DOJ, in collaboration with the HHS, should issue guidance to states (specifically Adult Protective Services [APS] agencies and probate courts) on their legal obligations pursuant to the ADA. Such guidance should address NCD's position that: 1) the ADA is applicable to guardianship proceedings; 2) the need for assistance with activities of daily living or even with making decisions does not give rise to a presumption of incapacity; and

(continued)

3) guardianship should be a last resort that is imposed only after less restrictive alternatives have been determined to be inappropriate or ineffective.

- In January 2017, the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) issued school-to-adult transition-related guidance that recognized alternatives to guardianship, including the use of supported decision making and powers of attorney for adult students with disabilities. While this policy development is promising, OSERS needs to do more to ensure consistent implementation of this guidance across state and local educational agencies—for example, the creation of model supported decision making and powers-of-attorney forms geared toward transition-age youth. School transition teams must inform parents/caregivers and students of less-restrictive decision making support options for adults, rather than promoting the overuse of guardianship or involuntary educational representatives.
- The Department of Education Office of Special Education Programs (OSEP) should instruct Parent Training and Information Centers to prioritize and provide meaningful training on school-to-adult transition and alternatives to guardianship.
- HHS should issue guidance regarding the responsibility of medical professionals and hospitals to accommodate the needs of individuals who may need assistance making medical decisions and to adequately explain procedures and draft documents provided to patients in plain language.
- Although the Federal Government generally leaves the content of medical school training to the accrediting bodies, federal advisory group recommendations and federal grants from CMS, HHS, and other federal agencies can influence the content of medical training and curriculum. Educating medical professionals about the ADA and the need to accommodate people with disabilities, including those with intellectual disabilities and cognitive impairments, should be prioritized as a part of medical training.
- The National Home and Community-Based Services Quality Enterprise (NQE) should include decision making assistance and use of alternatives to guardianship such as supported decision making in their priorities and include best practices as part of its resources, training, and technical assistance.
- The Administration for Community Living (ACL) has funded numerous projects that are geared toward expanding alternatives to guardianship, such as supported decision making. The agency also provides state grants to enhance adult protective services. Such funding should be allocated specifically to assist state adult protective services systems to develop greater awareness of ways to enhance the self-determination of adults considered vulnerable or in need of services, as well as the availability and use of alternatives to guardianship.

(continued)

- The Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities (UCEDDs), and the Protection and Advocacy (P&A) organizations should link work that has been done on advancing the self- determination of people with ID/DD with avoiding guardianship. There needs to be recognition that the appointment of guardians is not necessarily the preferred outcome for people with disabilities. Such appointments instead can be the result of systems failing to fully recognize people's right to direct their own life and to support them in developing self-determination and communication skills, use and build natural support networks, and have access to less-restrictive alternatives. . UCEDDs in particular have a role in educating physicians, medical professionals, and parents of people with ID/DD on self-determination, SDM, and other alternatives to guardianship.

Finding 3: People with disabilities are often denied due process in guardianship proceedings.

Guardianship is viewed as a benevolent measure that is sought in the best interest of people with disabilities and/or older adults who are seen as needing protection. Guardianship cases are often dispensed with as quickly as possible with little concern for due process or protecting the civil rights of individuals facing guardianship.

Recommendations:

- The Elder Abuse Prevention and Prosecution Act (P.L. 115-70) calls upon the Attorney General to publish best practices for improving guardianship proceedings and model legislation relating to guardianship proceedings for the purpose of preventing elder abuse. The Attorney General's model legislation should incorporate the UGCOPAA, including its provisions for preventing unnecessary guardianships.
- To ensure that due process requirements are met, it is especially important that alleged incapacitated individuals facing guardianship have qualified, independent legal representation that will advocate for the individual's desired outcome, especially if that person expresses a desire to avoid guardianship or objects to the proposed guardian. However, many courts lack sufficient resources to fund this type of representation and families often find that such representation is cost-prohibitive. Federal grant money should be made available to help promote the availability of counsel.

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- A state guardianship court improvement program should be funded to assist courts with developing and implementing best practices in guardianship, including training of judges and court personnel on due process rights and less-restrictive alternatives.
- The degree of due process provided in a guardianship matter should not be contingent on the type of disability that is the alleged cause of an individual's incapacity or inability to make and carry out decisions. The DOJ should take the position that such practices are discriminatory on the basis of the ADA.

Finding 4: Capacity determinations often lack a sufficient scientific or evidentiary basis.

Courts rely too heavily on physicians who lack the training, knowledge, and information needed to make an accurate determination.

Recommendations:

- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), National Institutes of Health, and other agencies that fund scientific research should provide grants to researchers who are trying to develop a better understanding of how people make decisions and how a variety of conditions—such as dementia, intellectual disabilities, brain injuries, and other disabilities—impact the ability of individuals to make and implement informed decisions.
- *Capacity* is a social and legal construct that is not necessarily provable or disprovable through scientific methods. Resources also should be geared toward developing functional approaches to capacity assessments that take into account the possibility that someone may need decision making assistance but not necessarily a surrogate or substitute decision maker.

Finding 5: Guardianship is considered protective, but courts often fail to protect individuals.

In some cases, guardians use their position to financially exploit people or subject them to physical neglect and abuse. Courts lack adequate resources, technical infrastructure, and training to monitor guardianships effectively and to hold guardians accountable for the timely and accurate submission of required plans, accountings, and other reports, as well as for conforming to standards of practice for guardians.

(continued)

Recommendations:

- The court improvement program proposed earlier could also enhance the ability of courts to monitor guardianships and should include the adoption of programs such as My MNConservator, which requires guardians to file reports electronically, allows for the flagging potential problems in filed accountings, and facilitates the periodic audit of guardianship files.
- Although professional and family guardians can both be the perpetrators of abuse in guardianship, there have been several high-profile cases of abuse by professional guardians. In most states, these professionals operate with minimal oversight except by the court. States should be provided with incentives to establish statewide boards that can provide for the accreditation and oversight of professional guardians.
- States should require family guardians to undergo training to ensure they understand their ongoing responsibilities to the person subject to the guardianship and to the court.

Finding 6: Most state statutes require consideration of less-restrictive alternatives, but courts and others in the guardianship system often pay lip service to this requirement.

Courts often find that no suitable alternative exists when, in fact, supported decision making or another alternative might be appropriate.

Recommendations:

- ACL currently funds the National Resource Center for Supported Decision making and several demonstration projects at the state and local levels. These grants should be expanded to be able to fund more geographically- and demographically-diverse projects and pilots that specifically test SDM models and use SDM and the court systems to restore people's rights as a matter of law, particularly for people who are older adults with cognitive decline, people with psychosocial disabilities, and people with severe intellectual disabilities.
- The DOJ should make funding available to train judges in the availability of alternatives to guardianship including, but not limited to, supported decision making. This training should also include information about the home and community-based–services system and the workforce development system so that judges understand the context in which decisions are being made by and for people with disabilities. See Finding 3.
- It's important that states adopt provisions of the UGCOPAA that recognize alternatives to guardianship can be used in place of guardianship even when it is determined that the individual meets the definition of incapacity. DOJ should develop guidance to this effect.

Finding 7: Every state has a process for restoration, but this process is rarely used and can be complex, confusing, and cost-prohibitive.

Data on restorations is seriously lacking, making it impossible to tell how many individuals are in unnecessary guardianship or whether individuals who would like to try to have their rights restored have access to information about their right to restoration, receive an appropriate response to their request for restoration, or have access to resources and representation to assist them in that effort.

Recommendations:

- As a part of the effort to improve data collection and monitoring, electronic filing and auditing systems ought to include data about restoration, including whether the individual was given information about restoration and whether the continued need for guardianship was reviewed by the court.
- The state court improvement program referenced throughout these recommendations should include improvements to the restoration process. DOJ should publish guidance regarding the right to restoration and best practices.
- A grant should be given to the Protection and Advocacy system to provide legal assistance to individuals who are trying to have their rights restored or avoid guardianship.

Appendix A: Table of Authorities—State Guardianship Statutes

AL	Ala. Code. T. 26, Ch. 2A, Art. 1-2	MT	Mont. Code Ann. T. 72, Ch. 5, Pt. 1-6
AK	Alaska Stat. Ann. T. 13, Ch. 26, Art. 1-6	NE	Neb. Rev. Stat. Ch. 30, Art. 26, Pt. 1-5
AZ	Ariz. Rev. Stat. T. 14, Ch. 5, Art. 1-8	NV	Nev. Rev. Stat. Ann. T. 13, Ch. 159
AR	Ark. Code. Ann. T. 28, Subpart 5, Ch. 74 Art. 1-5	NH	N.H. Rev. Stat. Ann. T. XLIV, Ch. 462-465
CA	Cal. Prob. Code §§ 1400-1490; 1500-1611; 1800-1970; 2100-2893; 2900-2955.	NJ	N.J. Stat. Ann. T. 3b, Ch. 12, Art. 4-7
CO	Colo. Rev. Stat. Ann. T. 15, Art. 14, Pt. 1-5	NM	N.M. Stat. Ann. Ch. 45, Art. 5, Pt. 1-4
CT	Conn. Gen. Stat. Ann. §§ 45a-591 to -602; 45a-628 to -705a	NY	N.Y. Mental Hyg. Law §§ 81.01 to 81.44; N.Y. Soc. Serv. Law §§ 473-d to -e
DE	Del. Code Ann. T. 12, Ch. 39, Subpart I-VII	NC	N.C. Gen. Stat. Ann. Ch. 35A, Subch. I-IV
FL	Fla. Stat. Ann. T. XLIII, Ch. 744, Pt. I-VIII	ND	N.D. Cent. Code Ann. T. 30.1, Art. V, Ch. 30.1—28
GA	Ga. Code Ann. T. 29, Ch. 1-11	OH	Ohio Rev. Code Ann. Sup. Rule 51, Form 15
HI	Haw. Rev. Stat. T. 30A, Ch. 560, Art. V, Pt. 1-6	OK	Okla. Stat. Ann. T. 30, Art. 3
ID	Idaho Code Ann. ST. T. 15, Ch. 5, Pt. 1-6	OR	Or. Rev. Stat. Ann. T. 13, Ch. 125, Art. 1-5
IL	Ill. Comp. Stat. Ann. Ch. 755, Act. 5, Art. XIA	PA	Pa. Cons. Stat. Ann. T. 20, Ch. 55, Subch. C-F
IN	Ind. Code Ann. T. 29, Art. 3, Ch. 1-13	RI	R.I. Gen. Laws Ann. T. 33, Ch. 15.2
IA	Iowa Code Ann. T. XV, Subpart 4, Ch. 633, Div. XIII, Pt. 1-7	SC	S.C. Code Ann. T. 62, Art. 5, Pt. 1-7
KS	Kan. Stat. Ann. Ch. 59, Art. 30	SD	S.D. Codified Laws T. 29a, Ch. 29A-5, Pt. 1-5
KY	Ky. Rev. Stat. Ann. T. XXXIII, Ch. 387	TN	Tenn. Code Ann. T. 34, Ch. 1-8
LA	La. Rev. Stat. Ann. T. 13, Ch. 24, Pt. I-V	TX	Tex. Est. Code T. 3, Subt. D-I
ME	Me. Rev. Stat. T. 18-a, Art. V, Pt. 5-a, Subpart 1-5	UT	Utah Code Ann. T. 75, Ch. 5, Pt. 1-6
MD	Md. Code Ann. T. 13, Subpart 2 & 7, Pt. II	VT	Vt. Stat. Ann. T. 14, Pt. 4, Ch. 111
MA	Mass. Gen. Laws Ann. T. 2, Ch. 190B, Art. V-5a	VA	Va. Code Ann. T. 37.2, Subt. IV, Ch. 10-10.1
MI	Mich. Comp. Laws Ann. Ch. 700, Art. V, Pt. 1-5	WA	Wash. Rev. Code Ann. T. 11, Ch. 11.88-11.92

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MN	Minn. Stat. Ann. Ch. 252A	WV	W. Va. Code Ann. Ch. 44A, Art. 1-5
MS	Miss. Code. Ann. T. 93, Ch. 14, Art. 1-5	WI	Wis. Stat. Ann. Ch. 54, Subch. I-VII
MO	Mo. Ann. Stat. T. XXXI, Ch. 475	WY	Wyo. Stat. Ann. T. 3, Ch. 2, Art. 1-3
DC	D.C. Code Div. III, T. 21, Ch. 20, Subpart I-VI		

Appendix B: Developmental Disability Specific Guardianship Statutes

AZ	Ariz. Rev. Stat. T. 36, Ch. 5.1, Art. 1	KY	Ky. Rev. Stat. Ann. T. XXXIII, Ch. 387.550-387.880
CA	Cal. Health & Safety Code Div. 1, Pt. 1, Ch. 2, Art. 7.5	MI	Mich. Comp. Laws Ann. Ch. 6, Sec. 330.1600-330.1644
CT	Conn. Gen. State Ann. §§45a-669 to -684	MN	Minn. Stat. Ch. 252A, Sec. 252a.01-252a.21
FL	Fla. Stat. Ann. T. XXIX, Ch. 393	NY	NY Surr. Ct. Pro. Act Law Ch. 59-a, Art. 17-a Sec. 1750
ID	Idaho Code Ann. T. 66, Ch. 4	SD	S.D. Cod. Laws T. 29A, Ch. 29A-5, Pt. 1-5
IA	Iowa Code Ann. T. XV, Subt. 4, Ch. 633, Div. XIV, Pt. 1		

Appendix C: Contact Information for WINGS Groups*

ACL Project WINGS	
Alabama	Bob Maddox; bob.maddox@alacourt.gov
Alaska	Stacey Marz; smarz@akcourts.us
Florida	Tina White; whitet@flcourts.org
Idaho	Nanci Thaemert; nthaemert@idcourts.net
Indiana	Erica Costello; erica.costello@courts.IN.gov
Oregon	Bryan Marsh; Bryan.B.Marsh@ojd.state.or.us
Utah	Karolina Abuzyarova; karolinaa@utcourts.gov
SJI Supported WINGS 2013	
New York	Jean Callahan; JCallahan@legal-aid.org
Oregon	Bryan Marsh; Bryan.B.Marsh@ojd.state.or.us
Texas	David Slayton; David.Slayton@txcourts.gov
Utah	Karolina Abuzyarova; karolinaa@utcourts.gov
SJI Supported WINGS 2015	
District of Columbia	Anne Meister; anne.meister@dcsc.gov
Indiana	Erica Costello; erica.costello@courts.IN.gov
Minnesota	Anita Raymond; araymond@voamn.org
Mississippi	Desiree Hensley; desiree.c.hensley@gmail.com
Washington	Stacey Johnson; Stacey.Johnson@courts.wa.gov
Additional WINGS-Type Groups*	
Maryland	Nisa Subasinghe; Nisa.Subasinghe@mdcourts.gov
Massachusetts	Wynn Gerhard; wgerhard@gbls.org
Missouri	Dolores Sparks; dsparks@moddcouncil.org
Montana	Sarah McClain; smcclain@mt.gov
North Carolina	Linda Kendall Fields; lkfields@email.unc.edu
Pennsylvania	Cherstin Hamel; Cherstin.Hamel@pacourts.us
West Virginia	Jennifer Taylor; jtaylor@lawv.net
Wisconsin	Andrew Bissonnette; bissonnetteandrew@yahoo.com
Virginia	Paul DeLosh; pdelosh@vacourts.gov

*Georgia, Guam, and Ohio also have WINGS-Type groups, but contacts for those groups were not readily available.

Appendix D: Attorney Representation in Initial Guardianship Cases

State	Entitlement to Appointment of Counsel in accordance with UGCOPA Sec. 305(a), Sec. 406(a)*		Statute specifies the advocacy role of Counsel in accordance with National Probate Court Standard 3.3.5(B)†	
Ala.	Yes	Code of Ala. § 26-2A-101(b); 26-2A- 135(b)	No	Code of Ala. § 26-2A-102(b); 26-2A-135(b)
Alaska	Yes	Alaska Stat. § 13.26.231	Yes	Alaska Stat. § 13.26.246
Ariz.	Yes	A.R.S. § 14-5303(c)	No	N/A
Ark.	Yes	A.C.A. § 28-65-213	No	N/A
Calif.	Yes	Cal Prob Code § 1823(b)(6); 1470(a); 1	No	N/A
Colo.	Yes	C.R.S. 15-14-305	No	N/A
Conn.	Yes	Conn. Gen. Stat. § 45a-649a; 45a-673; 45a-681	No	N/A
Del.	Yes	12 Del. C. § 3901(C)	No	N/A
D.C.	Yes	D.C. Code § 21-2041(d); 21-2054(a)	Yes	D.C. Code § 21-2033
Fla.	Yes	Fla. Stat. § 744.331	Yes	Fla. Stat § 744.102(1)
Ga.	Yes	O.C.G.A. § 29-4-11(c)(1)(D)	No	N/A
Hawaii	Yes	Haw. Rev. Stat. Ann. § 560:5-305.	No	N/A
Idaho	Yes	Idaho Code § 15-5-303(b)	No	Idaho Code § 15-5-303(b)
Ill.	Yes	755 Ill. Comp. Stat. Ann. 5/11a-10	No	N/A
Ind.	No	Ind. Code Ann. § 29-3-5-1.	No	N/A
Iowa	Yes	Iowa Code § 633.561.	No	N/A (but see *In re Guardianship of Griesinger*, 804 N.W.2d 527, 529 (Iowa Ct. App. 2011))
Kans.	Yes	Kan. Stat. Ann. § 59-3063.	No	N/A
Ky.	Yes	Ky. Rev. Stat. Ann § 387.560.	No	N/A
La.	Yes	La Code. Civ. Proc. Ann. Art. 4544.	No	N/A
Maine	Yes	Me. Rev. Stat. tit. 18-A, § 5-303	No	N/A
Md.	Yes	Md. Code Ann., Est. & Trusts § 13-705	No	N/A (but see *In re Lee*, 754 A.2d 426, 438-39 (Md. Ct. Spec. App. 2000)

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State	Entitlement to Appointment of Counsel in accordance with UGCOPA Sec. 305(a), Sec. 406(a)*		Statute specifies the advocacy role of Counsel in accordance with National Probate Court Standard 3.3.5(B)†	
Mass.	Yes	Mass. Gen. Laws ch. 190B, § 5-106.	No	N/A
Mich.	Yes	Mich. Comp. Laws Ann. § 700.5305, 700.5306a.	No	N/A
Minn.	Yes	Minn. Stat. Ann. § 524.5-304, - 307	No	N/A
Miss.	No	Miss. Code Ann. § 93-13-255.	No	Miss. Code Ann. § 93-13-255.
Mo.	Yes	Mo. Ann. Stat. § 475.075(3).	No	Mo. Ann. Stat. § 475.075(3).
Mont.	No	Mont. Code Ann. § 72-5-315(2)(4).	No	Mont. Code Ann. § 72-5-315(2).
Nebr.	No	Neb. Rev. Stat. Ann. § 30-2619	No	N/A
Nev.	Yes	Nev. Rev. Stat. Ann. § 159.0485.	No	N/A
N.H.	Yes	N.H. Rev. Stat. Ann. § 464-A:6.	No	N/A (but see In re Guardianship of Henderson, 838 A.2d 1277, 1278-79 (N.H. 2003))
N.J.	Yes	N.J.R. Super. Tax Surr. Cts. Acts. R. § 4:86-4 (b)	No	N/A (but see N.J.R. Super. Tax Surr. Cts. Acts. R. § 4:86-4 (b))
N. Mex.	Yes	N.M. Stat. Ann. § 45-5-303(C).	No	N.M. Stat. Ann. § 45-5-303(C).
N.Y.	No	No for people with IDD: N.Y. Surr. Ct. Proc. Act Law §§ 1750; 1750-a; 1750-b Yes for people without IDD: N.Y. Mental Hyg. Law § 81.10	No	N/A
N.C.	No	N.C. Gen. Stat. Ann. § 35A-1107.	No	N.C. Gen. Stat. Ann. § 35A-1107.
N. Dak.	Yes	N.D. Cent. Code Ann. § 30.1-28-03	No	N.D. Cent. Code Ann. § 30.1-28-03(4)(c)
Ohio	Yes	Ohio Rev. Code Ann. §§ 2111.02 (C)(7)	No	N/A (but see *In re Baby Girl Baxter*, 17 Ohio St.3d 229, 232 (1985) (superseded by statute on other grounds))
Okla.	Yes	Okla. Stat. Ann. tit. 30, § 3-106(A)(7), -107	No	N/A
Oreg.	No	Or. Rev. Stat. Ann. §§ 125.025; 125.080.	No	N/A
Pa.	Yes	20 Pa. Stat. and Cons. Stat. Ann. § 5511	No	N/A (but see *In re Estate of Rosengarten*, 871 A.2d 1249, 1257 (Pa. Super. Ct. 2005)
R.I.	Yes	R.I. Gen. Laws Ann. § 33-15-7.	No	N/A
S.C.	Yes	S.C. Code Ann. § 62-5-303(b).	No	S.C. Code Ann. § 62-5-303(b).

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State	Entitlement to Appointment of Counsel in accordance with UGCOPA Sec. 305(a), Sec. 406(a)*		Statute specifies the advocacy role of Counsel in accordance with National Probate Court Standard 3.3.5(B)†	
S. Dak.	Yes	S.D. Codified Laws § 29A-5-309	No	N/A
Tenn.	Yes	Tenn. Code Ann. § 34-1-125	Yes	Tenn. Code Ann. § 34-1-125(a)
Tex.	Yes	Tex. Est. Code Ann. § 1054.001	Yes	Tex. Est. Code Ann. § 1002.002
Utah	No	Utah Code Ann. § 75-5-303(2), (5)(3)	No	N/A
Vt.	Yes	Vt. Stat. Ann. tit. 14, § 3065	Yes	Vt. Stat. Ann. Title 14-3065(b).
Va.	No	Va. Code Ann. § 64.2-2006.	No	N/A
Wash.	Yes	Wash. Rev. Code Ann. § 11.88.045(a)	Yes	Wash. Rev. Code Ann. § 11.88.045(b)
W. Va.	Yes	W. Va. Code § 44A-2-7(a)	No	W. Va. Code § 44A-2-7
Wis.	Yes	Wis. Stat. § 54.42	Yes	Wis. Stat. § 54.42(b)
Wy.	No	Wyo. Stat. Ann. § 3-1-205(a)(iv)	No	N/A

* The UGCOPAA sets out two alternative counsel provisions: A) the court must appoint a lawyer to represent the respondent if 1) requested by the respondent, 2) recommended by the court visitor, or 3) the court determines it is needed; or B) unless the respondent is already represented by a lawyer, the court must appoint one.

† The National Probate Court Standards provide that "the role of counsel should be that of an advocate for the respondent." Standards 3.3.5(B).

Endnotes

1 Robert Dinerstein, "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making," *Human Rights Brief* 19, no. 2 (2012): 9.

2 American Bar Association Commission on Law and Aging and American Psychological Association, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, 5–8, last modified March 25, 2005.

3 John Stuart Mill, *On Liberty*, 4th ed. (London: Longman, Roberts, & Green Co., 1869), 9.

4 Robert Dinerstein, "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making," *Human Rights Brief* 19, no. 2 (2012): 9.

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415 CRPD Article 12.

416 Given this was a national project involving people living in various states across the country, all with variable consent laws, the decision was made to take a conservative approach and, when a person was determined to be subject to guardianship, obtain the guardian's approval for the interview to move forward. There also were two occasions where the guardians terminated the interview after it started, so those interviews were not able to be used as part of this report.

417 Please note that there were cases in which a participant was identified to participate as a representative of one category and, during the course of the interview, it became apparent they actually fit into multiple categories (e.g., a professional who was also a family member of a person with a disability).

418 The law student interviewers included Allison Mazzei, Myra Reyes, Abigail Silverman, and Emily Wolfford.

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

Turning Rights Into Reality:

How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities

National Council on Disability

June 10, 2019

National Council on Disability (NCD)
1331 F Street NW, Suite 850
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National Council on Disability, June 10, 2019
Celebrating 30 years as an independent federal agency

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The views contained in this report do not necessarily represent those of the Administration, as this and all NCD documents are not subject to the A-19 Executive Branch review process.

National Council on Disability
An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

June 10, 2019

President Donald J. Trump
The White House
1600 Pennsylvania Ave. NW
Washington DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit this report, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* as a follow-up to a report that was completed last year, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities*, which offers policy research and recommendations for the consideration of your Administration and Congress. This report provides a more in-depth examination of the unique challenges faced by individuals with intellectual and developmental disabilities (ID/DD), and how the use of alternatives such as supported decision-making may enable some individuals with ID/DD to exercise greater self-determination, participate more fully in their communities, and achieve greater economic self-sufficiency.

In this report, NCD examines why people with ID/DD are at increased risk for becoming subject to guardianship as adults, and how that impacts their ability to benefit from civil rights laws aimed at advancing the self-determination and opportunities available to people with ID/DD, including the Americans with Disabilities Act, the Individuals with Disabilities Education Act, the Developmental Disabilities Act, and the Workforce Innovation and Opportunity Act. The report also examines how people with ID/DD are treated differently than other adults who are the subjects of guardianship proceedings, including in several states that have separate guardianship laws for people with ID/DD. Finally, the report examines the available data on guardianship for people with ID/DD and highlights the stories of people with ID/DD in the nation's capital to increase policymakers' understanding of the impact of guardianship and alternatives to guardianship on the lives of people with ID/DD.

We hope that this report will increase the understanding of guardianship and its impact in the lives of people with ID/DD and their families across the Administration and in Congress. The report includes recommendations for the Social Security Administration, as well as the U.S. Departments of Education, Justice, and Health and Human Services. NCD stands ready to work with you and your Administration to ensure that Americans with ID/DD are provided with viable alternatives to guardianship if they need decision-making assistance, and that the due process protections they are afforded when they are faced with a petition for guardianship are robust and will avoid the unnecessary removal of civil rights.

Respectfully,

Neil Romano

Neil Romano
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the House of Representatives.)

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Contents

Glossary

ABLE Accounts: A type of tax-advantaged savings account, established under the Achieving a Better Life Experience (ABLE) Act of 2014, for people with significant disabilities that began before they turned 26 and who meet the Social Security Administration's (SSA) definition of disability. Eligible individuals who are the owner and designated beneficiary of the ABLE account can use funds from the account to pay for qualified disability expenses, which are defined in the ABLE Act and its regulations. The first $100,000 in ABLE accounts are exempted from the individual's resource limit for Supplemental Security Income (SSI). ABLE accounts are disregarded for the purpose of determining if a person meets the asset limit for Medicaid. For more information, visit http://ablenrc.org/.

Adjudication: The process of a judicial determination; an adult under guardianship has generally been "adjudicated" to lack *capacity*.

Adult: An individual who is at least 18 years of age.

Advance Directive: A witnessed document or documents that a person can use to provide instructions regarding their desires and preferences about medical treatment in the event the person becomes *incapacitated*. Such medical treatment may include, for example, life-prolonging treatment or psychiatric treatment during a crisis. Often, an Advance Directive will include a power of attorney and a health care surrogate designation.

Agent: A person with the legal authority to act on behalf of another.

Alleged Incapacitated Person (AIP): A person who is the subject of a petition to determine capacity or guardianship, but who has not yet been adjudicated *incapacitated*.

Annual Accounting: A report filed by a guardian of the property that some states require to be submitted to the court each year itemizing expenditures and receipts made on behalf of the person. Some states allow the court to waive this requirement, particularly if the only income the person has is Social Security and the guardian is also the representative payee of such funds.

Annual Guardianship Plan: A report filed by the guardian of the person that some states require to be submitted to the court each year specifying the medical, mental, and physical care of the person in guardianship for the upcoming year.

Attorney ad Litem: An attorney who is appointed by the court to act as a legal advocate in the best interest of a child or *incapacitated* adult. Unlike attorneys in a normal attorney-client relationship, Attorneys ad Litem do not necessarily advocate for the desired outcome of the individual they represent, but they may advocate for an outcome the Attorney ad Litem deems is in the person's best interest.

Best Interest: A type of decision-making standard that may be used when deciding on behalf of another person, particularly in court cases involving child custody or welfare. Compared to *Substituted Judgment*, the Best Interest standard tends to prioritize the person's safety and well-being, rather than their expressed wishes. While traditionally linked with decisions made by guardians, it is now considered the less-preferred decision-making standard. For example, the National Guardianship Association's standards indicate that, "only when the person's goals and preferences cannot be ascertained, may the guardian make a decision in the person's best interest."[1]

Capacity: An individual's ability to perform a specific task, such as to sign a contract. The term also refers to the legal ability to perform an act and to subsequently be bound by the act. May also be referred to as "competency."

Case Management Services: Coordinating services through community and government agencies, the extent of which depends on the specific state.

Clerk of the Court: A court officer responsible for filing papers, administering cases, and keeping records of court proceedings. In some courts, the Clerk of the Court may play a role in reviewing accountings and reports filed by guardians.

Conflict of Interest: Situations in which an individual may receive financial or material gain or advantage from a decision made on behalf of another person, with whom they have a relationship.

Court Visitor or Monitor: A person appointed by a court to advise the court regarding whether an individual needs a guardian (and, if so, who it should be) or to report to the court whether an existing guardianship continues to be appropriate or necessary, what the condition of the individual in guardianship is, or whether the decisions being made on behalf of that individual are appropriate.

Durable Power of Attorney: A durable power of attorney is effective even after the principal becomes *incapacitated* and unable to make decisions. The agent appointed by the principal in a durable power of attorney can continue to act within the scope of authority granted under this legal document.

Family Guardian: A non-professional guardian who serves as guardian for an individual. Although family guardians usually are related to the individual, they may be friends or even volunteers. Although they may be able to be reimbursed out of the individual's estate, family guardians do not serve as guardians in order to make a living. The definition of family guardian may vary from state to state.

Guardian: A person, institution, or agency appointed by a court to manage the affairs of another individual. The guardian may have the authority to manage personal and/or financial matters. Each state has specific laws that govern guardianship proceedings and the guardian's activities. States have separate laws and procedures regarding guardianship for minors and adults. States may use different terms to refer to guardians, such as *conservators*.

Guardian ad Litem: A person appointed to advise the court regarding the needs and best interests of a child or individual who either lacks *capacity* or, in some states, has been alleged to lack *capacity*.

Guardianship of the Person: A guardianship where the guardian is granted the authority by the court to make personal decisions for an individual. This means that the right to make personal decisions has been removed from the individual and transferred to a guardian. These rights may include, for example, the right to decide where to live, with whom to associate, and what medical treatment to receive or not receive.

Guardianship of the Property: A guardianship where the guardian is granted the authority by the court to manage and make decisions about another person's financial matters, benefits, real estate, and other property. This means that the right to make property decisions has been removed from the individual and transferred to the guardian. This is sometimes referred to as a *conservatorship* or *guardianship of the estate*.

Health Care Surrogate: An agent who has been given the authority to make health care decisions for a person either by the person through a *durable power of attorney* for health care or by operation of law.

Incapacitated: The current term used by most courts that employ a combination of medical and functional criteria to reach a determination that a person cannot exercise specific rights. Generally speaking, a person who is incapacitated has been determined by a court to be "unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care."[2] However, the concept of capacity is a social and legal construct that is not necessarily provable or disprovable through scientific methods, and the use of the terms "capacity" and "incapacity" is becoming disfavored by guardianship reformers. For example, the 2017 Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act[3] makes no reference to either term.

Indigent: An individual with little to no resources who may be entitled to an attorney paid for by the state, the appointment of a *public guardian*, and/or the waiver of court costs and fees.

Informed Consent: Consent, usually to a medical procedure or legal representation, given by a person after information disclosing the risks, benefits, and costs of undertaking a given action are divulged, so the person may make a free and uncoerced decision.

Joint Ownership: A situation in which two or more people co-own property. It allows a co-owner of land or bank accounts to manage an *incapacitated* co-owner's property as their own.

Limited Guardianship: A guardianship where the guardian only has the authority specifically given by court order. The person in a limited guardianship retains all other decision-making rights not specifically outlined by the court order.

Magistrate Judge: A state official who makes decisions in legal cases just like a judge but does not have as much power as a judge. A Magistrate Judge generally handles minor cases and, in some jurisdictions, may handle guardianships cases, especially those that are uncontested.

Money Management Services: Services that help people with their financial affairs such as check depositing and writing, bill paying, budgeting and checkbook balancing, and tax preparation. Money Management Services are voluntary, so the person must be able to ask for or accept them.

Physician Orders of Life-Sustaining Treatment ("POLST"): The POLST process requires a discussion between the treating health care practitioner and the person about key end-of-life care treatment options, so that the person's wishes can be identified and incorporated into doctor's orders kept in the medical record or with the person. Those orders are reviewed periodically and must travel with the patient whenever he or she moves from one setting to another, thereby promoting continuity of care.

Plenary Guardianship: A full guardianship where the court gives the guardian the power to exercise all delegable legal rights and duties on behalf of the person in guardianship. The guardianship is of both the *person* and the *property*, and the individual in a plenary guardianship has been adjudicated completely *incapacitated*. This is the most restrictive form of guardianship.

Power of Attorney: A legal document executed under state law whereby one person (called the *principal*) voluntarily designates someone else (called the *attorney-in-fact* or *agent*) to legally act on their behalf for certain decisions and in certain circumstances. A *durable power of attorney* continues even after the individual has lost capacity. A *power of attorney for health care* usually goes into effect when the person becomes incapacitated.

Professional Guardian: A professional guardian is generally a private individual or organization who serves as guardian for numerous individuals and is not a member of those individuals' families. Professional guardians charge fees for carrying out their duties. They are generally paid out of the resources of the person subject to guardianship, when that person has such resources.

Public Guardian: A guardian who generally is either employed or funded by the state or local government to provide guardianship services to individuals who have been determined incapacitated. Often, public guardians serve people who are *indigent* and/or are the responsibility of a governmental agency or entity.

Representative Payee: An individual, agency, or organization appointed by the Social Security Administration (SSA) to receive, manage, and spend Social Security benefits on behalf of and for the benefit of an individual who is entitled to the benefits but who has been determined by SSA to be unable to manage the resource.

Respondent: A person who is responding to a lawsuit or legal action. In guardianship, the *alleged incapacitated person is* the *respondent*.

Special Needs Trust: A type of trust that is established for the benefit of a person with disabilities. The assets in this type of trust are intended to supplement and protect public benefits, specifically Medicaid. The advantage of this type of trust is that its assets do not negatively impact the beneficiary's eligibility for Medicaid or other government programs if the trust is administered properly.

Standard of Proof: Refers to the duty or burden carried by the party responsible for proving the case. There are generally three standards of proof that can apply in legal cases: "beyond a reasonable doubt" (highest standard, applies in criminal cases and in guardianship cases in New Hampshire), "clear and convincing" (second highest standard, which applies in most states' guardianship cases), and "preponderance of the evidence" (lowest standard, which applies in some states' guardianship cases and also may be the burden of proof in restoration cases).

Substituted Judgment: A standard of decision-making that should generally be used when making decisions on behalf of an adult with a disability, according to the National Guardianship Association. It refers to deciding on behalf of an individual in a manner that is aligned with the decision they would have made for themselves if they had the *capacity* to do so. This includes understanding and considering the values and preferences of the individual for whom decisions are being made either as currently expressed or as expressed prior to the determination that the individual was *incapacitated*.

Supported Decision-Making: There is no singular definition or model, but this generally means an individual choosing one or more people to assist that person in understanding the nature and consequences of potential personal and financial decisions, supporting the individual in making their own decisions, and then communicating decisions as needed. It generally occurs when people with disabilities use friends, family members, and professionals to help them understand the everyday situations they face and choices they must make, allowing them to make their own decisions without the need for a substitute decision maker, such as a guardian. This process works in the same way that most adults make daily decisions—by seeking advice, input, and information from trusted knowledgeable others.

Trust: A fiduciary arrangement where the trustee manages money or property for the benefit of a beneficiary or beneficiaries. A trust is a separate legal entity that owns assets that are managed by the trustee for the benefit of the beneficiary or beneficiaries in accordance with the rules established by the trust. There are many kinds of trusts, each of which provides different benefits.

Executive Summary

In March 2018, the National Council on Disability (NCD) released a seminal report, "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities," which provided a comprehensive review of adult guardianship through the lens of civil rights reforms impacting people with disabilities. The report cited serious problems about how guardianship systems function in the United States, including:

- lack of reliable state and national data on guardianship,
- misperceptions about the ability of people with disabilities to make autonomous decisions,
- denial of due process within guardianship proceedings and meaningful consideration of less-restrictive alternatives,
- insufficiencies in capacity determinations,
- lack of court oversight of guardians, and
- inaccessibility and underutilization of rights restoration processes after a guardian is appointed.

In addition to its detailed findings, the 2018 NCD Report offers recommendations for reforms to improve the lives of people with disabilities who may need decision-making assistance. It also suggests reforms to prevent overly broad or undue guardianships, and to improve court oversight of existing guardianships to eliminate abuse, neglect, and exploitation.

The present report builds upon the work of the 2018 NCD report by specifically examining the role of guardianship and other alternatives in the lives of people with intellectual and developmental disabilities (ID/DD), a population that is known to be at increased risk of having guardians. The report also examines if the increased risk for people with ID/DD may be linked to the different ways states apply guardianship laws, as well as biases and/or assumptions about the ability of people with ID/DD to fully experience the dignity of risk.

Some view guardianship as necessary to protect people with ID/DD. Others raise concerns about its stigma and how it impacts the civil rights and personhood of people with ID/DD. Like its predecessor, this report seeks to acknowledge and balance both of those views, while holding to the belief that "people with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence."[4]

Summary of Methodology

The 2018 NCD report provided a broad overview of the current state of guardianship law and practice, as well as policy reforms and analysis of how effective or ineffective those efforts have been. The present report uses that overview as a springboard to explore the experiences of people with ID/DD, their families, and others through a multimodal blend of updated literature review, data analysis, key informant interviews, targeted outreach, and personal story gathering from stakeholders.

This report is organized into six chapters.

- Chapter 1 briefly explains what guardianship is and includes cross-references to the lengthier explanation in the 2018 NCD report. It also introduces the reader to what is meant by ID/DD and how people with ID/DD are at an increased risk for having guardians. It also explains how guardianship, while directly governed by state law, can negatively implicate important federal civil rights for people made subject to it.
- Chapter 2 describes what has become known as the "school-to-guardianship pipeline," as well as its impact on youth with ID/DD. It examines U.S. policy implications of this pipeline under important federal laws, including the Individuals with Disabilities Education Act (IDEA), the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act (ADA), the Rehabilitation Act, and the Workforce Innovation and Opportunity Act (WIOA).
- Chapter 3 explores how some states' guardianship laws have different standards and processes for obtaining guardianship over people with ID/DD than other populations who may need decision-making assistance. It also discusses the impact of the disparate treatment of people with ID/DD, as well as U.S. policy implications, which include concerns about the lack of procedural and substantive due process and the potential for discrimination based solely on disability diagnosis.
- Chapter 4 acknowledges the 2018 NCD report findings about the lack of reliable and consistent national and state data on guardianship. It includes an analysis based on available National Core Indicator data, which addresses key questions about guardianship and people with ID/DD, including whether or not people with ID/DD who have guardians are more or less likely to live in restrictive environments than those who do not; whether guardianships for people with ID/DD are increasing or decreasing; and what the prevalence is of guardianship broken down by race and general age group.
- Chapter 5 gives an in-depth analysis of guardianship's impact on people with ID/DD within Washington, DC, including never-before-published trends in DC guardianship data and lessons that other states can learn from DC's experience.
- Chapter 6 summarizes the input this project received from stakeholders who responded to our call for their experiences with guardianship and alternatives. This includes people with ID/DD, their family members, and other stakeholders, such as special

education advocates, guardians and administrators of guardianship programs, and staff who provide transition services to youth with ID/DD. To gather information from stakeholders, NCD developed templates to gather input through emails, an online tool, and personal interviews. NCD ultimately received 70 substantive responses from 19 states and the District of Columbia.

- Finally, Chapter 7 offers NCD's findings and recommendations, considering the information presented in this report.

Executive Summary in Plain English

The National Council on Disability (NCD) is a group that works to help the government learn more about how they can help people with disabilities. One way we do this is by writing reports about different topics that are important to people with disabilities, like this one. We wrote this summary in plain English to make it accessible to everyone.

NCD wrote a report about guardianship in March 2018. Guardianship is when someone—like a family member, friend, or paid person—is chosen by the court to make legal decisions for a person. In that report, we looked at rights of adults with disabilities, guardianship, and other ways people make choices in their lives. We found many problems with guardianship in the United States. Sometimes governments and courts think people with disabilities can't make decisions themselves. Sometimes people with disabilities can't ask to change or get rid of their guardian, even if they feel the guardian isn't helping them. Sometimes, they can't report problems with their guardian, or figure out other ways to make decisions without a guardian. Judges don't always pay attention to what the guardians are doing, even if a guardian has caused problems before. But people who have guardians still have some rights. Once a person gets a guardian, they don't always need one forever—but some people don't know that. NCD talked about how to help more people with disabilities make their own decisions, with the support they need and want. We also explained how guardians and courts could do a better job without hurting people with disabilities.

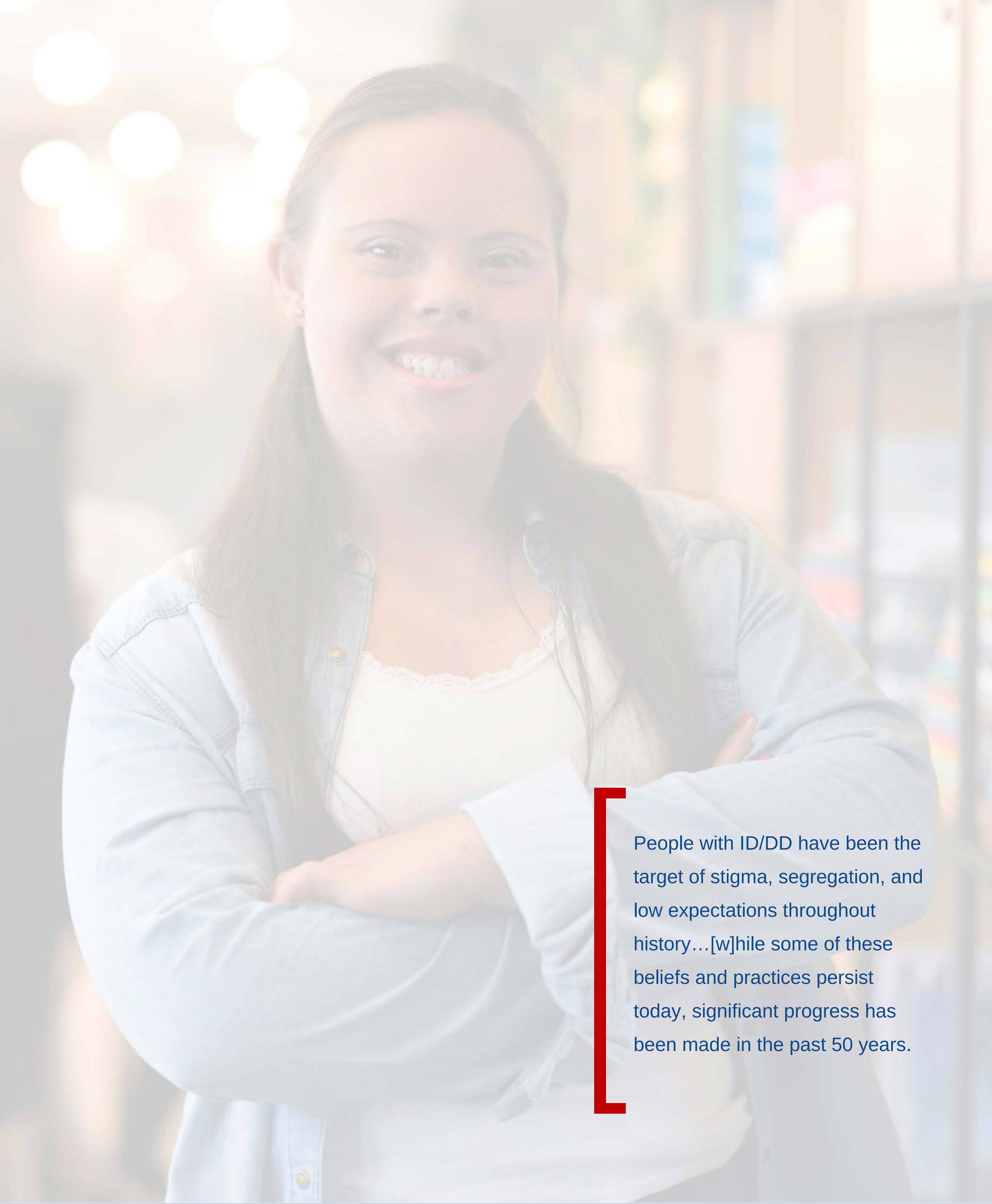
We know that there are many people with intellectual and developmental disabilities who have guardians. We wanted to focus on that, so NCD wrote this second report. We also wanted to know if more people with intellectual and developmental disabilities have guardians now than they did before. States have different guardianship laws, and that can be confusing for people with disabilities, family members, and judges. Sometimes people think that if you have an intellectual and developmental disability, you can't make decisions for yourself. They think you could get hurt, even though everyone makes bad decisions or gets hurt sometimes.

There is a big debate about guardians. Some people think guardians are a really good thing. They can help protect people with intellectual disabilities and help them make decisions. Some people are worried about guardians taking away the rights of people with disabilities or making bad decisions. Some people are embarrassed about having a guardian. NCD believes guardians are not always bad or always good. You should not be embarrassed if you need or want a guardian. But people with intellectual and developmental disabilities should always get to make decisions about their lives. You should be able to tell other people about any problems you’re having. You should always have rights and choices. Sometimes a guardian can help with these things. Other times, a person with an intellectual and developmental disability might not want or need a guardian.

We did a lot of work before we wrote this report. We talked to people with intellectual and developmental disabilities and their families and listened to their stories. We talked to experts who know a lot about guardianship. We read what people wrote about guardianship. After all that, we wrote this report. We came up with a lot of ideas about how guardianship in the United States should be made better for people with intellectual disabilities. We also talked about how other options besides guardianship should be used when they can. We are asking the Federal Government to think and make changes based on our ideas.

List of Acronyms

ACL	Administration for Community Living
ADA	Americans with Disabilities Act
ADAA	ADA Amendments Act of 2008
AIP	Alleged Incapacitated Person
AP	Associated Press
APS	Adult Protective Services
CMS	Centers for Medicare and Medicaid Services
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DOJ	U.S. Department of Justice
EAHCA	Education for All Handicapped Children Act
FHAA	Fair Housing Amendments Act of 1988
HCBS	Medicaid Home and Community-Based Services
HHS	Department of Health and Human Services
ID/DD	Intellectual and Developmental Disabilities
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
NCD	National Council on Disability
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NQE	National Home and Community-Based Services Quality Enterprise
OSEP	The Office of Special Education Programs at the U.S. Department of Education
OSERS	The Office of Special Education and Rehabilitative Services at the U.S. Department of Education
P&A	Protection and Advocacy
SAMHSA	Substance Abuse and Mental Health Services Administration
SDM	Supported Decision-Making
SSA	Social Security Administration
SSI	Supplemental Security Income
UCEDDs	University Centers for Excellence in Developmental Disabilities
UGCOPAA	Uniform Guardianship, Conservatorship & Other Protective Arrangements Act
UGPPA	Uniform Guardianship and Protective Proceedings Act
VA	U.S. Department of Veterans Affairs
WINGS	Working Interdisciplinary Networks of Guardianship Stakeholders
WIOA	Workforce Innovation and Opportunity Act



People with ID/DD have been the target of stigma, segregation, and low expectations throughout history…[w]hile some of these beliefs and practices persist today, significant progress has been made in the past 50 years.

Chapter 1: Introduction to ID/DD, Guardianship, and Alternatives

People with Intellectual and Developmental Disabilities

The group of people with disabilities addressed in this report are people with intellectual and/or developmental disabilities (ID/DD). According to the American Association on Intellectual and Developmental Disabilities : "Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills" and originates before the age of 18.[5] Prior to 2010 and the passage of federal legislation known as "Rosa's Law," intellectual disability was generally referred to as "mental retardation," which advocates with disabilities now consider a pejorative.[6]

While an intellectual disability is usually considered to be a developmental disability, the term "developmental disabilities" refers to a broader group of lifelong disabilities that can be intellectual, physical, or both. Federal law defines developmental disabilities as:

A severe, chronic disability of an individual that: (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) [s]elf-care; (II) [r]eceptive and expressive language; (III) [l]earning; (IV) [m]obility; (V) [s]elf-direction; (VI) [c]apacity for independent living; (VII) [e]conomic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.[7]

People with ID/DD have been the target of stigma, segregation, and low expectations throughout history.

Depending on their functional impact, examples of developmental disabilities under this federal definition may include intellectual disability, autism, cerebral palsy, Down syndrome, fragile X syndrome, fetal alcohol syndrome, spina bifida, and brain injuries occurring before the age of 22, among other disabilities.

People with ID/DD have been the target of stigma, segregation, and low expectations throughout history. It was a widely held belief that people with ID/DD were unable to benefit from typical life experiences or contribute to society in any meaningful way. It also was believed that people with ID/DD needed high levels of supervision and protection throughout their lifetimes.

These beliefs led to people being denied opportunities for education, confined to institutions, and being placed under guardianship primarily based on the presence of an ID/DD-related diagnosis.

While some of these beliefs and practices persist today, significant progress has been made in the past 50 years. The passage of IDEA (then known as the Education for All Handicapped Children Act) in 1975 and the ADA in 1990 were supported by new beliefs about the potential for people with ID/DD to learn, grow, and contribute to society, including equal access to education and human rights. People with ID/DD now are breaking down many of the old stereotypes with support from improved medical knowledge, access to education and technology, and opportunities for full community inclusion and participation.

Debunking Myths of Intelligence Testing of People with ID/DD

Diagnosing ID/DD frequently involves some sort of testing. This testing usually includes tests of intellectual functioning. A person’s intellectual functioning is generally determined by the demonstration of certain skills such as the ability to reason, solve problems, and navigate through a variety of life situations. Although intelligence testing has existed since the early 1900s, there has been much controversy within the field of psychology about whether the testing actually measures “intelligence.” One of the first of these tests, designed by Alfred Binet, was intended to identify children who might need extra assistance with learning, and was not intended to measure intelligence. Although Binet believed that intelligence was not fixed and could change over time, future tests building on his original work were developed by people who believed differently. These subsequent tests were frequently used to identify people who were considered less capable and therefore somehow inferior in society. This had the greatest impact on people with ID/DD during what is known as the "eugenics era," where people who were identified as "feeble minded" based on intelligence testing were removed from society, sterilized, and sent to institutions.

While significant scientific debate about the usefulness and meaning of intelligence testing continues within the field of psychology today, the greater practical problem is the general misconceptions of such testing by lay and legal communities. The Intelligence Quotient or "IQ" score that is produced by various tests is often misconstrued to be a measure of a how well a person's brain works, as well as their potential for learning in the future. "Mental age," a concept tied to IQ tests, is commonly misused to infer that people with ID/DD are incapable of developing beyond the abilities of young children. Originally, mental age, as determined by performance on the intelligence test, was used along with chronological age to calculate the IQ score. Although this concept is no longer used in most contemporary testing, it is still commonly used to explain the intelligence and abilities of people with ID/DD. For example, one family member explained that she was a guardian because "[o]ur daughter functions [as] a 5-year old to 16-year-old, depending on the context."

Properly used, intelligence and other tests can help practitioners understand individual learning challenges and make recommendations for improving educational and other learning support. In a 2003 article on "Intelligent Intelligence Testing," then president-elect of the American Psychological Association Diane Halpern noted that "We are not all the same; we have different skills and abilities. What's wrong is thinking of intelligence as a fixed, innate ability instead of something that develops in a context."[8] Science and experience have shown that human learning is a highly individualized process that can be facilitated by a variety of strategies and life experiences. While these interventions do not make a person's disability go away, they do function to strengthen other skills and help the person learn new ways to accomplish a challenging task.[9] This process is applicable to all areas of learning and life, including decision-making. It also means that not having the chance to learn to make decisions or taking away the opportunity and right to be involved in personal decision-making, preempts the person from becoming a better decision-maker over time.

Guardianship and People with ID/DD

Guardianship is a state legal process where a court removes some or many of the legal and decision-making rights from an individual and transfers all or some of them to another person, called a guardian or conservator. Although the particulars of guardianship depend on state law, an adult usually becomes subject to guardianship when a court, through a judge or magistrate judge, finds that the individual is incapable of making all or some of their own financial or personal decisions and deems it necessary to appoint a guardian to make those choices on their behalf. The guardianship process usually starts with someone, such as a family member, a governmental agency, or a service provider, filing of a petition in the court with jurisdiction. The petition is generally followed by a notice of the petition to interested parties that a guardianship petition has been filed, appointment of an attorney to represent the allegedly incapacitated person, a capacity evaluation, court hearing(s), and, if the petition is successful, letters of guardianship. Once a guardianship is put in place, in most circumstances, it lasts either until the individual in guardianship dies or has their rights restored. Guardians' responsibilities under state law vary but may include submitting guardianship plans and initial and annual reports to the court.

The 2018 NCD report reviews this general process and fundamentals of guardianship in more detail, including what rights are at risk in guardianship, how courts determine incapacity, and what the scope of the guardian's authority may be.[10] Guardianships are typically separated into two categories: guardianships of the person and guardianships of the property (also sometimes referred to as *conservatorship*). When the guardian controls decisions regarding both person and property, the guardianship is called plenary or full. Some rights may be removed without being transferred to the guardian, such as the right to marry, vote, drive, or seek or retain employment. Other rights may be removed and transferred to the guardian to exercise on behalf of the person, such as the right to contract, sue and defend lawsuits, apply for governmental benefits, manage money or property, decide where to live, consent to medical treatment, and decide with whom to associate or be friends. In many states, there are also some rights that a guardian can exercise on behalf of the person, but only after the court has issued a specific order allowing the action, such as committing the person to a facility or institution, consenting to biomedical or behavioral experiments, filing for divorce, consenting to the termination of parental rights, and consenting to sterilization or abortion.[11]

… [B]ecause of its legal implication on the person's civil rights, guardianship must be recognized as "an extraordinary intervention in a person's life and affairs," with the inherent potential to be a "drastic restraint on a person's liberty"…

In short, there are very wide-ranging actions that a guardian may be authorized to take on behalf of and instead of the person. This is why guardianship has been described as a "kind of civil death" for people subject to it, in that they are "no longer permitted to participate in society without mediation through the actions of another if at all."[12] Given the nature of our nation's existing legal system, there may well be times when guardianship is justified and necessary, although some disability rights advocates strongly disagree. Regardless, because of its legal implication on the person's civil rights, guardianship must be recognized as "an extraordinary intervention in a person's life and affairs,"[13] with the inherent potential to be a "drastic restraint on a person's liberty,"[14] and, as such, an option of last resort. As emphasized in the 2018 NCD report, although guardianship is created by state law, it raises fundamental questions concerning federal civil rights and constitutional due process worthy of examination and intervention at the national level.

This impact of guardianship is particularly relevant to people with ID/DD, who have been found to be at increased risk for being made subject to it.[15] Guardianship is often implemented, because service providers, family, judges, and others assume people with ID/DD cannot make decisions for themselves,[16] despite research to the contrary.[17] As scholars have said, "rather than being treated as the extraordinary proceedings that they are, guardianships are often treated as a routine part of permanency planning for persons with [intellectual disabilities.] . . . [G]uardianships—including plenary guardianships—appear to be routinely granted over persons with [intellectual disabilities]."[18] This may be due to a combination of factors including the "School-to-Guardianship Pipeline" (discussed in Chapter 2), ID/DD specific guardianship statutes (discussed in Chapter 3), barriers to accessing alternatives, pressures by governmental and other agencies providing or funding disability-related services; and societal biases regarding ID/DD diagnosis and capacity. This project's stakeholder outreach indicated that these barriers may be overcame in individual situations, but societal misunderstandings of what it means to live with ID/DD persist. For example, a person with ID/DD told us: "People are shocked [I don't have a guardian] because I have so many disabilities and I have been told from people who did tests on me that I am like a 2 year old."

> *"[R]ather than being treated as the extraordinary proceedings that they are, guardianships are often treated as a routine part of permanency planning for persons with [intellectual disabilities.]"*

Alternatives to Guardianship and People with ID/DD

As the American Association on Intellectual and Developmental Disabilities and The Arc of the United States have jointly concluded: "Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered."[19] Other common examples of legal alternatives to guardianship include health care surrogates by operation of state law, representative payees, trusts, and joint ownership. If alternatives to guardianship are thought of broadly—i.e., as services or supports that allow a person's needs to be met without a court-appointed guardian—many other options may be included within the continuum of decision-making support. These options include:

- voluntary participation in money management services
- case management services

- in-home care services
- food and prescription delivery
- daily call services
- direct deposit or bill pay
- medical or educational release forms to allow the sharing of confidential information with supporters
- other credit union and banking services technology [20]
- person-centered planning
- vocational services [21]
- supported living services.[22]

Emerging alternatives to guardianship in the United States include Physician Orders for Life-Sustaining Treatment (POLST) and, of particular relevance to people with ID/DD, ABLE accounts. The 2018 NCD report reviews at length the advantages and disadvantages of many of these less-restrictive options and includes discussion of the promising "PRACTICAL Tool," which was developed by the American Bar Association to encourage lawyers to identify and implement appropriate decision-making options for people with disabilities that are less restrictive than guardianship.[23]

For the purpose of the present report, NCD wants to emphasize that, from a rights perspective, alternatives that are voluntary in nature—i.e., decision-making support arrangements that are chosen and able to be cancelled or changed by the people with disabilities themselves—are less-restrictive than those that are involuntary in nature and, as such, are options that should be considered first for people with ID/DD. Voluntary alternatives to guardianship include tools such as supported decision-making (when people with disabilities use friends, family members, and others they trust to help them understand the everyday situations and choices they face, so that they can make their own decisions without the need for a substitute decision maker) and *powers of attorney* (written documents executed under state law that allows a person to voluntarily designate someone else to act for them in certain situations and to cancel or change that designation at a later time without court involvement).

> *[F]rom a rights perspective, alternatives that are voluntary in nature…are less-restrictive than those that are involuntary in nature and, as such, are options that should be considered first for people with ID/DD.*

Involuntary alternatives involve some entity other than a court or the person with a disability appointing and having control over who serves as the decision-maker. They include options such as representative payees (which are appointed by SSA when it determines beneficiaries cannot manage or direct the management of his or her own benefits and cannot be independently removed or changed by the beneficiaries themselves), surrogate health care decision-makers (which are not acting under the authority of a power of attorney or judicial determination, but rather by operation of other state law, and usually involve some form of professional certification(s) of a person's incapacity to make health care decisions), and Educational

Representatives (which are discussed further in Chapter 2).

NCD supports delinking perceptions about the ability of people with ID/DD to access voluntary alternatives to guardianship from their diagnosis alone. Many people with cognitive and intellectual disabilities can knowingly and voluntarily execute powers of attorney or advance directives, yet misconceptions about this persist, [24] and opportunities to access these options may not be offered to them. A family respondent reported: "An attorney has claimed that our son does not have legal capacity to enter into a durable medical power of attorney due to . . . his intellectual disability, but he is very clearly expressing preferences and making decisions about what he wants in life."

NCD also cautions against the over-use of involuntary alternatives to guardianship for people with ID/DD. While they do not involve the court system and are expressly limited in nature, they are still a form of substitute or surrogate, rather than supported, decision-making.[25] For example, having representative payees is a common alternative to guardianship for people with ID/DD, based on the stakeholder respondents in this project. Yet, while there are benefits to having a representative payee in certain circumstances, there also risks to the beneficiary that should not be forgotten, including loss in their feelings of self-worth and autonomy, encouragement of dependence, stigmatization, and the possibility that the representative payee will financially exploit or use the benefits as leverage to control the beneficiary.[26] As the Social Security Advisory Board has recognized, "[t]he appointment of a payee represents the curtailment of certain rights for the beneficiary and, therefore, should be undertaken carefully" and with consideration of the supported decision-making (SDM) as an alternative to appointment.[27] A respondent agreed with such careful consideration: "I am considering terminating [my] role [as representative payee] in light of what I now know about supported decision-making. I would like to return the right to decide how his SSDI is spent to [my family member with ID/DD]. He is already more confident and assertive since the conservatorship termination, and I expect him to continue to grow as he takes ownership of his decisions with my support." Possible ways states can address concerns about other involuntary alternatives to guardianship, such as Surrogate Health Care Decision-Makers and Educational Representatives, are discussed in Chapter 5.

Finally, NCD sees SDM as an ever more promising and recognized option for people with ID/DD. Based on information from the National Resource Center for Supported Decision-Making's website, as of June 2018, of the almost 20 cases where a court terminated or denied a guardianship explicitly in favor of SDM, almost 90 percent of the cases involved people with ID/DD. The first reported court decision terminating a guardianship specifically in favor of SDM occurred in 2012 in the state of New York and was followed by other cases in New York (2015, 2016, 2017), Virginia (2013), Massachusetts (2015), the District of Columbia (2016), Florida (2016), Vermont (2017), Kentucky (2017), Nevada (2017), Maine (2018), and Indiana (2018).[28] Two of the people with ID/DD involved in such cases, namely Jenny Hatch of

Virginia[29] and Ryan King of the District of Columbia,[30] were highlighted in the 2018 NCD report as representative of the third wave of guardianship reform. Additionally, the first formal SDM pilot program in the United States involved people with ID/DD and was held in Massachusetts (2014-2016).[31] Since then, it has been joined by ID/DD-specific pilots in states such as New York (2016—2021),[32] Maine (2016-2017)[33], and Georgia (2018 and ongoing),[34] among others.

Supported decision-making also is beginning to receive public attention for people with ID/DD in the health care realm. For example, in a film called *Supported Decision-Making: Gabby's Story*,[35] a young woman with spina bifida describes her experience working with a health advocate through The Arc San Francisco. The film uses Gabby's story to illustrate the benefits of SDM, both as a decision-making approach and as a way of maintaining personal autonomy in managing one's own medical care.

Lacking a robust natural support system can be a barrier to some people's ability to use SDM. Gabby's story highlights the role organizations and community supports can play in advancing the decision-making rights of people with ID/DD. Under its Health Care Management Services program, which began in 2003, health advocates at The San Francisco Arc are available to assist people with ID/DD by attending medical appointments with them, helping them understand medical decisions, and acting as a facilitator between the supporter person and medical providers—all at no change to the people with ID/DD. According to Jennifer Dresden, the Director for the Center for Health and Wellness, the program empowers people with ID/DD to have control over their health care decisions and helps medical providers better understand and serve their patients. The National Disability Rights Network is also exploring the use of supported decision making in the healthcare context with support from a grant by the WITH Foundation.[36] This report will explore more promising practices to further promote self-determination throughout the life spans of people with ID/DD.

Chapter 2: School-to-Guardianship Pipeline for Youth with ID/DD

The School-to-Guardianship Phenomenon

The Individuals with Disabilities Education Act (IDEA) generally requires—once students in special education reach the age of majority (usually 18, depending on state law [37])— the school to transfer all of their parents' educational rights to them as part of the transition planning process.[38] When that occurs, students have the right to make their own educational decisions for as long as they are entitled to receive special education services—i.e., until they graduate from high school or exceed the maximum age for receiving special education services, which, in most states, is 21 years old. [39] However, under IDEA, the transfer of rights will not occur if the adult student is subject to guardianship. The transfer also will not occur if the school uses a separately established non-judicial educational representative process to determine that the student cannot provide informed consent to educational decisions and to appoint another person (usually a family member) as the adult student's educational representative. It is often at the transfer-of-rights juncture that many parents and school personnel question the competence of students with disabilities, and parents seek to become the legal guardian of their young adult children.[40]

However, under IDEA, the transfer of rights [to make one's own education decisions] will not occur if the adult student is subject to guardianship.

At this point in the IDEA transition process, guardianship can be set in motion by a variety of factors. First, intentionally or unintentionally, school professionals may be biasing parents toward pursuing guardianship because of the way in which they notify them of the transfer-of-rights process. For example, they may start the conversation by asking parents if they have guardianship or are planning to obtain guardianship, rather than discussing the student's strengths and abilities and less-restrictive options of decision-making support, such as SDM or educational powers of attorney.[41]

[S]chool professionals may be biasing parents toward pursuing guardianship because of the way in which they notify them of the transfer-of-rights process.

Additionally, school personnel might not be aware of alternatives to guardianship or its legal impact. As one former educator explained: "I recall hearing the Department Chair and others saying that, if the student does not have a guardian, then the parents cannot attend the meetings and it just makes things more challenging. [I was] not told about alternatives to guardianship." Such conversations may pressure parents to pursue guardianship over their adult child, so that they are assured they can continue to be involved in their child's education.

While IDEA does not require appointing a guardian for adult students in special education, it allows—and arguably mandates—states to establish alternative procedures, short of guardianship and consistent with state law, for the appointment of the parent or another person to represent the educational interests of an adult student, if the school district determines that the student is unable to provide informed consent to his or her education program.[42] Such extra-judicial processes raise due process concerns in that rights are being taken away from the student without court adjudication. They also promote substitute or surrogate decision-making—rather than SDM—in the educational context.[43] Based on a 2012 review of state law

> *Such extra-judicial processes raise due process concerns in that rights are being taken away from the student without court adjudication.*

and regulations, at least six states had regulations that expressly provided for a non-judicial appointment of an educational representative for the student upon parental request and/or professional certification(s) or an Individualized Education Program (IEP) team finding that the student is incapable of providing informed consent for educational decisions. [44] The District of Columbia joined them in July 2016, as discussed in Chapter 5. Some states have other exceptions to the transfer of rights. In Maryland, for example, the general rule is that parents retain the special education rights of their adult child, unless they affirmatively or tacitly refuse or fail to participate in the special education decision-making process.[45]

[T]he majority (58 percent) of people with ID/DD ages 18 to 22 receiving publicly funded services have guardians …

There is no national data available on how many people with ID/DD get guardians right after high school. However, 2015-2016 National Core Indicator survey data indicates that the majority (58 percent) of people with ID/DD ages 18 to 22 receiving publicly funded services have guardians, which suggests guardianship is common for this age group. Moreover, as highlighted in the 2018 NCD report, stakeholders frequently reported that guardianship is presented by the school system as the main, if not only, option for decision-making support for young adults with ID/DD. A 2015 study supported by the TASH Human Rights Committee found that schools were the number one referral source for guardianship,[46] and guardianship is frequently considered the default option for students with ID/DD.[47] Many of the stories NCD collected affirm this.

A 2015 study supported by the TASH Human Rights Committee found that schools were the number one referral source for guardianship …

- A professional who used to work with transition-age youth in special education reported that she and her colleagues would give parents what was known as a "guardianship packet." She said: "It makes me cringe now, that that is how it was being passed around school, how nonchalant it is, and then how dangerous it can actually be . . . I didn't experience from my mentors that this was a human rights issue, that you were [contributing to] taking someone's rights away by recommending guardianship Parents see you as a representative and professional on behalf of the district, so if you say something like, '[H]ere is information on guardianship,' then they [may] not do their due diligence."
- As a Michigan family member reported: "Too often schools have told family members that a student with I[D]/DD must have guardianship if they want a family member or friend to assist with one's IEP when the student turns 18. School districts are terribly misinformed about guardianship and use this approach to limit families' involvement in IEPs."
- A Massachusetts family member reported: "People are encouraged by well-intended

educators to make the decision [about guardianship] at the age of majority. These educators do not connect the dots between transition when they should be teaching decision-making skills and the notion that guardianship is contrary to what they are supposed to be accomplishing."

- A person with ID/DD in Virginia said guardianship happens "at 18 because schools tell parents they have to have guardianship to make school and IEP decisions for and with their child, when people assume someone like me, who doesn't walk or talk, is stupid and needs to be put away and to make all the decisions about me for me."
- A family member from Kentucky said: "In my family's experience, we were prompted to begin the process [of obtaining guardianship] during his special education case conference meetings while he was still in high school. The school was not terribly helpful in informing us of the process, but did provide resources for where to go for more information."
- A Missouri family member reported: "It was recommended at my son's eighteenth birthday by the school officials that I file for guardianship."

Many stakeholders also referenced the lack of information on alternatives to guardianship provided by schools and its impact. For example: A family member reported: "Forms of limited guardianship were not discussed [in IEP team meetings], as it was assumed my brother [with ID/DD] would require plenary guardianship."

- A family member in Michigan responded: "Very, very little information [on this from schools]. Too often schools have told family members that a student with I[D]/DD must have a guardianship if they want a family member or friend to assist with one's IEP when the student turns eighteen. School districts are terribly misinformed about guardianship or use this approach to limit families' involvement in IEPs."
- A guardian in Missouri responded: "The educators do not support alternatives to guardianship."
- A lawyer in Indiana said: "There is no information available from the school. Our Protection and Advocacy organization has a website and will do information presentations."

Stories of the school-to-guardianship pipeline

A person with ID/DD in Virginia said guardianship happens "at 18 because schools tell parents they have to have guardianship to make school and IEP decisions for and with their child, when people assume someone like me, who doesn't walk or talk, is stupid and needs to be put away and to make all the decisions about me for me."

The Impact of the Pipeline and U.S. Policy Implications

Youth with ID/DD are ultimately disempowered by schools actively encouraging guardianship to the exclusion of less-restrictive alternatives, and not providing families and students in special education with sufficient information about the availability of a full continuum of decision-making supports. Research has found reduced self-determination can lead to diminished quality of life outcomes and reduced community integration and participation.[48] For young adults with ID/DD, guardianship may be an obstacle to the development of self-determination skills necessary for life after high school, such as critical thinking, self-advocacy, and knowledge of one's own skills, interests, strengths, and weaknesses.[49] Studies have found that students who have self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes.[50] Studies also have found that the appointment of a guardian for a young adult with ID/DD did not necessarily resolve the areas of concern prompting it and, in some cases, the young adult under guardianship would have done just as well, if not better, without a guardian.[51] The guardianship often appeared to have benefited the guardian, rather than the person under guardianship.[52]

If states' educational systems are promoting guardianship without appropriate consideration of less restrictive alternatives, including supported decision-making, they are arguably violating the ADA …

For young adults with ID/DD, guardianship may be an obstacle to the development of self-determination skills necessary for life after high school …

The U.S. policy implications of the school-to-guardianship pipeline are also troubling. There are strong arguments to be made that it runs contrary to important civil rights laws impacting people with ID/DD. As the 2018 NCD report found, guardianship must be seen as subject to the Americans with Disabilities Act (ADA),[53] which has been interpreted by the U.S. Supreme Court in the 1999 *Olmstead* decision[54] to give rise to an obligation to provide services to people in the least restrictive environment that will meet their needs. If states' educational systems are promoting guardianship without appropriate consideration of less restrictive alternatives, including supported decision-making, they are arguably violating the ADA[55] and promoting outcomes that run contrary to the *Olmstead* community integration mandate. As one interviewee stated: "By definition, if you are not the person making decisions, your ability to be a real member of the community [is] smaller."

In addition, while there may be "traces of guardianship"[56] found within it, IDEA also mandates individualized transition planning for qualified students with disabilities to increase the likelihood of post-school employment and/or education.[57] Transition planning outcomes should be tailored to students and their individual preferences, needs, and strengths, so they should contribute actively to the decision-making and planning process.[58] With that in mind, some scholars have suggested that "[t]he goals of transition planning, which focus on autonomy and independence, appear to be in direct conflict with the goal of guardianship, which is to facilitate the individual's dependence on another person's authority to make all or some of their decisions."[59] As one team of researchers observed, guardianship can work against the goals of transition planning, because it has broad implications regarding the loss of fundamental rights and personal liberty.[60]

"[t]he goals of transition planning, which focus on autonomy and independence, appear to be in direct conflict with the goal of guardianship, which is to facilitate the individual's dependence on another person's authority to make all or some of their decisions."

Moreover, the purpose of the federal Developmental Disabilities Assistance and Bill of Rights Act is to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life."[61] These goals are likely more readily achievable through alternatives that hold the promise of increasing self-determination, such as supported decision-making, rather than substitute decision-making. As one prior NCD interviewee stated: "[Guardianship is] never going to allow the person [subject to it] to really become integrated to [the] community because [others are] going to have to be always checking" with the guardian, not the person.

[NCI] data indicates people with ID/DD who receive publicly funded services who are not under guardianship are more likely to be employed in an integrated job.

Finally, one of the goals of the Rehabilitation Act of 1973[62] is to promote and support employment for people with disabilities, including ID/DD. Its regulations have long recognized the importance of intervening early in the lives of transition-age youth with disabilities by mandating that state vocational rehabilitation programs coordinate with special education transition teams "as early as possible."[63] The Workforce Innovation and Opportunity Act (WIOA)[64] further augmented these requirements by mandating vocational programs to "provide pre-employment transition services to assist students with disabilities make the transition from secondary school to postsecondary education programs and competitive integrated implement" [65] In addition, Section 511 of WIOA was designed to make it less likely that youth who have disabilities and are age 24 or under are inappropriately routed to segregated, subminimum wage employment without first exploring all the alternatives for meaningful work and postsecondary education and training. Research has found young adults with disabilities who are supported have greater self-determination in their lives, are more likely to be better employed,[66] and National Core Indicator data indicates people with ID/DD who receive publicly funded services who are not under guardianship are more likely to be employed in an integrated job.[67] and those who are in guardianship are significantly less likely to have employment as a goal in their service plans.[68] Both of these findings suggests the Rehabilitation Act's and WIOA's goals may be better achieved by requiring schools and transition teams to ensure awareness of decision-making support options that do not remove the legal rights of young adults with disabilities.

It is therefore critical that the school-to-guardianship pipeline be dismantled so that students with disabilities and their families receive the information they need to make thoughtful and informed choices when it comes to guardianship and alternatives. As one former educator noted, too often, "students are not informed, parents are uninformed, and educators are uninformed . . . It's a triple whammy." Fortunately, efforts to address this information gap have been undertaken by the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS). In January 2017, OSERS issued its "Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities" report, which recognized the serious implications of guardianship and encouraged schools to recognize and promote supported decision-making and self-determination by students before, during, and after the age of majority. It also recognized other alternatives to guardianship in the educational context, including educational powers of attorney.[69] OSERS archived and then updated and reissued this guide, retaining these important elements of its guidance.[70]

However, based on the information received from respondents as part of this project, more is clearly needed to ensure that teachers, schools, and school districts are complying with this guidance. This should include:

- Revision of all teacher education and certification programs and vocational the full rehabilitation agencies to include training on range of decision-making options for students who have reached the age of majority. As one former educator said: "Being a first-year teacher shouldn't be the first time that I [am] learning about age of majority and guardianship [and alternatives] . . . [I]f the district itself is unaware or has varying views of student's abilities to lead independent lives, then you are at the mercy of the vision of the school.
  The universities [are in] a powerful position to prime the teachers."
- Training parents for school-to-adult transition and alternatives to guardianship. As one parent said: "When it comes to guardianship and alternatives, you don't know what you don't know."
- Promotion of self-advocacy and self-determination at an early age for students in special education. As one former educator said: "[Schools have] the power to promote

self-determination as early as possible and that can be done by empowering the students to lead the [IEP and other] meetings It puts them in a position of leadership and empowers them to take an active role. If the student has been passive throughout their entire education, maybe not even attending the meeting, how would the team even know if the student could make a choice if they are not even empowered in participating and attending the [very] meeting that is planning their education?

Chapter 3: Unequal Treatment of People with ID/DD Under State Guardianship Law

ID/DD-Specific State Guardianship Laws

Most states have a single guardianship law that covers people across disability categories, including older people with progressive cognitive decline, people with mental-health disabilities, and people with ID/DD. However, as recognized in the 2018 NCD report, there are states that have different statutory procedures, standards, and processes for appointing guardians for people with ID/DD, as compared to other populations that may need guardians. A list of these states and the main ways statutory distinctions apply to people with ID/DD is available in Appendix A of this report.

California, Connecticut, Idaho, Michigan, and New York… have separate guardianship statutes for people with ID/DD versus those with other types of disabilities.

Existing scholarship has mainly focused on the ID/DD distinctions in five states—California, Connecticut, Idaho, Michigan, and New York—which have separate guardianship statutes for people with ID/DD versus those with other types of disabilities.[71] On paper, New York's statute is one of the most striking. New York maintains two separate systems of guardianship for people with disabilities—i.e., Article 17-A of the Surrogate Court's Procedure Act for people with developmental disabilities and Article 81 of the Mental Health Hygiene Law for all other people. Under the former, the basis for appointing a guardian is driven by diagnosis, rather than functionality. It also has less rigorous procedural requirements than Article 18 of the Mental Health Hygiene Law—e.g., a hearing on the guardianship petition is not required; the person with a disability does not have to be present; the guardianship cannot be limited; and guardians' decisions are based on a "Best Interest," rather than a Substituted Judgment, standard. Additionally, unlike many other statutes, New York's statute allows a guardian appointed under it to make "any and all health care decisions" for the person with ID/DD.

On the other side of the spectrum is Michigan, which has a guardianship statute for people with developmental disabilities that generally provides them with more statutory safeguards than people without such disabilities. For example, the Michigan developmental-disability-specific guardianship statute requires that guardianships be limited in scope to only that which is necessary because of the person's actual mental and adaptive limitations. Partial guardianships are preferred, but not required, and terminate after no more than five years.[72]

Apart from those states with entirely separate guardianship laws depending on a person's diagnosis, there are other states that make other kinds of distinctions for people with ID/DD, as indicated in Appendix A. For example, some allow for a governmental agency or representative to be appointed guardian of a person with ID/DD (e.g., Hawaii, Minnesota, and South Dakota), or others require additional court determinations (e.g., Iowa, with respect to voting rights) or clarify that an ID/DD diagnosis alone should not govern the scope of a guardianship (e.g., Arizona). As discussed in the 2018 NCD report, some states have so-called "alternatives to guardianship" that are essentially still guardianships. For example, Florida has a legal process for "guardian advocates" that is referred to in its statute as a less-restrictive alternative to guardianship and is only available to people with particular developmental disabilities. Rather than requiring Florida's standard determination of incapacity by an "examining committee" of experts, the judge (who may not have any expertise with disability) may use educational evaluations, IEPs, and other support plans to determine whether the person has the capacity to retain at least one right, but "needs" a guardian advocate appointed to exercise other rights. If so, that guardian advocate will essentially have the duties and responsibilities as a guardian under Florida law without the person having the same due process safeguards. [73]

Another example of the way in which some states relax due process protections for people with ID/DD—both expressly and indirectly—can be seen in Utah. Utah's law does not require a court visitor to investigate the appropriateness of appointing a guardian, if the person involved has an intellectual disability or an intelligence quotient score under 25—which, on its face, would appear to discriminate against people with certain ID/DDs. Additionally, in 2016, the Utah legislature passed a law that created an exception to a person's right to counsel when facing a guardianship petition. While not specifically referencing people with ID/DD, this law change made it easier for their parents to obtain guardianship over them and further bolstered the school-to-guardianship pipeline. The law was focused on the approximately 300 cases per year where parents seek guardianship over their adult children with disabilities in Utah state courts. [74] It eliminated the requirement that adults with disabilities have their own attorney when their parents petition the courts to be their legal guardians, their assets are less than $20,000, they appear in court with the petitioner, and they are "given the opportunity to communicate, to the extent possible, the person's acceptance of the appointment of petitioner." In July 2017, disability rights advocates filed legal action in federal court challenging the law on discrimination grounds. [75] In May 2018, the Utah Legislature amended this law to limit the applicability of the exception to the right to legal counsel and to require that, when it does apply, a court visitor, such as a social worker, be appointed to investigate and report to the court.[76] In November 2018, the federal court lawsuit was settled. As part of the settlement, the Utah Administrative Office of the Courts and the Utah Judicial Council agreed to strengthen legal protections for adults with disabilities in guardianship proceedings by ensuring judges are informed about the importance and availability of legal representation in such proceedings, first explore less restrictive alternatives, and consider full guardianship as a last resort.[77] However, Utah's exception to the requirement of legal counsel in cases where parents are seeking guardianship over their adult children remains "on the books", albeit in a modified form.

The Impact for ID/DD Guardianship Statutes on People with ID/DD and U.S. Policy

Stakeholders in the affected states express varying knowledge and opinions of the impact different statutes have on people with ID/DD. One family member in Michigan, who serves as co-plenary guardian for her two sons with ID/DD, felt that the separate ID/DD law was a "good thing," because she saw "the problems with guardianship [as] varying a great deal for people who are elderly and people with [ID/DD]," since the former are more likely to have accumulated savings and property that can be exploited. Other Michigan stakeholders reported that the supposedly bolstered procedural safeguards of the ID/DD guardianship law were not playing out in practice. For example, the statute was designed to promote partial guardianships over plenary guardianships, with partial guardianships automatically expiring after five years. However, in some Michigan counties, stakeholders reported that partial guardianships for people with ID/DD are never ordered, while in other counties, so-called partial guardianships are so broad as to be, for all intents and purposes, plenary. One advocate described partial guardianship only preserving, for example, a person's right to choose their own clothing. This would seem to suggest that the manner in which guardianship plays out for people with ID/DD has little to do with how the actual law is written.

[T]he manner in which guardianship plays out for people with ID/DD has little to do with how the actual law is written.

On the other hand, stakeholders in New York who commented on the different nature of the state's ID/DD guardianship statute raised serious concerns about its disparate impact, with one arguing that people with ID/DD deserved "equal protections under the law," and the other lauding a challenge to it on constitutional grounds. These concerns were forcefully brought to the fore in a 2015 report of the Mental Health Law Committee and the Disability Law Committee of the New York City Bar Association, which unequivocally concluded that the separate New York guardianship law "discriminates against persons with intellectual and developmental disabilities, denies procedural and substantive due process to those for whom guardianship is sought, and over whom guardianship is imposed, fails to honor or promote autonomy, self-determination and dignity, and fails to protect persons under guardianship from abuse, neglect and exploitation."[78] The New York Olmstead Cabinet made similar conclusions and recommended guardianship reform on the basis of the Americans with Disabilities Act, finding that "[c]ommunity integration includes the ability of people with disabilities to make their own choices to the maximum extent possible," and that guardianship "should, consistent with *Olmstead* only be imposed if necessary and in the least restrictive manner."[79]

Separate statutory guardianship schemes also may raise questions that are relevant to NCD's upcoming report series on bioethics and disabilities. One of the more pertinent questions with respect to bioethics is whether the separate guardianship schemes for people with ID/DD will protect the right of people with ID/DD to make important decisions about their health to the same extent as people covered by non-disability specific guardianship statutes. Many modern guardianship statutes prohibit the guardian from consenting on behalf of the person under guardianship to certain drastic medical procedures, such as removal of an organ or commitment of the person to a nursing facility or institution.[80] However, only some of the ID/DD-specific statutes prohibit guardians appointed under the subsection from making health care decisions that could permanently alter the health of the person under guardianship. For example, as noted in Appendix A, Connecticut's ID/DD-specific statute prohibits both plenary and limited guardians from "removing a bodily organ," except in accordance with statutory procedures to save the person's life or protect the person's physical or mental health. New York's statute, by contrast, allows the guardian to make "any and all health care decisions" for the person with a disability if it is in the person's best interests, which would include an organ transplantation or removal. New York's highly permissive statute would appear to raise significant concerns as to whether the bodily integrity of persons under guardianship under its provisions is truly respected.

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One of the more pertinent questions … is whether the separate guardianship schemes for people with ID/DD will protect the right of people with ID/DD to make important decisions about their health to the same extent as people covered by non-disability specific guardianship statutes.

Whether or not a state's disability-specific guardianship statute does, in fact, make it easier to obtain guardianship over a person with ID/DD, the fact that some state law has different guardianship standards that apply to this population is concerning, since it still links the removal and transfer of rights to a person's diagnosis. If, as a nation, we are to move away from a diagnosis and medically driven system for guardianship toward the functionally driven approach that recognizes less-restrictive options for all people with disabilities, we need to encourage a more uniform state approach, as endorsed by the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act[81] and the 2018 NCD report.[82]

Chapter 4: U.S. Trends in Guardianship/Alternatives and People with ID/DD

The Guardianship Data Problem

The 2018 NCD report recognized that national and state data on guardianship itself—let alone the demographics and type of disabilities of people subject to it—are scant to non-existent. Even identifying the number of active cases or their status is not possible in many states.[83] Record keeping is frequently inconsistent or dated, and most states do not have centralized data collection or tracking systems. The 2018 NCD report recommended that Congress and the Administration develop initiatives to produce effective and comprehensive data on guardianship. As one scholar said: "The starting point of any major reform is an accurate picture of the policy in need of reform; in this case, that means at a minimum that states are able to count the number of incoming and outgoing adult guardianship in the state courts." [84] In short, we collect data on issues that are important to us. Guardianship should be one of those issues, given its impact on the civil rights of people with disabilities and the potential impact on their ability to live, work, and participate in the community.

> *"The starting point of any major reform is an accurate picture of the policy in need of reform; in this case, that means at a minimum that states are able to count the number of incoming and outgoing adult guardianship in the state courts."*

This project adopted a two-pronged approach to identify data-supported trends in guardianship and alternatives specific to people with ID/DD. First, it turned to National Core Indicator (NCI) data publicly available through the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) NCI initiative. This data is the result of surveys across the nation of people with ID/DD who receive publicly funded services through the state and includes information about guardianship and life outcome measures. The results of that NCD's examination are summarized in this chapter and Appendix B and C. Second, this project conducted a "deep dive" analysis of guardianship's impact on people with ID/DD within the District of Columbia, the nation's capital, including identifying and analyzing ID/DD specific data points that are not yet publicly available in other jurisdictions. The results of that analysis are summarized in Chapter 5.

Review of National NCI Data

National Core Indicators (NCI) (https://www.nationalcoreindicators.org/) are standard measures to assess the outcomes of services provided by public developmental disabilities agencies to adults with ID/DD. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety. Using the NCI website developed by HSRI and NASDDS, users can generate charts related to specific outcome measures with NCI data from the years 2008-09 through 2015-16. Most importantly for the purpose of this report, the NCI Chart Generator can filter data by whether the person has a legal guardian or not. Users can also filter results by race, ethnicity, gender, age, and type of residence, among other key demographics. While not comprehensive of all persons with ID/DD in the United States, the NCI data is one of the only sources of nationwide data on people with ID/DD and guardianship.

NCD used the NCI Chart Generator to review relevant data from 2008-09 to 2015-16. We also reviewed the NCI In-Person Survey National Reports for 2016-17 and 2017-18, which were published by HSRI and NASDDDS in May 2018 and March 2019, respectively, and included NCI data points that are not available for filtering through the NCI Chart Generator. NCD's review of this data by state is set forth in Appendix B as a table, which includes the percentage of people with ID/DD in guardianship (limited, full or the scope of which was undetermined) and the NCI Average by year from 2008 to 2018. While the District of Columbia and all U.S. states except Iowa, Montana, North Dakota, and West Virginia have participated in the NCI initiative, Alaska, Idaho, and Nebraska did not have guardianship-specific data available through the NCI Chart Generator. Relevant information relating to the state percentage of guardianships was available for Idaho in the 2016-17 NCI In-Person Survey National Report and for Nebraska in the 2016-17 and 2017-18 NCI In-Person Survey National Reports.

As reflected in Appendix B, trending of NCI data sheds light on the prevalence of guardianship across participating states:

- The reported percentage of people with ID/DD in guardianship (full, limited, or of undetermined scope) varies widely between states. In 2017-18, the highest were Nebraska (89 percent), Connecticut (84 percent), Missouri (82 percent), Michigan (81 percent), and North Carolina (75 percent), and the lowest were Delaware (5 percent), South Carolina (9 percent), Georgia (16 percent), Louisiana (16 percent), and Pennsylvania (18 percent). In 2017-18, most people with ID/DD surveyed in 20 of the 36 participating jurisdictions included in the 2017-18 NCI In-Person Survey National Report that year had guardians.
- The overall average of state percentages of people with ID/DD in some form of guardianship has ranged between 45 and 55 percent annually across the ten years of NCI data reviewed. The NCI Averages of cases of guardianship across participating states ranged between 43 and 53 percent annually during that ten year time period. Of the 17 states that have NCI data available from both

the 2008-09 and 2017-18 reporting periods, most had guardianship percentage increases, some of which were relatively small – i.e., Alabama (1 percent), South Carolina (2 percent), Ohio (6 percent), Pennsylvania (6 percent) – and others that were more significant – i.e., New York (10 percent), Wyoming (11 percent), Arkansas (12 percent), North Carolina (12 percent), Connecticut (14 percent), and Indiana (19 percent). Three states – Louisiana, Missouri, and Oklahoma – had no change in the percentage of people with ID/DD in guardianships in 2008-09 compared to the percentage in 2017-18. Five states had decreases in the percentage of people with ID/DD in guardianship, four of which were relatively modest – i.e., Massachusetts (minus 2 percent), Georgia (minus 5 percent), Kentucky (minus 8 percent) and Illinois (minus 8 percent). Based solely on those two-years-worth of NCI data, Delaware had the most significant decrease – minus 24 percent.

- Based on the individual states' averages, when a person is in guardianship, most are full guardianships. Only California and the District of Columbia regularly had more limited guardianships than full guardianships. However, that trend changed for the District of Columbia in the years 2016-17 and 2017-18, when the percentage of full guardianships became slightly higher than limited ones.

Percentage of people with ID/DD in limited or full guardianship

In 2015-16, the highest percentages of people with ID/DD in limited or full guardianship were:

- Connecticut (83 percent)
- Missouri (80 percent),
- Maine (77 percent)
- Vermont (77 percent)

and the lowest percentages of people with ID/DD in limited or full guardianship were:

- Louisiana (13 percent)
- Georgia (16 percent)
- Pennsylvania (18 percent)

In terms of the five states that apply entirely separate guardianship statutes to people with ID/DD, two were well under the overall state average percentage of 49 percent—namely California (overall annual average of 23 percent) and New York (overall annual average of 32 percent). The other three—namely Idaho (overall annual average of 58 percent) Michigan (overall annual average of 76 percent) and Connecticut (overall annual mean of 80 percent) were well above that overall state average. This suggests that whether a person with ID/DD is under guardianship may have very little to do with the type of guardianship law that is applied to them.

Appendix C tabulates additional NCI guardianship data by gender, and race/ethnicity and was developed by NCD through the use of the NCI Chart Generator, which is currently limited to data from 2008-09 through 2015-16. NCD's review of that data indicates that here is no significant difference between the percentage of male and female participants who have guardians (annual average 48 percent versus 49 percent), but the percentage of people with ID/DD who have guardians was highly variable by race and ethnicity. There is no significant difference between the percentage of male and female participants who have guardians (annual average 48 percent versus 49 percent), but the percentage of people with ID/DD who have guardians was highly variable by race and ethnicity.

> ***[T]he percentage of people with ID/DD who have guardians was highly variable by race and ethnicity.***

After this report was nearly completed in April 2019, NASDDDS and HSRI, in partnership with the University of Missouri, Kansas City, released a report, "What Do NCI Data Reveal About the Guardianship Status of People with IDD?" ("NASDDDS/HSRI/UMKC Report").[85] This report included an analysis of new data from the NCI 2017-18 In-Person Survey National Report, which was published in March 2019 and includes data not currently available through the public NCI Chart Generator, and raised resulting policy questions, as well as promising practices. Among other findings, the NASDDDS/HSRI/UMKC report analyzed the demographics of people with ID/DD surveyed, based on their guardianship status. Findings trended by race included:

> ***Based on the new 2015-16 NCI Average, 18- to 22-year-olds were the most likely of all the age groups that year to be in guardianship (58 percent).***

- People with ID/DD surveyed who are White were significantly more likely to be in guardianship (46.4%) than people who were Black (34.2%) or Hispanic (26.3%).
- People with ID/DD surveyed who are Black and have a guardian were significantly more likely to have a public guardian or public administrator as a guardian (18.4%) than people who are White (11.2%) or Hispanic (4.3%).
- People with ID/DD surveyed who are Hispanic were significantly more likely to have a family member as guardian (91.1%) than people who are Black (71.6% or White (81.6%).[86]

Appendix C also has additional NCI guardianship data by age. For example, from 2008-16, roughly 50 percent of people with ID/DD between ages 18-74 had guardians, and this did not vary much between 18- to 34-year-olds (50 percent), 35- to 54-year-olds (48 percent), and 55- to 74-year-olds (48 percent). Based on the annual average, people with ID/DD who are 75 years or older were more likely not to have a guardian (71 percent). For its 2015-16 data collection, the NCI initiative broke down the 18- to 34-year-old category into two subcategories—18- to 22-year-olds and 23- to 34-year-olds. Based on the 2015-16 NCI average, 18- to 22-year-olds were the most likely of all the age groups that year to be in guardianship (58 percent). In addition, the 2015-16 NCI average percentage of people with ID/DD

75 years or older without guardianship (52 percent) was notably lower than the 2008-15 NCI average (71 percent).

NCI data, however, does not necessarily provide a complete picture of guardianship for people with ID/DD in all the participating states. For example, based solely on NCI data, Missouri has consistently been the state with one of the highest percentage of people with ID/DD under guardianships (ranging from 80 percent in 2015-16 and 2016-17 to 87 percent in 2009-10 and 2013-14). However, each state participating in the NCI initiative decides what population of people with ID/DD it surveys, and most do not survey all people with ID/DD in the state. According to stakeholder interviews, Missouri conducted NCI surveys of people with ID/DD receiving Individualized Supported Living and Residential Services. Therefore, if some people with ID/DD in Missouri receive different services (such as individual supports, self-direction services, or employment services) or no services, they would not be included as part of the NCI data set. To obtain a clearer picture of guardianship data, in September 2018, the Missouri Department of Mental Health's Division of Developmental Disabilities conducted an initial data analysis of all its Medicaid HCBS Developmental Disabilities Waivers, except for autism services. It determined that the percentage of people with ID/DD served under these waivers who had guardians and/or conservators was approximately 50 percent—which is much lower than indicated by NCI data.

NCI data, however, does not always provide a complete picture of guardianship ... [E]ach state participating in the NCI initiative decides what population of people with ID/DD it surveys, and most do not survey all people with ID/DD in the state.

In addition, some states may have existing NCI data relevant to guardianship that is not within the NCI Chart Generator or the In-Person Survey National Reports. For example, Alaska was one of the states for which guardianship-specific data is not included in either of those resources. However,the 2015-16 Alaska NCI Adult Family Survey Final report indicatesthat 100% of the the family members with ID/DD are under limited or full guardianship, and 96% of these individuals are under full guardianship. [87] Based on stakeholder interviews, that startling statistic is far above that of any of the states listed in Appendix B and reportedly led local advocates to push for legislation, making Alaska the first state to allow people with guardians to execute SDM Agreements with the permission of their guardians. [88] The reported reasoning was that Alaska should not leave such a large percentage of people with ID/DD behind in its reform efforts to recognize and promote decesion-making rights. In addition, SDM agreements of this kind may serve as a gateway for people to work with their guardians toward rights restoration and greater independence.

Even with the acknowledgment of its limitations, NCI data can provide indicia of the possible impact of guardianship in the lives of people with ID/DD. For example, the NASDDDS/HSRI/UMKC Report analyzed outcomes for people with ID/DD with and without guardians, based on the most recent 2017-18 NCI data. The report found that NCI respondents without guardians are less likely to live in their own homes or apartments, be included in the community, have their rights respected, have community jobs or service plans with that goal, be supported to communicate with friends, go on dates or marry, and be involved in making choices about their own lives (e.g., where and with whom to live, who their support staff or case managers are, what their schedule looks like, what to do during their free time or during the day, and what to buy with spending money. [89]

NCI data also can be used to explore whether or not people with ID/DD who have guardians are more or less likely to live in restrictive environments than those who do not. Scholars have disagreed as to whether people with guardians are predisposed or disproportionately subject to institutionalization. Some argue that they are,[90] pointing to studies done of residential decisions made by a sample of state public guardianship programs.[91] Others disagree,[92] citing studies indicating that guardianship may delay institutionalization, although ultimately not prevent it. NCI data indicates that the answer to this question may be more nuanced for people with ID/DD. In the NASDDDS/HSRI/UMKC Report, the most recent 2017-18 NCI data indicated that NCI respondents in guardianship were significantly more likely to live in group residential facilities and less likely to live in their own home/apartment.[93]

[A]ny NCI data correlation between guardianship and institutionalization does not get to the core question of whether it is guardianship itself that led to the person living in a more restrictive residential environment.

However, that report also found that respondents in guardianship were not more or less likely to live in an ICF/IDD, nursing facility, or other institutional setting than those who were not under guardianship.[94] – which is contrary what NCD found within older 2015-16 NCI data (see Table 6 of Appendix C).

Ultimately, any NCI data correlation between guardianship and institutionalization does not get to the core question of whether it is guardianship itself that led to the person living in a more restrictive residential environment. The answer is more complicated than that and likely dependent on other factors such as whether a state's service delivery systems or supports appropriately promotes community living for people with disabilities.

Chapter 5: Guardianship & People with ID/DD: A Story from the Nation's Capital

Introduction

Who is filing guardianship petitions over people with ID/DD? Are suspicions of a "school-to-guardianship" pipeline for people with ID/DD borne out in actual guardianship data? Do people with ID/DD in guardianship ever seek to have their rights restored? Data-supported answers to these and other more granular questions impacting people with ID/DD are not available for the United States as a whole. Therefore, this project turned to the local level by undertaking an in-depth examination and analysis of the experience of people with ID/DD who live in Washington, DC.

The District of Columbia is a prime place for such an examination. The treatment of the decision-making rights of DC citizens with ID/DD has recently been highlighted on the national stage. During recent U.S. Supreme Court justice confirmation hearings, repeated references were made to a 2007 U.S. Circuit Court for the District of Columbia decision, *Doe ex rel. Tarlow*.[95] This court decision was condemned by several disability rights organizations[96] for not respecting the wishes of all of DC's citizens with ID/DD with respect to their own medical care. In addition, this case highlights the way in which the DC government used to consent to elective surgeries, including abortions, for certain DC citizens with ID/DD without attempting to ascertain their wishes. Since that time, DC laws and governmental practice impacting the decision-making rights of people with ID/DD improved in significant ways. However, that concerning history remains in the minds of many local advocates and DC residents with ID/DD. As one DC advocate with ID/DD said with respect to the *Doe* decision: "Nothing about us without us."[97]

In addition, from a data gathering standpoint, identifying and tabulating guardianship cases that specifically involve people with ID/DD, rather than other disabilities, is easier in DC than in other larger jurisdictions, because DC has only one court branch with authority over guardianship matters. DC also has a computerized system, with court filings and other information publicly available for review. In addition, the DC Department on Disabilities Services is legislatively required to gather information on decision-making supports used by the people with intellectual disabilities[98] that it serves. DC also has recently undergone promising legislative and policy reform, designed both to bolster due process rights for people facing or in guardianship and to promote alternatives to guardianship for adults with disabilities in special education and beyond. This presented an opportunity to find out whether these reforms have yet resulted in meaningful outcomes for residents with ID/DD in the nation's capital, and, if so, whether DC's local approach can inform federal-level policy recommendations and serve as a model to other states.

Why NCD picked DC for an in-depth examination of guardianship

- DC has only one court branch with authority over guardianship matters, making it easier to identify and tabulate cases that specifically involve people with ID/DD.
- DC has a computerized system with court filings and other information publicly available for review.
- The DC Department on Disabilities Services is required to gather information on decision-making supports used by the people with ID that it serves.
- DC recently underwent promising reform designed to bolster due process rights for people facing or in guardianship and to promote alternatives to guardianship.

Key DC Legislative and Policy Reform

Legislative Reforms for Adult Guardianship Proceedings

In its guardianship law, DC has several long-standing safeguards and due process protections. For example, people facing or in guardianship have an established right to counsel, both in the initial and post-appointment court proceedings, such as restoration cases.[99] Even if a person is found by the court to be "incapacitated," a guardian may not be appointed unless it is "necessary as a means for providing continuing care and supervision of the person," which allows for court consideration of less-restrictive alternatives to guardianship. The law also states that incapacity must not be inferred from the fact that a person has an intellectual disability.[100] The law further provides for scope-limited and time-limited guardianships and requires the court to "exercise [its] authority … so as to encourage the development of maximum self-reliance and independence of the incapacitated person."[101] When the court appoints a guardian, it must be "the type of guardianship that is least restrictive to the incapacitated individual in duration and scope, taking into account the [person's] current mental and adaptive limitations, the [person's] ability to improve his or her condition, or other conditions warranting the appointment."[102] General and limited guardians are generally required to make decisions for the person using the substituted judgment standard[103] and to include the person "in the decision-making process to the maximum extent of the [person's] ability" and "encourage the [person] to act on his or her own behalf whenever he or she is able to do so, and to develop or regain capacity to make decisions in those areas in which he or she is in need of decision-making assistance, to the maximum extent possible."[104]

The [DC] law also states that incapacity must not be inferred from the fact that a person has an intellectual disability.

However, local disability rights advocates have raised concerns regarding how the due process protections within the DC guardianship law have been translated in practice for residents with disabilities.[105] Related advocacy led to the DC Guardianship Amendment Act of 2014,[106] which went into effect in March 2015. In addition to other reforms, it bolstered the due process rights of people in guardianship proceedings in two main ways. First, the Act requires attorneys who represent people in or facing guardianship to zealously advocate for their client’s expressed wishes. If the person is completely incapable of expressing such wishes concerning guardianship, then the attorney must advocate for a result that is least restrictive of the person’s liberty and consistent with the person’s interests as determined by a guardian ad litem.[107] This amendment was designed to counteract a 2010 DC Court of Appeals decision, *In re Martel,*[108] which held that the original guardianship statute’s wording allowed an attorney to meet his or her obligation by advocating for what a guardian ad litem determined was in the person’s “legitimate interests,” even if the client disagreed. Second, the Act mandated periodic court review of guardianships established after January 1, 2015, to determine whether the guardianship continue to be the least restrictive option or whether it should instead be modified or terminated.[109] The reviews occur every three years, after an investigation and report by a case reviewer, who is a social worker assigned through DC’s Guardianship Assistance Program. That investigation must include an updated medical or psychological information about the current capacity of the person in guardianship, as well as the person’s expressed preferences about the scope and duration of the guardianship and their opinion of the guardian. The law also requires a court hearing to be held if the person in guardianship requests one or if the case reviewer recommends the guardianship be modified or terminated or the guardian be removed.

DC WINGS Complaint Process and Trainings on Alternatives to Guardianship

In 2015 and 2016, as a result of the efforts of the DC Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) initiative,[110] led by the DC Courts, other steps were taken to improve the guardianship system in DC. In addition to its efforts to improve public education on guardianship through the court website, brochures, and videos, DC WINGS developed a new complaint process, by which anyone can raise concerns about guardians and conservators that are appointed with the court. When such a complaint is submitted, the Court may take several actions, including appointing a social worker to investigate the case, referring the case for mediation, holding a hearing, or referring the complaint to a law enforcement agency,[111] among others.

DC WINGS developed a new complaint process, by which anyone can raise concerns about guardians and conservators that are appointed with the court.

In the fall of 2015, DC WINGS also provided training to attorneys and other legal stakeholders to reinforce that guardianship was the option of last resort, ensure alternatives to guardianship were understood, and improve understanding of capacity assessments. The trainings included discussion of the full range of decision-making options then available in DC, including SDM, advance directives, powers of attorney, representative payees, and substitute health care decision-makers under DC Code 21-2210 (“21-2210 Medical Decision-Makers”), among others.

DC Special Education Reforms to Promote Alternatives to Guardianship

In DC, while general education students typically graduate from high school by the age of 18, students in special education have the right to remain in school until the end of the semester in which they turn 22 years old.112 Under DC law, when students turn 18, their parents' rights under the Individuals with Disabilities Education Act (IDEA) automatically transfer to the student, unless a court has found that the adult student is incompetent.[113] This process is referred to as the "transfer of rights," and it frequently triggers discussions about guardianship. As one DC disability rights advocate said: "In my experience working with transition-age students with ID/DD, I have seen a bias by schools and support teams to use the transfer-of-rights process to push parents towards going to court to get guardianship over their adult child, rather than first exploring less-restrictive decision-making options, like powers of attorney and supported decision-making. Because of this institutional bias within [the] disability service delivery system, we have had to expend much effort and energy on counseling and supporting families to understand that guardianship is not the only option available."

In 2012, a coalition of DC disability rights advocates issued a call of action against the Transfer of Rights Guidelines of the DC Public Schools (DCPS).[114] These March 2010 guidelines failed to inform parents and students about less-restrictive alternatives to guardianship, such as educational powers of attorney or SDM, instead presenting the issue as a dichotomous choice between the students exercising their IDEA rights completely by themselves or their parents seeking guardianship if they wanted to remain involved in educational planning.[115] In addition, DCPS was taking the position at some administrative hearings that students in special education could not delegate their IDEA rights to their parents or caregivers through the use of educational powers of attorney, despite the fact that District law expressly allowed parents to delegate rights and responsibilities for all school-related matters when their child was a minor.[116] As a result of this community advocacy effort, in August 2013, DCPS amended its Transfer of Rights Guidelines[117] to expressly recognize SDM and, also developed a standardized form[118] by which such arrangements by adult students in special education can be documented. In addition, DCPS began an initiative to introduce SDM, beginning in pre-kindergarten, to teach "students how to build networks of support early to ensure that [they] are familiar with the process and utilize it in day-to-day activities."[119]

> *DCPS began an initiative to introduce SDM, beginning in pre-kindergarten, to teach "students how to build networks of support early to ensure that [they] are familiar with the process and utilize it in day-to-day activities."*

Alternatives to guardianship for adult special education students were also included in comprehensive special education reform legislation that was passed by the DC legislature in late 2014. The DC Special Education Student Rights Act of 2014,[120] which went into effect in March 2015, affirmed that students who have reached the age of 18 have the right to receive support from another adult to aid them in their decision-making.[121] In so doing, it extended DCPS' formal recognition of SDM to all schools in DC, including public charter schools. The Act also affirmed the right of adult students in special education to execute educational powers of attorney[122] and required the DC Office of the State Superintendent of Education (OSSE) to create a new alternative to guardianship for students who were unable to make educational decisions—even with support—or to knowingly and voluntarily execute a power of attorney.[123] This new alternative became known as an Educational Representative. The Act also required parents be notified of the transfer-of-rights, as well as all these alternatives to guardianship, no less than one year before the student turned 18 years old.[124]

In July 2016, OSSE implemented regulations for this Act[125] and issued a model SDM form that can be used by all schools, whether they are connected to DCPS or not.[126] Among other things, the regulations describe how the Educational Representative process works. An Educational Representative is someone, usually a parent, appointed by OSSE to make educational decisions for an adult student who is unable to make those decisions, even with support, and it does not require court involvement. A parent or other interested adult may submit to OSSE the request for appointment, along with two signed professional certifications of the student's incapacity to make educational decisions. If all its rules are met, OSSE will then appoint the Educational Representative and provide notice of the appointment to the parents, student, and school. The notice describes the steps that the student may take to challenge the appointment; and the school is required to give a copy of the notice and explain it to the student. If the student objects, then the certifications are invalidated, and all educational rights transfer back to the student.[127]

However, respondents that were interviewed raised questions about whether information about the full continuum of decision-making support are really making its way from schools to students and families. For example, one parent reported that, coordinators at public charter schools and DCPS do not have a full understanding of the impact of guardianship or the availability of alternatives such as powers of attorney and SDM: "Maybe a handful out of the 200 or so that are out there [do] . . . We really do need to get [them] . . . much, much more comfortable in explaining the difference or at least pointing parents in the right direction [when students are] 15, 16 . . . in their IEP [meetings]. I think they really need to ramp up the trainings .I know it's a very low-priority level, unfortunately, but I think that they are the ones who are going to open the door of understanding to the parents."

Reforms Recognizing Supported Decision-Making Across the Life Span

On September 21, 2015, the Chairman of the DC Council, at the request of the DC Mayor, introduced Bill 21-0385, the Citizens with Intellectual Disabilities Civil Rights Restoration Act of 2015. This bill, among other things, proposed to formally recognize SDM across the life span through the codification of a SDM agreement form and was drafted under the leadership of the DC Department on Disability Services. Although it did not pass the DC Council that legislative session, the introduction of Bill 21-0385 started a broader dialogue about SDM that made lawmakers, governmental agencies, and the public more familiar with the concept and how it could be operationalized in DC. The legislation was reintroduced on March 3, 2017, in a modified form, as Bill 22-0154, now known as the "Disability Services Reform Amendment Act of 2018." It passed the DC Council on February 28, 2018, and became law effective May 5, 2018, making DC the fourth jurisdiction in the United States to codify SDM agreements.[128]

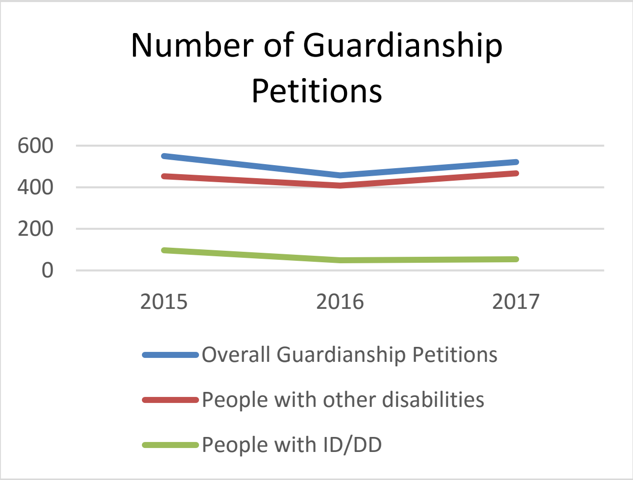
This law change was preceded in October 2016 by the first DC case to terminate a guardianship in favor of SDM.

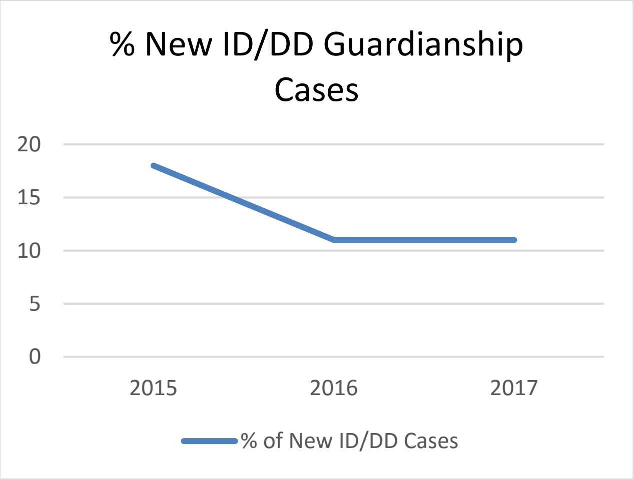
This law change was preceded in October 2016 by the first DC case to terminate a guardianship in favor of SDM.[129] The case involved Ryan King, a person with ID/DD whose victory was showcased in the 2018 NCD report and shown a spotlight on SDM locally and nationally. In addition, DC's 2016 Olmstead Plan—which is a way for states to document their plans to provide services to people with disabilities in the inclusive and integrated settings, pursuant to the Americans with Disabilities Act (ADA)—recognized that: "Guardianship is often seen as the only option for parents of children with disabilities rather than self-determination and supported decision-making." To combat this, it included governmental action steps that required the development and implementation of long-term care competency criteria, standards, policies, and protocols on the "consistent use of person-centered approaches to service and planning, including using principles of supported decision-making."[130]

By the Numbers: Guardianship and DC Residents with ID/DD

Data Collection Initiative at the DC Probate Branch

Using publicly available information from the DC Probate Branch, this project gathered key data points for the over 1,500 new guardianship cases opened over the course of 2015-17 and identified the subset of cases where the alleged disability was ID/DD. There are several trends that are worth highlighting.



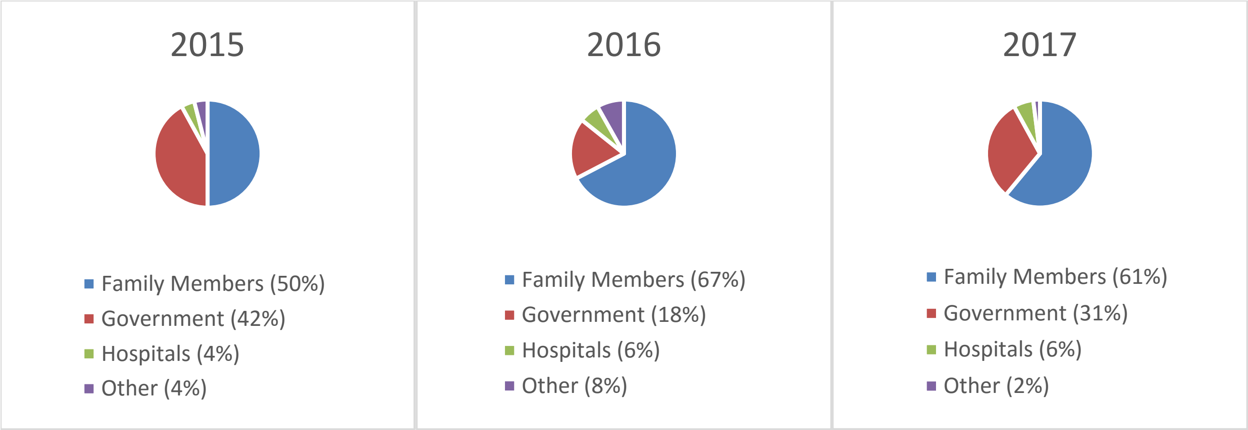


The number of new guardianship petitions for people with ID/DD, as well as their percentage compared to overall guardianship petitions filed, has generally decreased over the course of the three-year period. While there are many reasons why this is the case, the timing of the decrease coincides with the public dialogue surrounding the SDM bill that was first introduced in the DC legislature in 2015, as well as the DC WINGS trainings on alternatives to guardianship.

Most of the petitions were filed by family members. Others were submitted by government agencies, including Adult Protective Services (APS), the Department on Disability Services, and Child and Family Services. In a handful of cases, the person's own attorney or guardian ad litem from another matter, such as an eviction proceeding, filed the petition. The overall percentage of family guardianship petition filings increased over the three-year period, which speaks to a need for targeted outreach to that population to ensure they are fully aware of less-restrictive options.

> *The number of new guardianship petitions for people with ID/DD, as well as their percentage compared to overall guardianship petitions filed, has generally decreased … [T]he timing of the decrease coincides with the public dialogue surrounding the SDM bill … as well as the DC WINGS trainings on alternatives to guardianship.*

Guardianship Petitioners for ID/DD Cases



The majority of ID/DD guardianship petitions are for transition-age adults, indicating that there is indeed some form of pipeline to guardianship for that population in DC. While the number of cases for that age group has dropped since 2015, their percentage of the overall number of guardianship petitions involving people with ID/DD has steadily increased. This is a troubling finding, as it suggests that the special education reforms to promote alternatives to guardianship may not yet be having an impact on the ground for youth with ID/DD.

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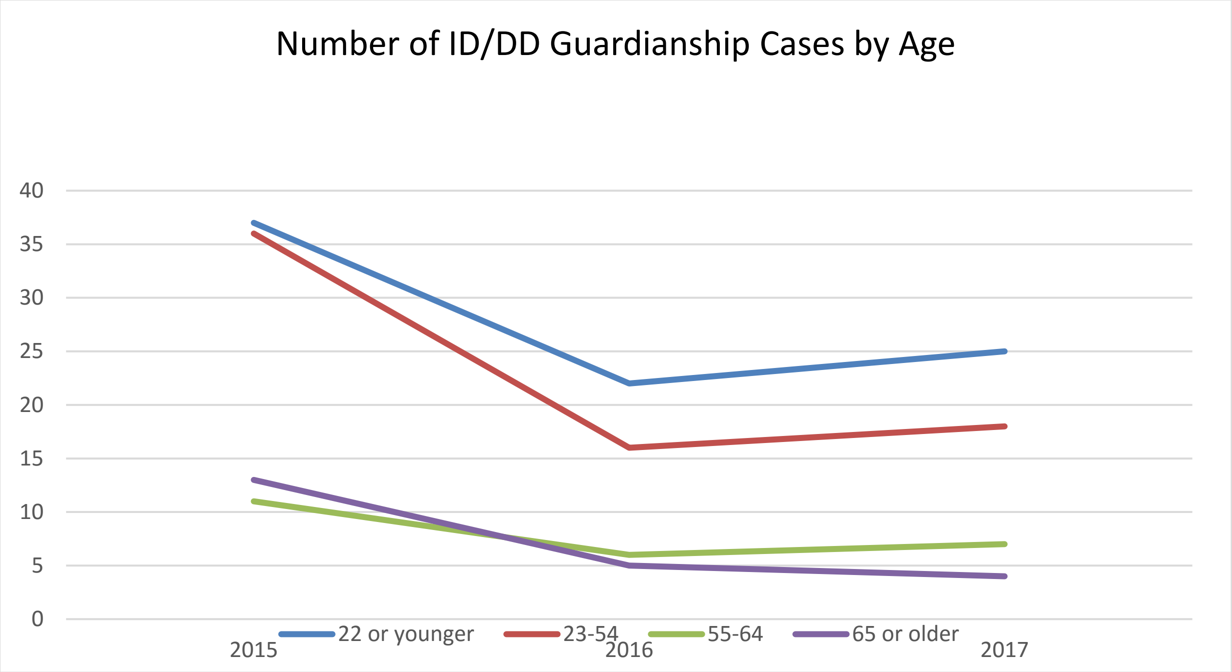
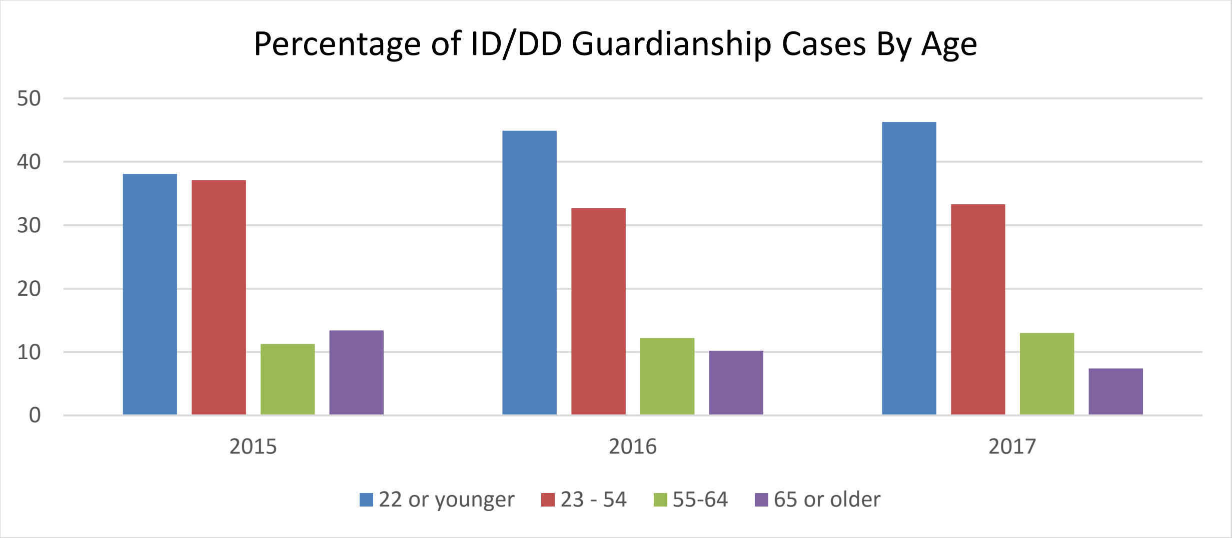
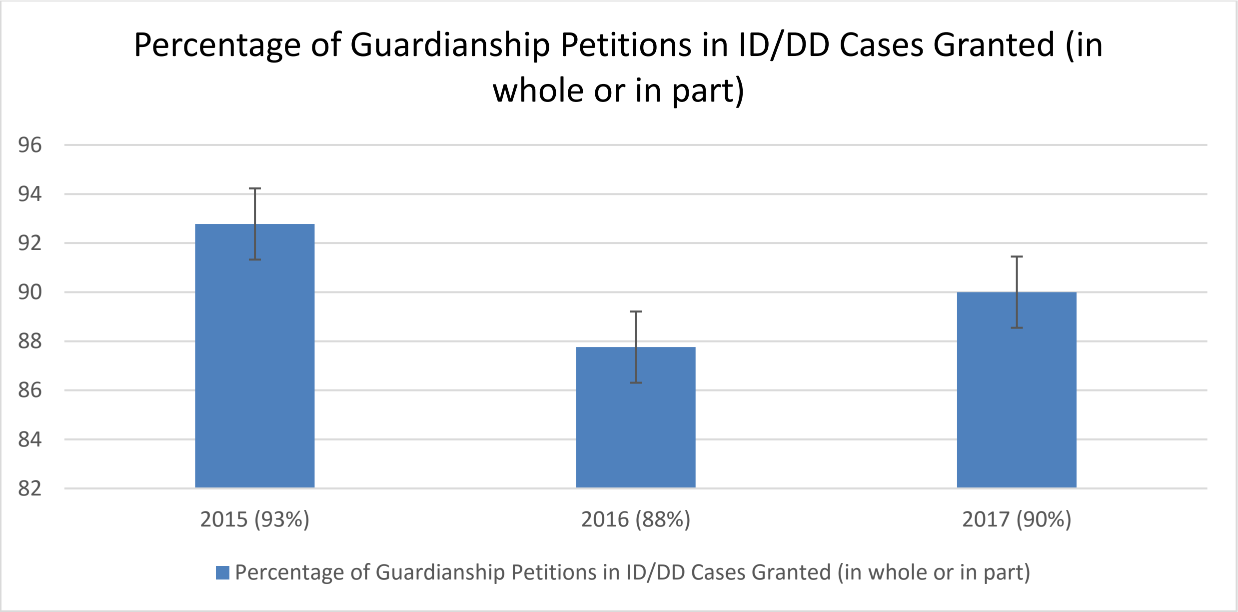




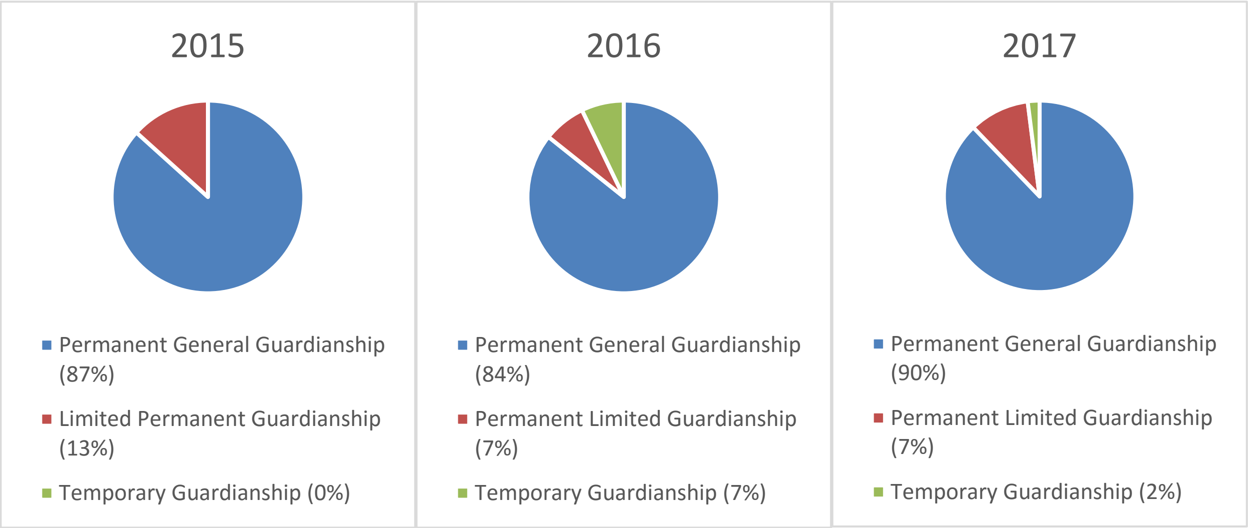
These data-driven concerns regarding ineffective implementation of promising special education agency policy and procedures are consistent with what the project learned from interviews with personnel at DCPS and OSSE. Currently, these agencies reportedly do not comprehensively track the use of alternatives to guardianship, such as SDM, educational powers of attorney, or educational representatives, by adult students in special education. Although several of their trainings incorporate the concept of SDM, there reportedly have been no standalone trainings on that topic presented by these agencies, other than those periodically offered by local disability rights organizations.



Most of the people with ID/DD who faced guardianship petitions were placed under guardianship by the court. The percentage did decrease somewhat from 2015-16, which may be attributed, in part, to the court education efforts to attorneys and legal professionals on the availability of alternatives to guardianship. However, the percentage increased slightly in 2017, which underlines the need for continued training efforts by the court.

When the petitions were granted, most of the individuals with ID/DD were placed under permanent general guardianship, the most restrictive form. This data raises questions about whether courts are using guardianship as the last resort and whether they are consistently appointing the type of guardianship that is least restrictive in duration and scope to meet the person's needs. It may also indicate persistence in stereotypes about people with ID/DD and their ability to be independent with supports, which could lead courts to weigh heavily toward full guardianship instead of alternatives.

Type of Guardianship Granted in ID/DD Cases



The review also indicated that the people with ID/DD in the data set did not seek to have their guardianships reviewed, either through a petition post-appointment for restoration of rights or through the new court guardianship/conservatorship complaint process. There was not a single complaint filed in these cases. There were only three petitions post-appointment requesting restoration of rights, and none of them were filed by the person under guardianship. However, all three were successful and the individual's rights were restored. More education on these due process options for people with ID/DD and their support networks is likely needed, particularly with respect to the complaint process, which has only been in existence for a few years. Careful these consideration should also be given to ensure that tools are sufficiently accessible to and navigable by people with ID/DD.

Pursuant to the DC Guardianship Amendment Act, the first year of court triennial case reviews began in 2018. For this project's data set, 21 such reviews occurred for people with ID/DD through the Guardianship Assistance Program. Only two of the individuals involved were appointed an attorney to help them navigate the process, and none of the reviews resulted in restoration of rights. While a periodic review of the continued necessity of guardianship is a promising DC reform, more time and analysis are needed to determine whether it will have a concrete impact on people with ID/DD under guardianship and whether it will result in any restoration of rights for them.

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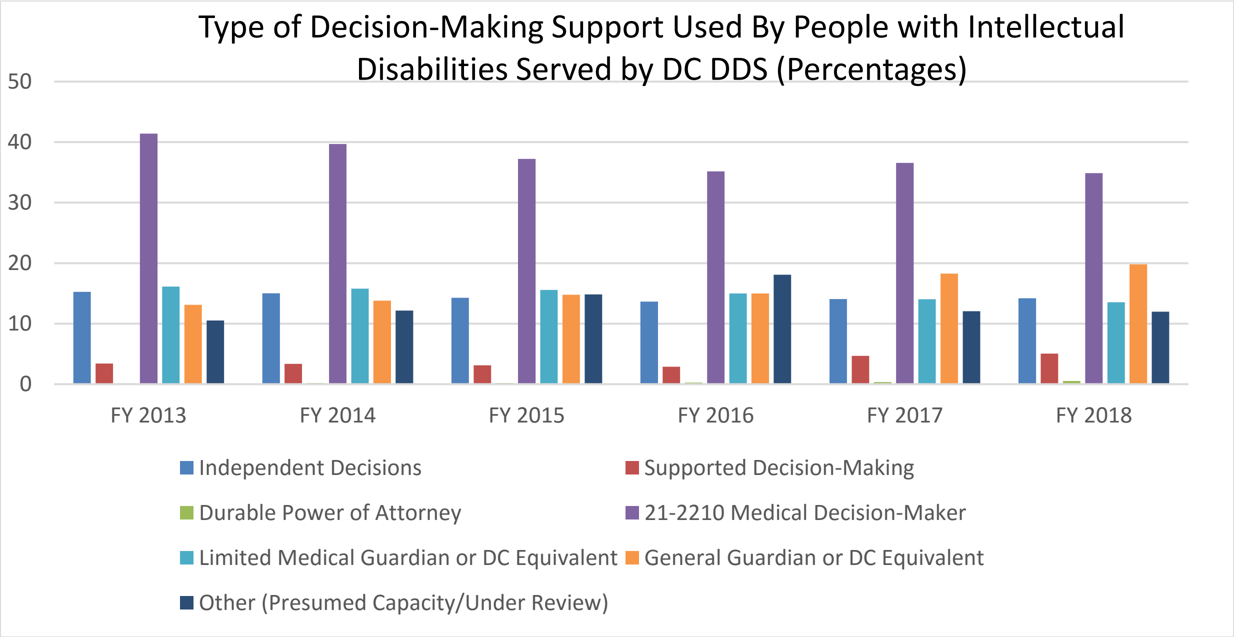
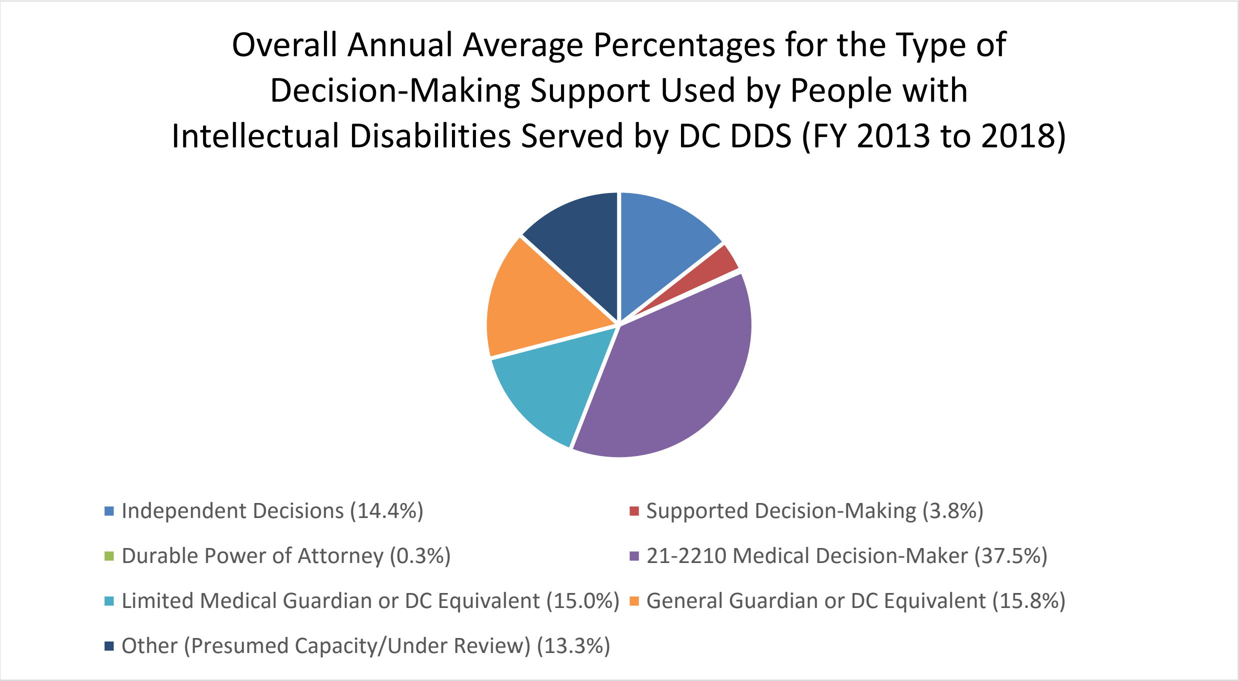

Type of Decision-Making Support Used By People with Intellectual Disabilities Served by DC DDS (Percentages)


Overall Annual Average Percentages for the Type of Decision-Making Support Used by People with Intellectual Disabilities Served by DC DDS (FY 2013 to 2018)

Data from the DC Department on Disability Services on Guardianship and Alternatives

Under DC Law 17-249, the "Health-Care Decisions for Persons with Developmental Disabilities Amendment Act of 2008," the Department on Disability Services (DDS) is required to submit to the Council of the District of Columbia (DC Council) an annual report and plan assessing the current and potential health care decision-making needs for all people served by DDS,[131] which includes DC residents with intellectual disabilities.

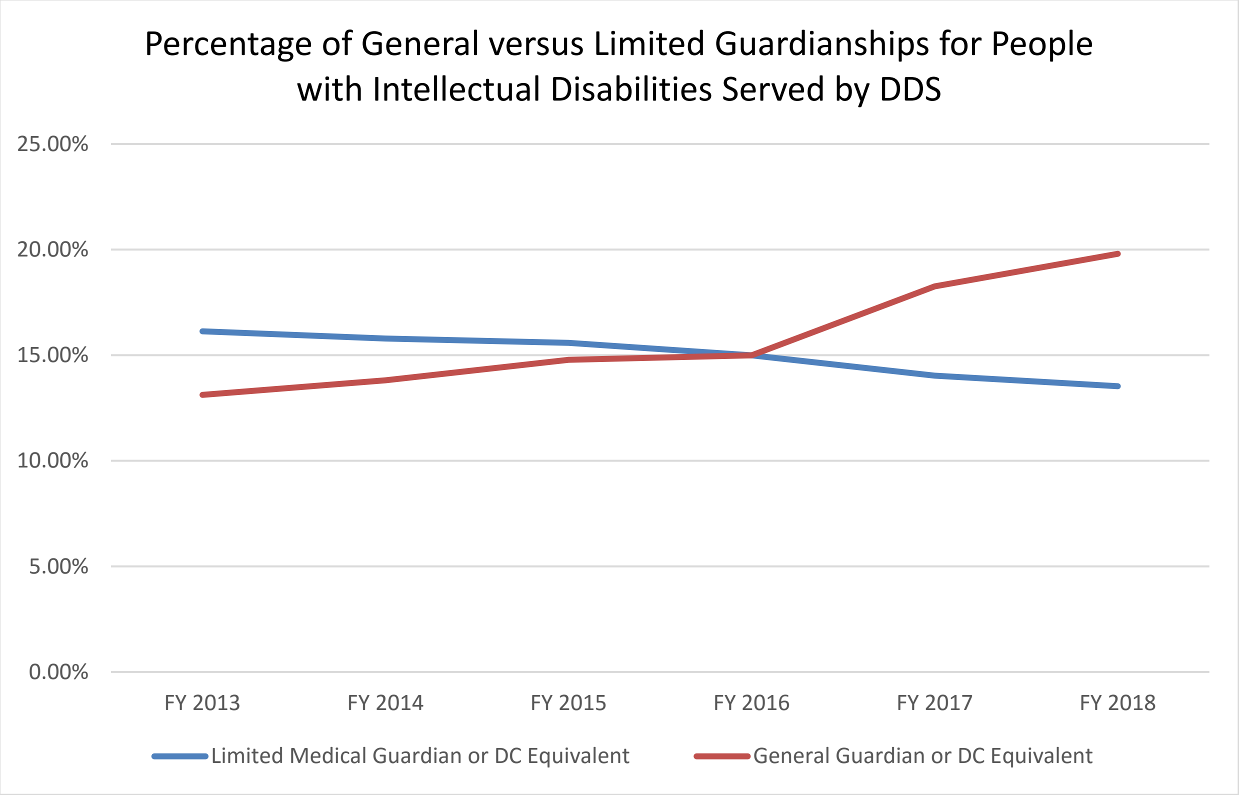
This report includes data on the type of decision-making support used, including SDM, Durable Power of Attorney, 21-2210 Medical Decision-Maker, Limited Medical Guardian, and General Guardian. DDS has described the data as a "snapshot," "an approximation, because the numbers fluctuate from day to day as individual needs continue to change." However, the data tells an interesting story about the type of decision-making support that is being legally recognized as used by this population.

While the number of people with intellectual disabilities identified as using SDM has increased over the past five years (from 75 to 111), it has consistently remained the second least-used decision-making support with the DDS intellectual disability system. With the May 2018 statutory recognition of SDM across the lifespan, this statistic may change in the future.

[T]he most common form of decision-making support used by people with intellectual disabilities served by DDS is a 21-2210 Medical Decision-Maker (MDM).

As the data shows, the most common form of decision-making support used by people with intellectual disabilities served by DDS is a 21-2210 Medical Decision-Maker (MDM). In DC, when a person does not have a durable power of attorney for health care and has been certified to lack the mental capacity to make health care decisions by both a qualified medical doctor and a psychiatrist or psychologist, the law turns to a prioritized list of individuals to make those decisions for the person under DC Code 21-2210 of the DC Health Care Decisions Act. For the purpose of DDS' statistics, these 22-2210 MDMs are generally family members or friends who have not been appointed as the legal guardian by the court. The advantage of this law is that it allows the person to receive the health care he or she needs without having to go to court and risk having all his or her other non-medical-related decision-making rights taken away in a guardianship proceeding. The downside is that the law requires non-judicial certifications of the person's incapacity to make health care decisions and does not provide a clear way for the person to challenge the 21-2210 (MDM) designation.[132] In its most recent report, DDS states: "those listed as having a §21-2210 SDM may make many of their own decisions, with or without support, and may simply rely on the designated § 21-2210 SDM in certain situations."

According to this data, the least common form of decision-making support used by people with intellectual disabilities served by DDS is durable powers of attorney, with consistently less than 1 percent of the people served having one that DDS knows about. Durable powers of attorney, unlike 21-2210 MDMs, are a way a person can voluntarily designate someone to act for them in the event they are unable to make decisions themselves, and thus are a less-restrictive option. The high percentage of people who were identified as having 21-2210 MDMs (who, in DDS' system, are usually family members), as compared to the extremely low number with identified powers of attorney, raises concerns that DDS may be over-relying on a more restrictive tool than necessary to support the people it serves. Some of these individuals may be able to voluntarily execute a power of attorney instead, but have not been offered a meaningful opportunity to do so.



Unlike the DC Probate Court data review for people with ID/DD, DDS data indicates that where there is guardianship, it is roughly as likely to be limited as it is to be general. This may be a result of DDS' stated commitment to "the use of lesser restrictive types of decision-making supports whenever possible."[133] It is interesting to note that over time, general guardianship for people served by DDS is becoming more common.

While DC has been a national leader in reforming guardianship and promoting less restrictive alternatives … data demonstrates that there is still a need for further initiatives designed to implement these changes…

Lessons Learned from the DC Experience

As indicated throughout this report, reliable national data on guardianship is scarce, let alone data specific to particular populations, such as individuals with ID/DD. This "deep dive" analysis of guardianship's impact on people with ID/DD within the District of Columbia provides rare data about what the number and types of guardianships are, whether guardianship disproportionately involves young adults, whether people with ID/DD are using tools to restore their rights, and whether recent legislative and policy reforms have yet had a significant impact. While DC has been a national leader in reforming guardianship and promoting less restrictive alternatives, the previous data demonstrates that there is still a need for further initiatives designed to implement these changes in a way that will significantly advance the decision-making rights of people with ID/DD. For example, data shows evidence of a continued pipeline to guardianship for young adults with ID/DD, despite the special education reforms designed to promote recognition of alternatives for that population.

Lessons for other states

Lessons other states can learn from the DC experience include:

- SDM can and should be recognized as an alternative to guardianship for transition-age youth, including those with ID/DD, in special education. While it is helpful to have a legislative mandate, state law change is not required for implementation of SDM in schools. Existing Family Educational Rights and Privacy Act (FERPA) forms can be modified to document SDM arrangements and ensure parents and caregivers, in their capacity as supporters, receive access to the student's educational information and continue to be invited to IEP team meetings.
- SDM can and should be introduced early in the educational process, ideally beginning in pre-kindergarten. This is particularly true with respect to the development of general decision-making and self-advocacy skills, which are required for effective SDM later in life. Conversations and skill-building efforts relating to decision-making should therefore begin early, well before the student's eighteenth birthday, in order to maximize the chances that less-restrictive alternatives to guardianship will be used.
- Educational agencies and schools must recognize the right of adult students in special education to knowingly and voluntarily execute powers of attorney under state law that designate an agent to exercise their IDEA rights. To do otherwise denies adult students with disabilities an important civil right simply because they receive special education services, which is discrimination based on disability in violation of Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act.
- Given the link between self-determination and community integration, states should include benchmarks related to SDM in their Olmstead plans. These official documents are ways states document their commitment to and plans for providing services to people with disabilities in the inclusive and integrated settings, pursuant to the ADA.
- To minimize the chance that they are overused or misused, any non-judicial alternatives to guardianship that are triggered by some form of certification of a person's incapacity—such as the DC Health Care Decisions Act or the DC Educational Representative process—must: (a) first require the express ruling out of the availability of alternative voluntary options, such as durable powers of attorney for health care or educational powers of attorney; and (b) be easily

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- While state law, regulation, and policy changes to advance alternatives to guardianship are needed, more is required to ensure full implementation for people with ID/DD on the ground. This includes intense and frequent education of people with ID/DD, their families, state agencies, school personnel, judicial and court officers, attorneys, health care professionals, and financial institutions.
- When promising procedures and policies to promote alternatives to guardianship are introduced in schools, educational oversight agencies must develop tracking mechanisms, so that they can trend the way in which IDEA decision-making rights are exercised by and/or for adult students with disabilities—e.g., through SDM, powers of attorney, educational representatives, or Guardianship—so that the impact of these reforms can be concretely assessed and monitored.
- Probate court resource centers that provide prose assistance to people seeking guardianship should also proactively provide information about less-restrictive alternatives that are also available under state law, such as SDM, powers of attorney, representative payees, and substitute or surrogate health care decision-makers.
- State laws should not only ensure that there is an unconditional right to counsel for people in initial and post-appointment guardianship proceedings, but also that counsel is expressly required to zealously advocate for their clients' expressed wishes.
- DC's law promoting limited guardianship is not significantly impacting the scope of an appointed guardian's authority over people with ID/DD, which has tended to be general or plenary in nature, based on recent data. Judicial education to ensure limited guardianships are a viable option for people with ID/DD is needed.
- Although it is too early to meaningfully assess its impact in DC, instituting periodic court reviews of whether a guardianship continues to be the least-restrictive option for a person is a promising DC reform. DC Courts should ensure this review process remains fully funded and should continue to move towards expanding it to more people whose guardian was appointed before 2015. Establishing such review processes should be considered in other states.

The DC Superior Court Probate Branch offers regular orientations to family members on what the legal responsibilities of guardians are. It and other state courts should also train family member and professional guardians on using SDM within a court-appointed guardianship to increase self-determination, as well as train people who have guardians about ways they can access the new complaint process and initiate restoration of rights proceedings.

As one community advocate in DC said, "DC is at the forefront of a lot of important legal reforms designed to promote recognition of the decision-making rights of people with ID/DD. Yet, I still regularly get calls from parents and other family members who say they were told to get guardianship and are not aware of the many less-restrictive options that are available in DC. For these promising reforms to have an impact, a culture shift still needs to happen—at the family level, at the school level, at the judicial level, at the governmental agency level—that recognizes guardianship is not the only game in town for DC residents with ID/DD."

Beyond DC Institutionalization: Donna and Ricardo's Story

A Powerful Love Story

Donna and Ricardo Thornton have a unique love story: They met at Forest Haven, an institution for DC residents with ID/DD. When the institution was shuttered in 1991 by a court order, Donna and Ricardo embarked on a journey together toward self-determination.[134] Their story is one that is marked by significant progress and achievements, made more remarkable by the obstacles they faced. They were told that they could not get married while they were considered wards of the District, but they did just that in 1994.[135] Shortly thereafter, they had a son named Ricky and raised him themselves, despite the common state practice at that time of rssemoving children born to married individuals with ID/DD.[136] They have become powerful activists by serving as leaders of Project ACTION! —a DC-based self-advocacy organization— by giving presentations around the country and testifying before the U.S. Senate.[137] Their story has been featured in the *Washington Post*, on 60 Minutes, and in a 2003 movie starring Kirstie Alley and Delroy Lindo.[138]

Journey to Greater Decision-Making Freedom

Donna and Ricardo have come a long way since Forest Haven, and have other powerful stories to share about how their lives have impacted their decision-making.

Finances

When Donna and Ricardo lived at Forest Haven, they worked at a local fast-food restaurant, but were not allowed to cash their own paychecks. Ricardo described a moment when they decided to take charge of their own money: "The rehab counselor would pick [us] up and drive us in the snow, but then he would leave, and he wouldn't pick us up . . . We had to walk back [in a blizzard]. And that's when Donna said, 'Well, you know what, since we did all this work, why don't we just keep this check?'" Donna recalled they later had to stand up to the institution's staff. "When we got back to the cabin, they told us, 'You weren't supposed to cash that check.' And I told them, 'This is our check and we spent [it].'" Donna and Ricardo got no "allowance" for that week.

After leaving Forest Haven, Donna and Ricardo were placed in separate group homes, where they had completely different experiences with financial freedom. Donna was taught how to open and manage a bank account. "When I first went into a group home, this lady counselor asked me if I wanted to learn how to open my own bank account . . . And when she taught me how to do this, I was so happy . . . Ever since then I know how to budget and save my money." Ricardo, on the other hand, could only watch as Donna gained more financial independence. "[S]he had her . . . checkbook, so she was able to manage her money . . . I was watching her and thinking, 'Someday I'm gonna do that.'" One day he decided to realize that dream by opening a bank account on his own and depositing his paycheck. However, his group home provider was not happy with his decision. "I got into trouble . . . [because] I didn't ask them to open [it] . . . [I was told] 'Next time you have to come to me so I can assist you so you know what you're doing.'"

Since that time, Donna and Ricardo have lived together for years in their home and both regularly manage their paychecks. Ricardo described his economic empowerment: "Now I put [my money] in my account and check my statement and how much I'm saving and how much I'm spending. [I]t's just being able to have that freedom . . . You can manage your own money and not let people spend your money or tell you how to spend your money. It's a good feeling—like I finally now can make decisions."

Health Care and Domestic Life

Ricardo recalls that Forest Haven made some efforts to connect its residents with counselors and jobs outside the facility. However, he does not believe Forest Haven prioritized education that focused on independence and decision-making outside the institution. He sees the lack of education as significantly impacting not only residents' human rights, but their physical health. For example, there was no formalized sex education. Ricardo recalls: "It was prohibited to talk about it, because if you did it and got caught, you'd get locked up . . . maybe three to four days . . . . If they would have had more education early, [sexually transmitted disease] could have been prevented."

When Donna and Ricardo were living on their own and expecting the birth of their son, they had to deal with assumptions about their inability to make health care decisions. For example, a medical provider did not believe Donna could make a difficult decision about whether to have an amniocentesis. Donna recalls: "[A nurse said], 'They're from institutions, they have no clue of what we're talking about.' … I kept trying to tell her, 'If you just teach us and show us, we can learn this.'" Ricardo said, "I was so proud of [Donna] that she was able to make that decision. Donna went through a period where she was hoping that someone would . . . make that decision for her, but she did it."

Now, Donna and Ricardo more confidently make their own decisions with the support from people they trust. They are in the process of executing advance planning documents, including advance directives and durable health care powers of attorney. These tools are important to them because, as Ricardo said, “If something were to happen to us, and we’re not able to make . . . decisions on our own at that time, hopefully [our agents] will be able to make the decision for us. We put our trust in it, knowing that we’re going to be all right.” Donna and Ricardo both feel that it is important for people with ID/DD to surround themselves with good supporters who will treat them with respect. “Just remember that we are all on one team, and I would love to have respect. Work with me and know that I’m not perfect, but I’m willing to make a difference.”

Chapter 6: Other Stakeholder Experiences with the Guardianship System and Alternatives

Rights Taken, Rights Restored: Tosha's Story from Texas

Tosha Woodward has a developmental disability, and up until she was in her 30s, she was gainfully employed, living as a contributing member of society with no need for guardianship.

Unfortunately, her father was mistakenly told that he needed to file for guardianship for her to live in a group home. This is a common issue for families. Tosha did not want the guardianship, and during the initial hearing, many of her due process rights were violated. For instance, her court-appointed attorney did not arrange for Tosha to participate in the hearing and signed an agreed order that removed all her legal rights including the right to vote, to choose where she lived, and even to work where she wanted.

Guardianship had a serious and detrimental impact on Tosha's life. She ended up in a segregated, sheltered workshop where she was paid subminimum wage for a job that underutilized her abilities. Her job was to take a bag filled with birdseed from the hand of a peer, rotate her body, and then drop the bag in a bin. Also, immediately after the guardianship was granted, she was moved into a group home with very restrictive rules. "I did not like all the rules that the group home and my guardian made me follow," said Tosha. "I had no freedom and wasn't allowed to make decisions for myself."

Disability Rights Texas learned about Tosha when they met her during their routine monitoring of sheltered workshops that paid subminimum wage. Their attorney informed her of her right to seek restoration from guardianship, and she asked for representation in this effort.

According to Disability Rights Texas, Tosha's guardian and the group home put up many obstacles to keep her attorney from successfully restoring her from being under guardianship, such as putting more restrictions on her life and moving her outside of the jurisdiction of the court. And then sadly, her guardian died, which made for a more complex and lengthier process to finally achieve restoration for Tosha.

When Disability Rights Texas was finally successful at getting Tosha's rights restored, she cried in relief, "I am so happy to have my freedom back. I get to make my own decisions again about where I work and live." She is now working again in the community making a fair wage at a job she enjoys.

Tosha's story illustrates the concerns NCD raised in its 2018 report with respect to the implementation of guardianship regimes, including barriers to due process in initial guardianship proceedings, lack of zealous representation by some court-appointed attorneys, the expansive loss of rights, and barriers to pursuing restoration. But it goes further than that by highlighting the restrictive impact guardianship can have on people with ID/DD, depending on the actions of the more restrictive living and working environment, with guardian. In Tosha's case, she was moved to a hardly a clear way out. It also illustrates how difficult it is for people with ID/DD to get information about their rights, whether from the guardian, the courts, the group home system, and in Tosha's case, a sheltered workplace that didn't provide any information to her. If the Texas protection and advocacy system hadn't run across Tosha during a routine monitoring, would she have been able to get her rights restored?

In Their Own Words: Other Lessons Learned from Stakeholders

NCD gathered stories about experiences with guardianship and alternatives and their perceived impact on people with ID/DD through a variety of methods, including online story collection, a focus group, and one-on-one interviews. This resulted in input from people with ID/DD, family members, and other stakeholders, including special education advocates, state employees, guardians, or administrators of guardianship programs, and staff who provide transition services to youth with ID/DD. Qualitative information was collected from more than 80 respondents from 19 states and the District of Columbia. NCD identified several themes within these stakeholder stories that shed light on the perceived impact—both positive and negative—that guardianship and alternatives have on people with ID/DD. These themes are consistent with many of the findings and recommendations in this report, which seeks to balance the importance of promoting the self-determination for people with ID/DD with the recognition of the existing state legal systems designed to provide safeguards for this population.

Qualitative information was collected from more than 80 respondents from 19 states and the District of Columbia.

Reasons Adults with ID/DD Become Subject to Guardianship

When asked when an adult with ID/DD gets put under guardianship or conservatorship, most respondents identified 18 as being the magic age at which such legal intervention is or should be sought.

- One guardian stated: "[G]uardianship should be in place by their eighteenth birthday. Otherwise, it is impossible to be included in their medical care or finances."
- A family member agreed: "At or by the age of 18, since that is when medical providers no longer include the parents in conversations about medical care. It is also when SSI begins and management of this as well as waiver supports starts."
- A family member responded: "When [people with ID/DD] turn 18, unfortunately, parents are led to believe it is needed in order to maintain involvement in their child's life or to get access to services."
- Another family member indicated guardianship referrals for people with ID/DD happen "[o]ften at or around 18, upon the advice of doctors, teachers, and others."

As indicated in Chapter 2, the educational system was frequently seen as the reason behind such referrals, but there were other reasons cited as well. Many respondents included the medical profession as a common source of guardianship referrals. For example:

- A disability rights attorney reported: "Medical providers also push for guardianship when the person presents for care and the provider believes they are not competent to consent to medical treatment."
- A respondent with ID/DD stated: "Doctors who don't know you will make a decision that you are incompetent."
- A family member reported that some providers may exclude supporters unless they have guardianship: "There has been involvement with a misinformed medical provider and says [guardianship] is required in order for individuals who support the person to be involved or support the individual with the issue."
- A family member described her experience: "Doctors thought there were a fifty percent chance he would come out of the coma and a five percent chance he would be able to live independently. [Based on that,] I thought we needed the conservatorship in order to conduct business on his behalf, but as I stated before, it was not needed. We even refinanced our mortgage without it—I explained it to the bankers/realtor, but they said he could sign for it."

Another referral source, according to respondents, comes from attorneys and judges.

- One family member said: "Schools and attorneys tell parents that they need to get Guardianship to protect their handicapped son [or] daughter when they turn 18 (or 21). I feel this is misleading! guardianship strips a person of their rights . . . [E]ssentially they become a piece of property."
- Another parent recalled her experience with an attorney: "My divorce attorney told me about power of attorney as an option, but when he met my son, he was unsure if my son understood what giving

someone POA meant . . . I [now] have medical power of attorney for my son.”

- An additional family member reported that an attorney recommended guardianship for her nephew with ID/DD because it would make it “easier” for them to set up a trust for him.
- An attorney described an interaction she once had with a judge: "I think of a conversation with a judge 15 years ago about a person with Down syndrome. The judge told me that of course anyone with Down [syndrome] should have a guardian by virtue of the diagnosis. We have come a ways, but there is so much farther to go."

[O]ne of the reasons people obtain guardianship is because of what they fear may happen without it …

Based on several respondents, one of the reasons people obtain guardianship is because of what they fear may happen without it—fear of being taken advantage of, fear of dangerous choices, and fear that supporters will be cut out of the decision-making process. For example:

- One parent said: “Parents fear their child will be taken advantage of and that their own advocacy will not be heard. Parents do not think their children will grow and develop beyond what they have accomplished by the time they are 18 and fear they will never be able to make important decisions and need to be protected.”
    - Another parent described the difficult choice she faced: “Guardianship was difficult to get for our son. Some people said, ‘He looks normal. Why do you want it?’ . . . Left on his own, someone could take advantage of him and take his money. Before we had guardianship, our son thought he was spending one-hundred dollars to take a class, but he was actually charged one-thousand. It took my husband and me two months to get the money back.”
- According to another respondent, a parent seeks guardianship when he or she “fears that they will be shut out of helping to make decisions for a family member who does not communicate in traditional ways or quickly enough during medical or financial discussions.”
- One family member who is a standby partial guardian of a sibling with ID/DD said people turn to guardianship because of “Fear. And it’s not an irrational fear. Our adult service system has a long way to go to [prove] that it can properly care for people with IDD. Our communities have a long way to go to fully accept and care for all community members in an inclusive way.”

Perspectives on the Impact of Guardianship on People with ID/DD

When answering whether they thought guardianship or conservatorship influences or changes the way people with ID/DD are treated, most respondents answered in the affirmative, although many of the responses focused on whether the guardian was skilled and knowledgeable (or not), highlighting how individual experiences within a system may vary considerably. Some respondents pointed to perceived positive changes for people with guardians. For example:

- A family member stated: "Others know the adult with ID/DD has an advocate and, in our case, a very active and involved advocate. They know they cannot take advantage of him and, more importantly, know it is OK to be helpful without fearing they may be asked for considerably more help."
- A case manager reported: "Ones without guardians are way too easy to exploit, abuse and/or neglect."
- A family member guardian said: "Those individuals [in guardianship] may be viewed as safer because there is a team of people keeping watch over their best interests."
- Some participants, mostly family member guardians, described what they felt to be the beneficial aspects of guardianship. For example:
- A parent of a person under guardianship stated: "We feel we can be proactive rather than reacting [to] a problem. Having guardianship makes it easier to speak and make [decisions] with professional[s] — medical and governmental—about our son."
- Another parent and guardian agreed: "My son has medical as well as cognitive issues. It was imperative that his health and well-being would be overseen by us, his parents who have his best interests at heart. Having guardianship has meant that we can make medical decisions and program decisions that benefit him, as no one else knows him as well as we do. He is incapable of understanding these things and he needs protection, which we can supply as his guardian."

Others saw benefits when guardianship is used with SDM to encourage the development of decision-making skills and self-determination.

- One disability rights attorney recalled her experience with a client who was placed in guardianship: "My client, who has an intellectual disability, was found wandering the streets at the age of 19 after her father died. Having completed high school, she was no longer receiving services and was unable to care for herself. She was placed in a nursing home and put under guardianship. Her guardian was an incredible advocate for her. He got her connected with services, which truly allowed her to grow. Eventually, she completed a training program and began full-time employment with benefits. Her guardian recognized the growth in skills and independence that had happened and worked with me to assist my client in terminating her guardianship in favor of supported decision-making. Now my client makes all decisions."
    - Another parent and guardian described how they incorporate SDM in the guardianship: "[W]e strongly support our daughter in self-direction, on her own, as much as possible . . .

> She is a recipient of our state's DD waiver program . . . It supports therapies, direct support services such as transportation, and community or homemaker direct support. This helps her with supported decision-making to have an improved quality of life in the community."

Many stakeholders who responded to this question saw a negative change in the way society treats people with ID/DD after a guardian is appointed. For example:

- A family member stated: "In my experience, the person [under guardianship] is then seen as having nothing to contribute to decisions about any aspect of their life. Instead of presuming competence people begin to presume inability and lack of intelligence."
- Another family member agreed: "They are viewed as people who need to be protected, who do not have preferences, stresses, interests, desires . . . and will likely never achieve independence or full active lives in the community."
- A person with ID/DD who does not have a guardian stated: "I've seen people not be treated like humans—like they're just a disability."
- A family member guardian stated: "They talk to me, not him—it's like he is not there beside me."
- A social worker said: "They may be looked down upon as being unable to care for themselves or meet their own needs."
- A family member from Kentucky pointed to "lower expectations, less opportunities, seen as less valuable."

Some respondents noted that guardianship is sometimes used as a tool for control. As one attorney explained: "In [my state], providers are not prohibited from becoming guardian over those who use their services. Sometimes this has been done 'benevolently,' other times it has been done manipulatively to prevent the person from leaving services or changing service providers."

Some respondents mentioned due process concerns, specifically how easy it is to obtain guardianship over a person with ID/DD and how difficult it can be to terminate:

- One family member of a person with ID/DD stated: "I am aware of a handful of individuals who would like to have their rights restored and their efforts are stalled by a lack of legal support to execute the proper documents. The[y] are unaware of the process. Those served by service providers without family have no resources to terminate guardianship, despite having an interested party attempting to make it happen."
- One professional described not knowing what to do when a person she supported wanted to fire his guardian: "I felt that I don't really know what to do, because there was always talk about getting guardianship. There was never talk about . . . reinstating rights. [Guardianship is seen as] the one-way ticket… There wasn't an

idea: How do we reverse this?"

Other respondents described people with ID/DD experiencing a regression of their decision-making abilities while under guardianship:

- One family member stated: "[My family member under guardianship] has overcome many obstacles and her potential is unknown, but one thing she is not, is incompetent. Nobody cares. She is regressing. She is learning to be helpless and does not want to live this way. Watching what is happening to her reminds me of experiments I have read about like the Stanford Prison experiment, and how over time you become the person you are made to be."
- A sibling of a person under guardianship stated: "My brother has a severe intellectual disability and autism. He's primarily nonverbal and is dependent on others for many of his daily life activities . . . I think the lowered expectations associated with my brother being under guardianship have caused him to lose the progress on skills and independence that he was making towards the end of high school. In many ways, he has regressed and become more dependent on others. It's very frustrating both as his sister and as a researcher to see this happen and be limited in intervening."
- Some respondents pointed to both positive and negative consequences. For example:
- One family member stated: "I hate to say this, but in general, I feel that it makes people treat disabled people like they are children incapable of doing anything by themselves. In extreme cases like my cousin, [however, guardianship] is absolutely vital."
- Another family member in a different state agreed: "It can be associated with lowered expectations for individuals with ID/DD, but also the perception of more oversight and regulations as it is not the person with ID/DD making most decisions."
- An administrator of guardianship explained: "We have witnessed both positive and negative changes: As decision-makers for individuals supported in guardianship, agencies are hard pressed to go against the wishes of the guardian, especially if we disagree with plans for the individual. I am concerned that sometimes, treating physicians and other professionals may not embrace the person, instead there may be a focus on the guardian/decision-maker."

Perceptions on the Impact of Alternatives to Guardianship on People with ID/DD

Many respondents described how they use alternatives to guardianship, such as powers of attorney or SDM, and the benefits of using these options.

- One mother described her son's experience: "supported decision making has given my son a very good experience of forming the life that he wants while we ensure his safety and locate a great network of support. People with intellectual disabilities should be able to create a life that they enjoy filled with their desires."

- A respondent explained how her family member has become more confident since guardianship was terminated: "I continue to be the representative payee, and I am considering terminating that role in light of what I now know about supported decision-making. I know that my family member will continue to need help handling interactions with Social Security, Medicare, et cetera, but I would like to return the right to decide how his SSD is spent [on] him. He is already more confident and assertive since the conservatorship termination, and I expect him to continue to grow as he takes ownership of his decisions with my support."
- When it comes to people with ID/DD, some recommended considering and using a combination of alternatives. For example, a respondent reported: "My sibling has a power of attorney to assist her with her medical, financial, and legal needs. In addition, [she] has a representative payee to assist [her] with managing her Social Security benefits. In addition, my sibling has a formal circle of support to assist her with helping to address the things that are important to her: her business, her employment, finding/hiring direct support workers, managing her supports, and living a good quality of life."

Others cautioned against overzealously promoting alternatives to the point where guardianship became a "dirty word." For example:

- A lawyer and family member agreed with the exploration of alternatives, while recognizing that guardianship may remain a valid option in certain cases: "As long as the concept of using the least restrictive alternative/intervention appropriate for that person is used, I have seen these alternatives to guardianship be successful. However, guardianship should not be turned into a dirty word. My brother needs a guardian for his own safety and welfare, but, of course, that does not remove the obligations in [Massachusetts] of the guardian to take into account his express desires and to only exert the amount of authority necessary."
- One parent expressed concern that people were too often being discouraged from getting guardianship and described an "anti-guardianship movement" that could be perceived as an "attack on families" of people with ID/DD.

Importance of Self-Determination for People with ID/DD

Another common theme expressed by some self-advocates, family members, and professionals is that promoting self-determination can have a host of positive benefits for people with ID/DD.

- As one self-advocate explained, "My belief is that a person with a disability can get confidence with making decisions from their family members, when they figure out what they need. My belief is that they get support from their family members and, later on . . . they pretty much got a skill to make decisions and that is like adaptability."

- A parent of a person with ID/DD also described the confidence that can come with decision-making: "In my opinion, the key is teaching [my daughter with cerebral palsy] decision-making skills and helping her feel confident enough to express her opinions and decisions. However, I knew very early that my daughter was very capable of making her own decisions, regardless of what others thought."
- An attorney recounted the experience of her client whose guardianship was terminated: "My client had her guardianship terminated in favor of using supported decision-making. This arrangement has allowed her to exercise self-determination and independence. One of the first things she did was sign up for her benefits at work. It means so much to my client to be able to make her own decisions and have control over her life."
- A parent expressed how important it was to involve people with ID/DD in decisions about health care. "More than 20 years ago when my daughter was a teen, her doctor recommended that she have surgery to restructure her hip socket, which would help prevent arthritis and other painful conditions. I sought a second opinion, which validated the recommendation. My daughter had the surgery, which was very painful, required a body cast and a fairly long recovery period. I made this decision for her, but she suffered. I decided then that I would never do that again, without her understanding and agreement, except in dire circumstances. Since that time, we have always discussed her health care and made decisions together."

Societal Biases Impacting the Decision-Making of People with ID/DD

Several respondents also described the negative assumptions people with ID/DD have faced regarding their ability to make their own decisions or the need by others to control their decisions.

- A person with ID/DD described the reactions he received after he purchased a house: "When I got the house . . . a lot of the people were shocked . . . [T]hey didn't think I deserve to have anything that they have because of my disability . . . But for the first two years I didn't think [the house was] mine . . . I thought somebody is going to come to me and tell me 'Get your retarded butt out of my house, it's not yours.' . And I was paying the mortgage and everything but because for so many years I was told what I couldn't have, what I couldn't do, I didn't believe the house was mine. And then when I realized the house was mine, I cried."
- A parent explained: "Often people with visible [ID/DD] are assumed to be less than whole and not capable of knowing what they want or what they're doing. For instance, a waiter will often address the companion of the person with [ID/DD] when taking an order in a restaurant, rather than asking the person directly."
- A self-advocate agreed: "[W]hen you have a disability, everybody sees themselves a

bit above you and they see themselves a bit above me, because, even [in] my personal life, I have very close people who wanted to control me . [T]hen they disrespect you, but they think they [are] doing something for you. [B]ut sometimes, people they want to control you."

The Power of Communication in All Forms for People with ID/DD

Communication is a vital part of decision-making, and some of the assumptions made about people with ID/DD may spring from their non-traditional method of communication.

- As stated by a parent of an adult child with ID/DD, "[P]eople with [ID/DD] who don't use words to communicate or whose language is hard for others to understand, are assumed to be less than capable of having their own opinions. Not true . . . [W]e need to understand how the individual with [ID/DD] communicates, and share that information, so that the voice of the person with [ID/DD] will be heard."
- Another family member agreed: "Most people who have trouble with traditional communication because of the pace or complexity of the interaction are perceived as someone who needs help to make decisions."
- A self-advocate told a story about how a person who did not communicate through words was treated: "[S]omebody that I knew long time ago… he was throwing a fit and was making noises and [the provider] thought that he was acting up . . . [T]hey got mad at him and got ready to write him up. [R]ather than enforcement, he is very intelligent. He should've been able to [be supported to] communicate like [with] a notepad or a keyboard."

When supporters and others learn how to effectively communicate, it can unlock the person's decision-making ability. A self-advocate in DC recalled her experience of learning how to creatively communicate with a peer who did not communicate verbally: "When I was in school riding the school bus, I ran into this pretty young girl . . . I asked the bus driver who [she was] . . . He said she can't walk or talk, and I said . . . 'Not now, but she will.' and by the end of that school year . . . me and her came up with a way of talking. She talks [with] her eyes [by blinking] . . . It's just a different form or way of talking."

The Impact of a Lack of Opportunity to Make Decisions on People with ID/DD

Multiple respondents discussed how a lack of education on decision-making negatively impacts people with ID/DD. For example:

- One parent of an adult child described her feeling that people with ID/DD are not always encouraged or asked to weigh in on their own decisions or encouraged to advocate for themselves: "[M]any people] with [ID/DD] are not taught to make their own decisions or given the go-ahead to do so. We need to teach all children, including those with [ID/DD], about decision-making and the give and take that's sometimes involved. They need to learn to choose in small ways whenever possible.”

- A self-advocate who regularly gives following story: “One year we was asking people what they wanted out of life and this one man, I think he was in his fifties, he started crying, and we was asking him why, and he said that that was the first time anybody ever asked him what he wanted, and he grew up in the system and nobody cared about what he wanted.”
- Another self-advocate with ID/DD, on the other hand, recalled the advice she received that not everyone does: “My mother always told me to speak up so that I won’t be left behind.”

> *“One year we was asking people what they wanted out of life and this one man, I think he was in his fifties, he started crying, and we was asking him why, and he said that that was the first time anybody ever asked him what he wanted, and he grew up in the system and nobody cared about what he wanted.”*

Many respondents tied the lack of education on and opportunity for decision-making to the effects of living in a more restrictive community setting such as a group home. Several self-advocates described how such a living situation shaped their perspectives on decision-making and self-determination. One person with ID/DD wondered how people would learn from their mistakes if they are not allowed to make any: “I feel like a group home is another small institution. [I]f somebody keeps telling you [not to] do something, how are you going to learn from something?”

Chapter 7: Findings and Recommendations

As a supplement to the corresponding section in the 2018 NCD report, below are additional findings and federal level recommendations designed to improve the experience of people with ID/DD in systems of guardianship and in the implementation of less-restrictive alternatives.

Key Findings and and Recommendations

Finding 1: The lack of data on existing guardianships and newly filed guardianship includes information on the specific nature of the person's disability, thus making it difficult to have reliable state and national information on how guardianship systems impact people with ID/DD and whether that population is likely to be in limited or full guardianship than people with other disabilities.

Recommendations:

- The Social Security Administration has data based on disability-related eligibility Listings. Therefore, it should not only conduct data on whether individuals it serves are subject to guardianship, but trend it against the type of disability.
- Offer states incentives and technical assistance with developing electronic filing and reporting systems that collect basic information about guardianships, including the alleged disability of the person served—as well as their age—among the other information recommended in the 2018 NCD report.
- The National Core Indicators (NCI) website should also specify, on a state-by-state basis, precisely to what population of people with ID/DD the state is administering its survey, so that one can assess whether the data collected is truly representative of the full population of people with ID/DD in that state.

Finding 2: People with ID/DD currently are at higher risk for guardianship because of the school-to-guardianship pipeline.

Recommendations:

- The U.S. Department of Education OSERS renewed its previously archived 2017 "Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities," which recognized the serious implications of guardianship and encouraged

Key Findings and and Recommendations*, continued*

schools to recognize SDM and other less restrictive decision-making support for adults in special education. OSERS should do more to promote implementation of this guide at the state and local level, including requiring State Educational Agencies to:

  - Ensure robust and repeated trainings of educational professionals at the agency and school level on options for supporting the decision-making of adult students with disabilities, including people with ID/DD, that are less-restrictive than guardianship.
  - Create a modified FERPA form for the transition process that documents SDM arrangements that ensure parents and caregivers can support transition-age youth in making educational decisions after rights transfer to them.
  - Ensure local school systems do not unlawfully discriminate against adult students with disabilities who wish to exercise their civil right to execute a power of attorney under state law.
  - Develop tracking mechanisms to determine how decision-making rights are exercised by and/or for adult students in special education to assess and monitor the use of guardianship and alternatives by transition-age youth.

- OSEP should instruct its Parent Training and Information Centers to prioritize and provide meaningful training on school-to-adult transition and alternatives to guardianship.
- The Department of Education should issue a "Dear Colleague" letter to all teacher education programs and vocational rehabilitation agencies urging them to cover the full range of decision-making options in their transition programming and instruction of accommodations for people with ID/DD.
- The Department of Education should issue regulations and/or guidance clarifying the requirements for states that, pursuant to their own state law, create an educational representative appointment option for adult students who cannot provide informed consent for their special education services, pursuant to IDEA (30 U.S.C. § 1415(m)(2)) and its regulations (34 C.F.R. § 300.520(b)). When such appointment is triggered by a parent's request or an alleged certification of incapacity, states must require that: (1) less-restrictive options, such as educational powers of attorney or other voluntary delegation by the student are exhausted first; and (b) such appointments are easily challengeable by the students involved through, for example, a mere objection rather than by a due process hearing before an administrative law judge.

Key Findings and and Recommendations, *continued*

Finding 3: A minority of states have guardianship provisions that are applicable solely to people with ID/DD, as opposed to other alleged disabilities. While some of these statutes incorporate additional procedural safeguards, there is not demonstrable proof that they are advancing the due process and substantive rights of people with ID/DD in practice and, in treating people with ID/DD uniquely, may be promoting unfavorable stereotypes about the inherent capacity or incapacity of this population. In addition, these statutes could represent an ADA violation for discriminating against people with different disabilities.

Recommendations:

- The U.S. Department of Justice should take the position that the degree of due process in a guardianship matter under state law or practice should not be different for people with ID/DD simply because of their diagnosis, and states that have such statutes or practices are engaging in discrimination under the ADA.
- The state adult guardianship court improvement program that NCD recommends be created and funded in the 2018 NCD report should require that guardianship be used as a matter of last resort and that the person's functional abilities be assessed on an individualized basis rather than on the basis of the person having an ID/DD, consistent with the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act.

Finding 4: While more states should advance alternatives to guardianship in their state laws, regulations, and policies, more is required to ensure that these changes are fully implemented on the ground, creating a cultural shift at the judicial, governmental agency, and business levels that significantly recognizes and advances the decision-making rights of people with ID/DD.

Recommendations:

- DOJ should issue guidance to states on their legal obligations pursuant to the ADA in the context of ensuring that guardianship should be a last resort that is imposed only after less-restrictive alternatives have been determined to be inappropriate or ineffective. This guidance should include requirements that states consider including benchmarks related to SDM in their Olmstead Plans.
- The state adult guardianship court improvement program referenced above should require states to:
    - Not fund probate court resource centers that only provide pro se assistance to people seeking guardianship. Those resource centers should also provide people with information about less-restrictive alternatives under state law, such as SDM, powers of

Key Findings and and Recommendations*, continued*

    attorney, representative payees, and substitute or surrogate health care decision-makers.
    - Ensure that there is an unconditional right to counsel for people in initial and post-appointment guardianship proceedings and that counsel is expressly required to zealously advocate for their clients' expressed wishes.
    - Provide judicial and attorney trainings on the availability of less-restrictive options for decision-making support under state law.
- The DOJ should issue guidance to states on how to minimize the risk of overuse or misuse of involuntary, non-judicial alternatives to guardianship, such as those in educational or health matters, which raise due process concerns. States should legally require ruling out voluntary options—such as SDM and powers of attorney—before such involuntary options can be used. Those involuntary options should also be easily challenged by the person.
- The U.S. Department of Health and Human Services should explore ways to facilitate decision-making support for people with ID/DD, particularly for those who may not have a large network of trusted family members and friends. This should include providing funding to support:
    - Community services such as health advocate programs, in which a supporter attends medical appointments, assists the supported person with understanding and making major medical decisions, and acts as a facilitator between the supported person and his or her doctor.
    - Financial case management services, including regular meetings with supported individuals to discuss budgeting, establishing direct debit and deposits, and assisting in the management and recertification of public benefits.
    - Educational advocate services to help adult students with ID/DD understand and make educational decisions. Examples of this type of support could include attending IEP meetings, assisting with transition planning, and facilitating communication between the supported person and education officials.

Finding 5: Despite the existence of restoration of rights procedures in many state laws, many people with ID/DD and their families are unaware of those options, let alone the broad array of less-restrictive options. People with ID/DD may therefore remain in guardianships that are overbroad or undue for most of their lives.

Key Findings and and Recommendations, *continued*

Recommendations:

- The state adult guardianship court improvement program referenced above should require states to:
    - Regularly notify people in guardianships, their guardians, and other interested parties in their life that guardianship need not be permanent and that there are concrete ways to pursue restoration of rights.
    - Periodically review guardianships to determine whether they remain the least restrictive option or should be modified or terminated.
    - Train family and professional guardians on using SDM within a court-appointed guardianship to increase self-determination and the potential for restoration of rights.
    - Train people in guardianship on ways in which they can complain about their guardian and initiate restoration of rights proceedings.

Finding 6: There is a dearth of reliable data on the number of adult abuse, neglect, or exploitation cases in which the perpetrator is the court-appointed guardian or other substitute decision-maker of the victim. According to the National Adult Maltreatment Reporting System (NAMRS), eighteen states do not collect any perpetrator information.[139] Of the states that do track general perpetrator information, the vast majority do not collect specific information regarding a perpetrator's role as the court-appointed guardian or other substitute decision-maker.[140] Although the NAMRS requests data from states about the perpetrators' role as the victims' court-appointed guardian or other substitute decision-maker, in 2017 only four states submitted data for the start of the investigation. No state has ever submitted data to NAMRS for the end of the investigation.[141]

Recommendations:

- States should continue to be encouraged through the NAMRS and other mechanisms to collect, track, and report the number of cases in which perpetrators are the victims' court-appointed guardian or other substitute decision-maker.
- The state adult guardianship court improvement program referenced above should require that state courts review the annual reports of guardians for signs of unusual or deficient accounting and signs of abuse and neglect.

Appendix A: Analysis of ID/DD Specific Guardianship/Conservatorship Statutory Provisions

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
Alabama Ala. Code § 12-13-21 et seq.	▪ Defines "developmentally disabled" person as a person "whose impairment of general intellectual functioning or adaptive behavior meets the following criteria: (1) It has continued since its origination or can be expected to continue indefinitely; (2) it constitutes a substantial burden to the impaired person's ability to "perform normally in society"; (3) it is attributed to one or more of the following: "including intellectual disability, cerebral palsy, epilepsy, autism, a condition found to be 'closely related' to intellectual disability because it 'produces a similar impairment'" or requires similar treatment or services, or dyslexia related to these conditions. ▪ "Perform normally in society" is not defined by the statute, and the language used in the statute to refer to specific disabilities is outdated. ▪ Guardianship for a developmentally disabled person shall be used "only as is necessary to promote and protect the well-being of the person, including protection from neglect, exploitation, and abuse; shall be designed to encourage the development of maximum self-reliance and independence in the person; and shall be ordered only to the extent necessitated by the person's actual mental and adaptive limitations." ▪ The court may appoint as guardian for a developmentally disabled person "any suitable person or agency, public or private, including a private association or nonprofit corporation capable of conducting an active guardianship program for a developmentally disabled person." The court cannot appoint the Department of Mental Health as guardian or any other agency that directly provides services to the person with ID/DD. ▪ A petition for the appointment of a guardian may be filed by "an interested person or entity," or "by the individual." "Interested person or entity" means an adult relative or friend, an official or private agency, corporation,

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	or association "concerned with the person's welfare," or any other person the court found suitable. ▪ While it does not specifically cross-reference the standard Alabama guardianship statute, this provision does not set forth separate and specific procedures for the appointment of a guardian. The impact of the two provisions above on guardianship for persons with ID/DD is not evident from the text.
Arizona Ariz. Rev. Stat. § 36-564 et seq.	▪ Appointed under and governed by the same procedures, with clarification that guardianship and conservatorship "shall be utilized only as necessary to promote the well-being of the individual . . . and shall be ordered only to the extent necessitated by the individual's actual mental, physical and adaptive limitations." ▪ Department of Economic Security may request the appointment of a guardian if it feels a guardian would be in the person's best interest. When no one is available to act as the guardian, the Department must notify the public fiduciary in the county where the person receives services of "the need for a guardian."
California Cal. Health & Safety Code Div.1, Pt. 1, Ch. 2, Art. 7.5, §§416 to 416.23	▪ Governed by the same procedures, with main exceptions listed below. ▪ Provides that the court may appoint the Director Developmental Disabilities as guardian or conservator of the person and estate, stating that the typical order of preferences for that appointment do not apply. ▪ Sets forth unique requirements for the Director, such (a) payment of a single official bond, rather than bonds per individual; (b) responsibilities to maintain close contact with the person, no matter where they live in the state; "act as a wise parent would act in caring for his developmentally disabled child"; and "permit and encourage maximum self-reliance" on the part of the person; (c) provide at least an annual review in writing of the physical, mental, and social condition of the person. The Director may receive reasonable fees for such services. ▪ Provides additional requirement that regional centers provide the court with a "complete evaluation" of the person, including "current diagnosis of his physical condition prepared under the direction of a licensed medical practitioner and a report of his current mental condition and social

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	adjustment prepared by a licensed and qualified social worker or psychologist." ▪ Requires the court to appoint an attorney to represent the person if he or she does not have attorney, with the person paying the cost if able. In non-ID/DD cases, appointment of an attorney for the person is at the court's discretion, unless the person requests one. ▪ Allows for exceptions to person's attendance at the hearing that is similar to those in non-ID/DD cases. ▪ Requires that when a person will not be present at the hearing, that the psychologist or social worker who evaluated the person visit and "be prepared to testify as to his or her present condition." However, the psychologist or social worker in question is required to consult the person to determine the person's opinion concerning the appointment" and must be prepared to testify as to the "person's opinion, if any." In non-ID/DD cases, a court investigator is required to interview the person, petitioner(s), and proposed conservator(s), spouses/domestic partners, and certain relatives; make investigative findings; and submit a report to the court. ▪ No costs or fees may be charged or received by the county clerk for any official services performed, including the filing of the conservatorship or guardianship petition.
Connecticut Conn. Gen. State Ann. 45a 802h §§-669 to -693	▪ Intellectual disability diagnosis is part of standard for appointment of a guardian, but the person must also be found to be unable to meet essential requirements of physical health and safety and unable to make informed decisions about matters related to their care. ▪ There is a stronger requirement for counsel for the person "Unless the respondent is represented by counsel, the court shall immediately appoint counsel for the respondent" paid through the state if the person is indigent. The non-ID/DD statute allows a person to knowingly waive counsel. ▪ The person will be present at the hearing, except that "the court may exclude the respondent from such portions of the hearing at which testimony is given which the court determines would be seriously detrimental to his or her emotional or mental condition."

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	▪ The statute uses a "clear and convincing evidence" standard of proof. ▪ Neither plenary nor limited guardians can: (1) admit the person to a mental institution, except under specific provisions of law at 17a; (b) admit the person to any "training school or other facility provided for the care and training of persons with intellectual disability" if there is a conflict between the guardian and the protected person, or their next of kin; (c) sterilize the person, perform "psychosurgery" on the person, terminate the protected person's parental rights, prohibit the person's marriage, or consent on the person's behalf to the removal of an organ, except under specific provisions of law at 17a and 45a; (d) consent to any experimental medical procedure, except under specific circumstances in which the procedure is necessary to preserve the person's life or endorsed by a court, an institutional review board, or the person's physician. ▪ If the person is eligible for Department of Disability Services (DDS) s, a written report or testimony must be provided from a DDS assessment team on the severity of the ID/DD and the specific areas, if any, where supervision and protection of a guardian is needed. ▪ The court is required to review each guardianship at least every three years and shall either continue, modify, or terminate the order of guardianship. Written reports on the condition of guardianship are required on the person's condition, with less mandated reports for people within the severe or profound range of intellectual disability. The person has a right to counsel.
Florida Fla. Stat. Ann. §§ 393.12, 744.3085	▪ Guardian advocates are only appointed for individuals with developmental disabilities. The court considers them a "less restrictive form of guardianship," even though the guardian advocates have the same powers, duties, and responsibilities required of a guardian under chapter 744." ▪ Guardian advocate may be appointed, without an adjudication of incapacity, if the person lacks some, but not all, decision-making capacity to take care of person or property or if the person voluntarily petitioned for appointment. The guardian advocate is qualified to act as a guardian with the same powers, duties, and responsibilities.

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	▪ Restoration of rights procedures are detailed under this subsection, but appear substantially similar to those in other guardianship statutes.
Hawaii Haw. Rev. Stat. Ann. §§ 333F-11	▪ Director of health may be appointed guardian of a person with an intellectual or developmental disability if: (a) there is no other suitable guardian; (b) the person is expected to need treatment in a residential facility; (c) the person was found "incapacitated" as defined in the guardianship statute; (d) the person is intellectually or developmentally disabled.
Idaho Idaho Code Ann § 66-404 et seq.	▪ Determination of the presence of a developmental disability is part of the required findings for appointment of a guardian, but so is the person's "ability to meet essential requirements of physical health or safety and manage financial resources." Additionally, , "developmental disability" is defined in such a way that substantial adaptive functioning services and a continuing need for services are part of the definition. ▪ Institutional commitment proceedings and guardianship appointment procedures are part of the same series of statutes entitled "Treatment and Care of the Developmentally Disabled." ▪ Legislative intent that "the citizens of Idaho who have developmental disabilities are entitled to be diagnosed, cared for, and treated in a manner consistent with their legal rights in a manner no more restrictive than for their protection and the protection of society, for a period no longer than reasonably necessary for diagnosis, care, treatment and protection, and to remain at liberty or be cared for privately except when necessary for their protection or the protection of society." ▪ Evaluation committee must be appointed to evaluate the individual's needs for a guardian and the appropriateness of the potential guardianship. The committee is made up of persons associated with the Idaho Department of Health and Welfare's Bureau of Developmental Disabilities Services. In its report, the committee should state what specific skills the person has and suggest ways to limit the guardian, among other things.
Iowa Iowa Code §§ 222.34 et seq.	▪ Statutory provision states, "if a guardianship is proposed for a person with an intellectual disability, guardianship proceedings shall be initiated and

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	conducted" pursuant to Iowa's standard guardianship statute (Iowa Code § 222.34). - However, "[i]f the court appoints a guardian based upon mental incapacity of the proposed ward because the proposed ward is a person with an intellectual disability . . . the court shall make a separate determination as to the ward's competency to vote. The court shall find a ward incompetent to vote only upon determining that the person lacks sufficient mental capacity to comprehend and exercise the right to vote" (Iowa Code § 633.556(1)).
Kentucky Ky. Rev. Stat. Ann 33 §§ 387.550 to .880	- Kentucky's "Guardianship and Conservatorship for Disabled Persons" refers to those who may be appointed a guardian as "having a legal disability." The definition of "developmental disability" from the state's general definitions of "disability" in this statute and uses the federal definition to define the former. However, nowhere else in the statute is the term "developmental disability" used, so it is not statutorily clear how this may impact people with ID/DD. Concerns may be raised that a person with a developmental disability could be presumed to need a guardian. - The Kentucky statute otherwise appears to pertain to all people with disabilities (who do not fall into some other category, such as minors or people under the jurisdiction of Veterans Affairs), rather than specifically people with ID/DD.
Michigan Mich. Comp Laws Ch. 4 330.1600 et seq.	- Guardianship of adults with ID/DD can only be appointed under this chapter. - Petition must be accompanied by a report that contains (1) a description of the person's developmental disability, (b) current evaluations of the person's mental, physical, social, and educational condition, adaptive behavior, and social skills, (c) an opinion whether guardianship is needed, the type and scope of the guardianship, and the reasons for the guardianship, (d) a recommendation concerning appropriate rehabilitation and living arrangements, (e) the signatures of those who performed the evaluations, one being a physician or psychologist who is competent in evaluating persons with developmental disabilities, and (f) a list of the person's medications.

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	▪ Appointment requires specific court findings on the record regarding the nature and extent of the person's impairment, the person's capacity to care for himself, the person's ability to manage his financial affairs, and the appropriateness of the proposed living arrangement. ▪ To appoint a guardian there must be a finding on the extent of the person's ability to make and communicate "responsible decisions concerning his or her person." It is not clear from the context what a "responsible decision" would be. ▪ Any limited guardianship established for developmentally disabled persons must be substantially and specifically limited in scope only to the extent necessitated by the individual's actual mental and adaptive limitations. ▪ The probate court needs only give "due consideration" to the individual's preference regarding the person to be appointed guardian, rather than being required to appoint that designee unless he or she is unsuitable or unwilling to serve as guardian.
Minnesota Minn. Stat. §§.252a.01-252a.21.	▪ Allows for the Commissioner of Human Services to be named as public guardian for an individual with a developmental disability if no other person is willing to become the person's guardian. ▪ Whether the individual has a defined developmental disability is relevant to the proceedings. ▪ For people subject to ID/DD guardianship, an annual review of physical, mental, and social adjustment and progress is required. ▪ If the Commissioner determines the person no longer needs public guardianship, the commissioner or local agency shall petition the court to restore capacity and modify the court's previous order. ▪ The person has certain rights including the right to petition the court for termination or modification of the guardianship and to be represented by an attorney in any proceeding. ▪ As public guardian, the commissioner is required to take actions and make decisions on behalf of the person that encourages and allows the maximum level of independent functioning in a manner least restrictive to personal freedom "consistent with the need for supervision and protection" and permit and encourage maximum self-reliance and input by

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	the person's nearest relative.
New York NY Surr. Ct. Pro. Act Law §§ 1750-1761	▪ Appointments are driven by diagnosis (intellectual disability and developmental disability) rather than function, relying on a finding by health care professionals of the presence of certain developmental disabilities. ▪ A hearing on the guardianship petition is not required in all cases. For guardianship brought by parents, or another person with the consent of the parents, the court may dispense with the hearing. ▪ Where there is a hearing, the person's presence may be more easily dispensed (if "likely to result in physical harm," or the person is "medically incapable" of attendance, or there are "such other circumstances which the court finds would not be in the best interest" of the person). ▪ The burden of proof is lower—unlike the non-ID/DD statute (clear and convincing evidence of three-prong criteria) —and there is no indication of the burden of proof; and as a civil proceeding, it is presumptively preponderance of the evidence. ▪ There is no clear right to counsel. ▪ There is no clear right to cross-examine. ▪ There is no requirement for court findings after a hearing. ▪ There are no provisions for considerations to be taken by the court as to the eligibility and qualification of the guardian to be appointed. ▪ Upon determination of diagnosis and "best interest" finding, no less restrictive alternatives are required to be considered. ▪ Guardianship cannot be limited. ▪ It only requires annual financial reports by a guardian of property. ▪ Guardianship presumptively continues for the life of the person and can be modified to protect the person's "financial situation and/or his or her personal interests" without a hearing. ▪ The decisions of a guardian are based on "best interest." ▪ The guardian can make "any and all health care decisions" for the person with a disability—including those decisions which are typically prohibited by other states unless the person or next of kin directly consents—or is limited to only being authorized under very specific circumstances (such as withholding of life-saving care).

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
South Dakota S.D. Cod. Laws 27B-3-1 to 3-52 & 29A-5-110	▪ Allows state institutions for people with developmental disabilities to file a guardianship petition if an individual they are serving cannot consent to being institutionalized. ▪ An employee of the institution *can* be appointed as guardian "if the court finds the appointment is in the best interest of the minor or protected person."

Appendix B: Table of Analysis of NCI Data for States & Guardianship for People with ID/DD

Source of Data: National Core Indicators, Chart Generator 2014-15, National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved from the National Core Indicators website (http://www.nationalcoreindicators.org/charts/) on October 31, 2018 (for 2008 to 2015 data) and January 18, 2018 (for 2015 to 2016 data)

Key: G = Limited Guardianship, Full Guardianship, or Has a Guardian but unable to distinguish level; F = Full Guardianship; DK = Don't Know; N/A = Chart not available; Total Resp. = Total Respondents

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
AL	27% G 26% F 0% DK	23% G 20% F 1% DK	20% G 18% F 1% DK	40% G 39% F 0% DK	23% G 22% F 0% DK	25% G 23% F 1% DK	N/A	22% G 19% F 1% DK	3031	**26% G 24% F 1% DK**
AR	42% G 33% F 0% DK	54% G 35% F 0% DK	54% G 31% F 1% DK	60% G 43% F 0% DK	60% G 45% F 0% DK	62% G 45% F 1% DK	60% G 43% F 1% DK	63% G 44% F 1% DK	3067	**57% G 40% F 1% DK**
AZ	N/A	N/A	N/A	54% G 51% F 2% DK	N/A	56% G 55% F 3% DK	N/A	59% G 53% F 1% DK	1333	**56% G 53% F 2% DK**
CA	N/A	16% G 7% F 5% DK	N/A	25% G 12% F 21% DK	N/A	N/A	31% G 11% F 7% DK	N/A	25304	**24% G 10% F 11% DK**
CO	N/A	N/A	N/A	N/A	N/A	43% G 39% F 0% DK	46% G 46% F 0% DK	47% G 41% F 0% DK	1217	**45% G 42% F 0% DK**
CT	78% G 64% F 0% DK	N/A	N/A	80% G 67% F 0% DK	77% G 67% F 0% DK	79% G 69% F 1% DK	79% G 72% F 0% DK	83% G 75% F 1% DK	2385	**79% G 69% F 0% DK**
DE	29% G 24% F 6% DK	N/A	N/A	N/A	N/A	N/A	14% G 9% F 3% DK	24% G 11% F 3% DK	1060	**22% G 15% F 4% DK**

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
DC	N/A	42% G 14% F 7% DK	N/A	N/A	N/A	37% G 14% F 10% DK	33% G 14% F 36% DK	54% G 17% F 11% DK	1222	**42% G 15% F 16% DK**
FL	N/A	N/A	25% G 20% F 1% DK	27% G 19% F 1% DK	28% G 21% F 1% DK	28% G 20% F 1% DK	29% G 19% F 1% DK	30% G 20% F 1% DK	7381	**28% G 20% F 1% DK**
GA	11% G 9% F 1% DK	14% G 11% F 2% DK	14% G 11% F 1% DK	17% G 14% F 0% DK	17% G 15% F 0% DK	17% G 14% F 0% DK	12% G 11% F 1% DK	16% G 15% F 0% DK	3886	**15% G 13% F 1% DK**
HI	N/A	N/A	N/A	76% G 75% F 1% DK	77% G 76% F 1% DK	70% G 67% F 1% DK	70% G 67% F 1% DK	66% G 64% F 0% DK	2045	**72% G 70% F 1% DK**
IL	74% G 70% F 1% DK	65% G 59% F 1% DK	65% G 61% F 2% DK	65% G 62% F 2% DK	64% G 60% F 1% DK	62% G 57% F 1% DK	64% G 62% F 0% DK	71% G 68% F 0% DK	2950	**66% G 62% F 1% DK**
IN	34% G 29% F 0% DK	N/A	N/A	N/A	51% G 47% F 0% DK	57% G 53% F 1% DK	48% G 41% F 1% DK	52% G 47% F 1% DK	3039	**48% G 43% F 1% DK**
KS	N/A	N/A	N/A	N/A	N/A	66% G 62% F 0% DK	66% G 63% F 2% DK	66% G 64% F 1% DK	1170	**66% G 63% F 1% DK**
KY	75% G 73% F 0% DK	75% G 74% F 0% DK	67% G 65% F 0% DK	63% G 62% F 1% DK	60% G 57% F 1% DK	63% G 60% F 0% DK	59% G 57% F 0% DK	64% G 62% F 0% DK	3581	**66% G 64% F 0% DK**
LA	16% G 13% F 4% DK	19% G 16% F 3% DK	23% G 19% F 3% DK	17% G 16% F 2% DK	14% G 12% F 2% DK	7% G 6% F 0% DK	8% G 8% F 1% DK	13% G 8% F 2% DK	3336	**15% G 12% F 2% DK**
MA	57% G 50% F 1% DK	N/A	N/A	66% G 58% F 0% DK	N/A	58% G 54% F 0% DK	N/A	60% G 56% F 0% DK	2063	**60% G 54% F 0% DK**
MD	N/A	N/A	N/A	N/A	16% G 14% F 2% DK	16% G 13% F 4% DK	N/A	N/A	745	**16% G 14% F 3% DK**
ME	N/A	77% G 74% F 0% DK	77% G 74% F 0% DK	82% G 78% F 0% DK	46% G 21% F 0% DK	72% G 67% F 1% DK	78% G 74% F 0% DK	77% G 71% F 0% DK	2812	**73% G 66% F 0% DK**
MI	N/A	N/A	N/A	72% G 51% F 0% DK	N/A	N/A	73% G 56% F 0% DK	75% G 54% F 0% DK	1255	**73% G 54% F 0% DK**

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
MN	N/A	N/A	N/A	N/A	N/A	87% G 87% F 1% DK	52% G 42% F 28% DK	54% G 0% F 29% DK	1239	**64% G** **43% F** **19% DK**
MO	82% G 78% F 0% DK	87% G 85% F 0% DK	83% G 80% F 1% DK	83% G 82% F 0% DK	84% G 82% F 1% DK	83% G 80% F 0% DK	85% G 84% F 0% DK	80% G 76% F 0% DK	3656	**83% G** **81% F** **0% DK**
MS	N/A	N/A	N/A	N/A	16% G 14% F 13% DK	N/A	N/A	20% G 4% F 0% DK	805	**18% G** **9% F** **7% DK**
NC	63% G 56% F 1% DK	60% G 54% F 1% DK	64% G 56% F 1% DK	66% G 58% F 1% DK	71% G 64% F 0% DK	73% G 66% F 1% DK	68% G 61% F 1% DK	69% G 58% F 0% DK	6794	**67% G** **59% F** **1% DK**
NH	N/A	N/A	78% G 75% F 0% DK	N/A	72% G 69% F 0% DK	N/A	73% G 70% F 0% DK	N/A	1213	**74% G** **71% F** **0% DK**
NJ	70% G 64% F 4% DK	68% G 58% F 3% DK	N/A	65% G 51% F 2% DK	63% G 56% F 3% DK	70% G 63% F 1% DK	73% G 67% F 1% DK	N/A	2580	**68% G** **60% F** **2% DK**
NV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	33% G 29% F 0% DK	400	**33% G** **29% F** **0% DK**
NY	31% G 28% F 12% DK	29% G 26% F 11% DK	29% G 27% F 11% DK	33% G 29% F 10% DK	35% G 30% F 10% DK	36% G 33% F 6% DK	30% G 25% F 10% DK	35% G 26% F 6% DK	7548	**32% G** **28% F** **10% DK**
OH	41% G 28% F 2% DK	42% G 29% F 0% DK	49% G 37% F 1% DK	51% G 39% F 1% DK	50% G 35% F 0% DK	46% G 31% F 0% DK	34% G 25% F 0% DK	49% G 30% F 1% DK	3775	**45% G** **32% F** **1% DK**
OK	62% G 52% F 0% DK	61% G 49% F 0% DK	61% G 49% F 0% DK	N/A	N/A	67% G 61% F 0% DK	58% G 53% F 0% DK	68% G 63% F 0% DK	2995	**63% G** **55% F** **0% DK**
OR	N/A	N/A	N/A	N/A	16% G 15% F 1% DK	N/A	N/A	N/A	396	**16% G** **15% F** **1% DK**
PA	12% G 10% F 8% DK	13% G 11% F 8% DK	14% G 13% F 7% DK	13% G 12% F 7% DK	13% G 11% F 7% DK	13% G 12% F 9% DK	14% G 12% F 8% DK	18% G 13% F 6% DK	8571	**14% G** **12% F** **8% DK**
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	26% G 22% F 5% DK	394	**26% G** **22% F** **5% DK**

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
SC	7% G 7% F 10% DK	N/A	N/A	9% G 8% F 4% DK	8% G 6% F 13% DK	11% G 8% F 13% DK	9% G 7% F 10% DK	N/A	1942	**9% G 7% F 10% DK**
SD	52% G 49% F 0% DK	N/A	N/A	N/A	N/A	N/A	52% G 49% F 0% DK	68% G 64% F 0% DK	702	**57% G 54% F 0% DK**
TN	N/A	N/A	N/A	N/A	N/A	56% G 44% F 1% DK	58% G 47% F 1% DK	60% G 43% F 1% DK	1308	**58% G 45% F 1% DK**
TX	37% G 34% F 1% DK	35% G 30% F 1% DK	N/A	N/A	39% G 37% F 2% DK	N/A	49% G 43% F 3% DK	N/A	5608	**40% G 36% F 7% DK**
UT	N/A	N/A	N/A	N/A	47% G 37% F 0% DK	46% G 31% F 1% DK	44% G 31% F 2% DK	55% G 36% F 0% DK	1639	**48% G 34% F 1% DK**
VA	N/A	N/A	N/A	N/A	33% G 30% F 1% DK	38% G 34% F 1% DK	38% G 31% F 6% DK	39% G 30% F 2% DK	3094	**37% G 31% F 3% DK**
VT	N/A	N/A	N/A	N/A	N/A	N/A	75% G 71% F 0% DK	77% G 70% F 0% DK	653	**76% G 71% F 0% DK**
WA	N/A	51% G 43% F 1% DK	N/A	47% G 43% F 1% DK	N/A	N/A	N/A	52% G 49% F 0% DK	1519	**50% G 45% F 1% DK**
WI	N/A	N/A	N/A	N/A	84% G 83% F 1% DK	N/A	N/A	48% G 14% F 48% DK	758	**66% G 49% F 25% DK**
WY	59% G 59% F 0% DK	69% LF 66% F 0% DK	N/A	N/A	N/A	N/A	N/A	66% G 62% F 0% DK	1117	**66% G 62% F 0% DK**
Average (state)	**46% G 41% F 2% DK**	**47% G 40% F 2% DK**	**48% G 42% F 2% DK**	**51% G 44% F 3% DK**	**45% G 39% F 2% DK**	**50% G 43% F 2% DK**	**49% G 42% F 4% DK**	**52% G 41% F 3% DK**	**131588**	**49% G 42% F 3% DK**

Appendix C: Additional Tables of Analysis of NCI Data for Guardianship and People with ID/DD

Source of Data: National Core Indicators, Chart Generator 2014-15, National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved from the National Core Indicators website (http://www.nationalcoreindicators.org/charts/) on October 31, 2018 (for 2008 to 2015 data) and January 18, 2018 (for 2015 to 2016 data)

Key: Y = Limited Guardianship, Full Guardianship, or Has a Guardian but unable to distinguish level; F = Full Guardianship; DK = Don't Know; N/A = Chart not available; Total Resp. = Total Respondents

Table 1: Age & Guardianship Status

Age	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond.	Annual Average
18-34	45% Y 52% N 3% DK	46% Y 52% N 2% DK	51% Y 48% N 2% DK	52% Y 46% N 2% DK	47% Y 50% N 3% DK	51% Y 47% N 2% DK	52% Y 48% N 4% DK	54% Y 42% N 4% DK See Note	403655	**50% Y 48% N 3% DK**
35-54	45% Y 53% N 2% DK	45% Y 53% N 2% DK	47% Y 50% N 2% DK	52% Y 46% N 2% DK	43% Y 54% N 2% DK	49% Y 49% N 2% DK	48% Y 48% N 4% DK	51% Y 46% N 3% DK	10708	**48% Y 50% N 2% DK**
55-74	44% Y 54% N 3% DK	48% Y 51% N 2% DK	49% Y 49% N 2% DK	55% Y 44% N 1% DK	44% Y 55% N 1% DK	49% Y 49% N 1% DK	47% Y 48% N 4% DK	49% Y 47% N 3% DK	24363	**48% Y 50% N 2% DK**
75 +	30% Y 65% N 6% DK	13% Y 79% N 9% DK	15% Y 78% N 7% DK	35% Y 60% N 5% DK	8% Y 87% N 5% DK	22% Y 76% N 2% DK	28% Y 68% N 1% DK	44% Y 52% N 3% DK	785	**24% Y 71% N 5% DK**

Note: 18-22: 58% Y, 38% N, 5% DK (Total Respondents: 1178)
23-34: 53% Y, 43% N, 4% DK (Total Respondents: 5110)

Table 2: Gender & Guardianship Status

Gender	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond.	Annual Average
Male	44% Y 53% N 3% DK	46% Y 52% N 2% DK	49% Y 50% N 2% DK	53% Y 46% N 2% DK	44% Y 53% N 2% DK	50% Y 48% N 2% DK	50% Y 49% N 2% DK	51% Y 45% N 4% DK	65088	**48% Y 50% N 2% DK**

Gender	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond.	Annual Average
Female	46% Y 51% N 2% DK	47% Y 51% N 2% DK	48% Y 50% N 2% DK	54% Y 45% N 2% DK	54% Y 45% N 2% DK	45% Y 52% N 5% DK	49% Y 47% N 4% DK	51% Y 45% N 3% DK	48657	**49% Y** **48% N** **2% DK**

Table 3: Race/Ethnicity & Guardianship Status

Race/ Ethnicity	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond	Annual Average
American Indian or Alaska Native	N/A	47% Y 51% N 2% DK	54% Y 41% N 5% DK	71% Y 29% N 0% DK	N/A	83% Y 19% N 5% DK	N/A	69% Y 31% N 0% DK	2128	**65% Y** **34% N** **3% DK**
Asian	52% Y 35% N 13% DK	0% Y 100% N 0% DK	N/A	57% Y 35% N 8% DK	80% Y 21% N 0% DK	71% Y 29% N 1% DK	56% Y 41% N 4% DK	56% Y 44% N 1% DK	1686	**53% Y** **44% N** **4% DK**
Black/ African American	38% Y 59% N 3% DK	39% Y 57% N 3% DK	36% Y 61% N 3% DK	44% Y 54% N 2% DK	35% Y 62% N 3% DK	40% Y 57% N 4% DK	38% Y 58% N 4% DK	41% Y 54% N 4% DK	20815	**39% Y** **58% N** **3% DK**
Pacific Islander	N/A	N/A	N/A	73% Y 26% N 1% DK	72% Y 28% N 0% DK	61% Y 37% N 1% DK	66% Y 33% N 1% DK	63% Y 38% N 0% DK	385	**67% Y** **32% N** **1% DK**
White	48% Y 50% N 2% DK	50% Y 48% N 2% DK	51% Y 48% N 2% DK	55% Y 43% N 2% DK	48% Y 51% N 2% DK	52% Y 46% N 1% DK	51% Y 45% N 4% DK	54% Y 43% N 3% DK	80067	**51% Y** **46% N** **2% DK**
Hispanic/Latino	45% Y 51% N 5% DK	23% Y 70% N 7% DK	34% Y 57% N 9% DK	47% Y 48% N 5% DK	49% Y 47% N 5% DK	47% Y 50% N 3% DK	42% Y 54% N 4% DK	39% Y 58% N 3% DK	6704	**41% Y** **54% N** **5% DK**
Other	51% Y 43% N 10% DK	11% Y 80% N 9% DK	24% Y 63% N 14% DK	39% Y 51% N 10% DK	28% Y 64% N 8% DK	48% Y 48% N 3% DK	33% Y 63% N 4% DK	43% Y 57% N 0% DK	3847	**35% Y** **59% N** **7% DK**
Two or More Races	N/A	N/A	N/A	76% Y 23% N 1% DK	68% Y 32% N 0% DK	61% Y 37% N 2% DK	35% Y 62% N 3% DK	69% Y 30% N 0% DK	290	**62% Y** **37% N** **1% DK**

Table 5: Type of Residence & Guardianship Status

Type of Residence	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respondents	Annual Average
Specialized Institutional Facility for Persons with ID/DD	69% Y 27% N 4% DK	64% Y 32% N 3% DK	76% Y 22% N 2% DK	72% Y 24% N 4% DK	71% Y 27% N 2% DK	71% Y 27% N 2% DK	N/A (see below)	N/A (see below)	5335	**71% Y** **27% N** **3% DK**

Type of Residence	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respondents	Annual Average
Nursing Facility	24% Y 73% N 3% DK	28% Y 64% N 8% DK	26% Y 59% N 15% DK	34% Y 60% N 6% DK	20% Y 81% N 0% DK	38% Y 55% N 7% DK	N/A (see below)	N/A (see below)	210 (PA, VA)	**28% Y** **65% N** **7% DK**
Institutional Setting (ICF/ID, nursing home, or other institutional setting)	N/A (see above)	N/A (see above)	N/A (see above)	N/A (see above)	N/A (see above)	N/A (see above)	62% Y 33% N 6% DK	64% Y 25% N 11%DK	2892	**63% Y** **29% N** **9% DK**
Group Home*	51% Y 46% N 3% DK	50% Y 48% N 2% DK	54% Y 45% N 2% K	60% Y 39% N 1% DK	49% Y 49% N 2% DK	54% Y 45% N 2% DK	57% Y 40% N 3% DK	58% Y 39% N 3% DK	31807	**54% Y** **44% N** **2% DK**
Agency-Operated Apartment Type Setting	37% Y 62% N 1% DK	47% Y 52% N 2% DK	40% Y 57% N 2% DK	52% Y 46% N 2% DK	37% Y 59% N 4% DK	51% Y 48% N 1% DK	N/A	N/A	3804	**44% Y** **54% N** **2% DK**
Independent Home/Apartment**	22% Y 77% N 1% DK	28% Y 71% N 1% DK	29% Y 70% N 1% DK	31% Y 68% N 1% DK	25% Y 74% N 1% DK	28% Y 71% N 1% DK	28% Y 69% N 4% DK	34% Y 64% N 2% DK	16949	**28% Y** **71% N** **2% DK**
Parent/Relative's Home	41% Y 56% N 3% DK	33% Y 64% N 3% DK	46% Y 52% N 2% DK	49% Y 50% N 2% DK	46% Y 52% N 2% DK	48% Y 50% N 3% DK	49% Y 47% N 4% DK	54% Y 43% N 4% DK	39914	**46% Y** **52% N** **2% DK**
Foster Care/Host Home	48% Y 49% N 3% DK	46% Y 51% N 3% DK	55% Y 44% N 2% DK	55% Y 43% N 2% DK	53% Y 46% N 0% DK	61% Y 39% N 0% DK	54% Y 44% N 2% DK	57% Y 40% N 3% DK	5818	**54% Y** **45% N** **2% DK**
Other	40% Y 55% N 4% DK	52% Y 43% N 6% DK	58% Y 40% N 2% DK	49% Y 45% N 6% DK	36% Y 59% N 5% DK	50% Y 46% N 4% DK	20% Y 66% N 15%DK	N/A	2461	**44% Y** **51% N** **6% DK**

* Referred to as a "Community-based residence/group home" in 2014-15 and "Group residential setting (group home)" in 2015-16.

** Referred to as "own home or apartment" in 2015-16.

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Matter of Dameris L.

Surrogate's Court of New York, New York County

December 31, 2012, Decided

2009-0892

Reporter
38 Misc. 3d 570 *; 956 N.Y.S.2d 848 **; 2012 N.Y. Misc. LEXIS 5844 ***; 2012 NY Slip Op 22386 ****

[**1]** In the Matter of the Guardianship of Dameris L.

Subsequent History: As Corrected January 10, 2013.

Core Terms

guardianship, disabilities, least restrictive, decision making, baby, legal capacity, parties, appointed, decisions, human rights, due process, pregnant, housing, spoke

Case Summary

Overview

Ward's husband petitioned to revoke a mother's letters as co-guardian. The court found, inter alia, that the ward was able to exercise her legal capacity to make and act on her own decisions, with the assistance of a family and community support network. Consequently, terminating the guardianships of the ward's mother and husband recognized and affirmed the ward's constitutional and human rights and allowed a reading and application of SCPA art. 17-A that was consistent with both.

Outcome

Guardianships terminated.

LexisNexis® Headnotes

Family Law > Guardians > Appointment

HN1[⬇] **Guardians, Appointment**

In the context of adult guardianship, *SCPA 1750-a(1)* requires certifications by two health care professionals, whose credentials are spelled out in the statute. In almost all art. 17-A proceedings those certifications--that the subject of the proceeding "suffers from" "mental retardation" or "developmental disability," that such condition began before the age of 21, that the condition is likely to be permanent--are made by checking boxes on a form "Affidavit (Certification) of Examining Physician or Licensed Psychologist."

Family Law > Guardians > Appointment

Family Law > Guardians > General Overview

HN2[⬇] **Guardians, Appointment**

In the context of adult guardianship, *SCPA 1750-a(1)* permits a hearing to be dispensed with if the petition is brought by a parent or parents, or if the parent(s), consents. SCPA 1754(1). Even where hearings are held in all cases, use of the form affidavits completely eliminates any possibility of cross-examination.

Family Law > Guardians > General Overview

HN3[⬇] **Family Law, Guardians**

Guardianship on consent is not only autonomy-enhancing, it also generally results in greater cooperation between the guardian(s) and the ward.

Family Law > Guardians > General Overview

HN4[⬇] **Family Law, Guardians**

The use of supported decision-making, rather than a guardian's substituted decision-making, is consistent with international human rights, most particularly Article 12 of the Convention on the Rights of Persons with Disabilities, Gen. A. Res. 61/106, U.N. Doc. A/RES/6/106 (Dec. 13, 2006).

Constitutional Law > Substantive Due Process > Scope

HN5[⬇] **Constitutional Law, Substantive Due Process**

Substantive due process includes a requirement that when a state interferes with an individual's liberty on the basis of its police power, it must employ the least restrictive means available to achieve its objective of protecting the individual and the community. New York courts have embraced the principle of least restrictive alternatives.

Constitutional Law > Substantive Due Process > Scope

HN6[⬇] **Constitutional Law, Substantive Due Process**

To subject a person to a greater deprivation of his personal liberty than necessary to achieve the purpose for which he is being confined is, it is clear, violative of due process.

Constitutional Law > Substantive Due Process > Scope

Family Law > Guardians > General Overview

HN7[⬇] **Constitutional Law, Substantive Due Process**

See *Mental Hygiene Law § 81.01*.

Family Law > Guardians > Appointment

HN8[⬇] **Guardians, Appointment**

Under Mental Hygiene Law art. 81, in determining the conditions under which a guardian may be appointed, a court is specifically directed to consider the sufficiency and reliability of available resources, as defined in *Mental Hygiene Law § 81.03(e)*, to provide for personal needs or property management without the appointment of a guardian.

Family Law > Guardians > General Overview

HN9[⬇] **Family Law, Guardians**

In an adult guardianship context, *Mental Hygiene Law § 81.03(e)* defines "available resources" as meaning resources such as, but not limited to, visiting nurses, homemakers, home health aides, adult day care and multipurpose senior citizen centers, powers of attorney, health care proxies, trusts, representative and protective payees, and residential care facilities.

Family Law > Guardians > Appointment

Family Law > Guardians > General Overview

HN10[⬇] Guardians, Appointment

To the extent that New York courts have recognized least restrictive alternative as a constitutional imperative, it must, of necessity, apply to guardianships sought pursuant to SCPA art. 17-A, as well as under the more recent and explicit Mental Hygiene Law art. 81. Thus, proof that a person with an intellectual disability needs a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends, and mental health professionals.

Constitutional Law > ... > Case or Controversy > Constitutionality of Legislation > General Overview

Family Law > Guardians > Appointment

Family Law > Guardians > General Overview

HN11[⬇] Case or Controversy, Constitutionality of Legislation

In order to withstand constitutional challenge, including, particularly, challenge under New York's due process guarantees, SCPA art. 17-A must be read to include the requirement that a guardianship is the least restrictive alternative to achieve the state's goal of protecting a person with intellectual disabilities from harm connected to those disabilities. Further, a court must consider the availability of "other resources," like those in *Mental Hygiene Law § 81.03(e)*, including a support network of family, friends, and professionals before the drastic judicial intervention of guardianship can be imposed.

Constitutional Law > Equal Protection > Disability

Family Law > Guardians > Appointment

Constitutional Law > Equal Protection > Nature & Scope of Protection

Family Law > Guardians > General Overview

HN12[⬇] Equal Protection, Disability

The equal protection provisions of the federal and state constitutions require that mentally retarded persons in a similar situation be treated the same whether they have a guardian appointed under SCPA art. 17-A or Mental Hygiene Law art. 81.

Civil Rights Law > Protection of Rights > Protection of Disabled Persons > General Overview

International Law > General Overview

HN13[⬇] Protection of Rights, Protection of Disabled Persons

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities provides that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." Legal capacity is not only the capacity to have rights, but also the capacity to act on, or exercise those rights, which includes the right to make one's own decisions. Recognizing that persons with disabilities may require support to exercise their legal capacity, Article 12(3) requires States Parties to provide access to those supports.

Civil Rights Law > Protection of Rights > Protection of Disabled Persons > General Overview

Family Law > Guardians > General Overview

International Law > General Overview

HN14[⬇] **Protection of Rights, Protection of Disabled Persons**

Guardianship laws that impose substituted decision-making on persons with mental and intellectual disabilities violate Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, and thus the human rights of persons subjected to guardianship.

Civil Rights Law > Protection of Rights > Protection of Disabled Persons > General Overview

International Law > General Overview

HN15[⬇] **Protection of Rights, Protection of Disabled Persons**

International adoption of a guarantee of legal capacity for all persons, a guarantee that includes and embraces supported decision making, is entitled to persuasive weight in interpreting a state's own laws and constitutional protections.

Constitutional Law > Equal Protection > Nature & Scope of Protection

Family Law > Guardians > Removal & Termination

International Law > General Overview

HN16[⬇] **Equal Protection, Nature & Scope of Protection**

The internationally recognized right of legal capacity through supported decision-making can and should inform the understanding and application of the constitutional imperative of least restrictive alternative. That is, to avoid a finding of unconstitutionality, SCPA art. 17-A must be read to require that supported decision making must be explored and exhausted before guardianship can be imposed or, to put it another way, where a person with an intellectual disability has the other resource of decision-making support, that resource/network constitutes the least restrictive alternative, precluding the imposition of a legal guardian.

Headnotes/Summary

Headnotes

Incapacitated and Mentally Disabled Persons — Guardian for Mentally Retarded and Developmentally Disabled Persons — Requirement That Guardianship is Least Restrictive Alternative

Termination of the letters of guardianship previously granted to the husband and mother of respondent, an individual with mild to moderate mental retardation, was appropriate upon respondent's demonstration that she was able to exercise her legal capacity, to make and act on her own decisions, with the assistance of a support network which had come together for her since she first appeared in court. Terminating the letters of guardianship previously granted to respondent's husband and mother recognized them as persons assisting and supporting respondent's autonomy, not superseding it. In order to withstand constitutional challenge, SCPA article 17-A must be read to include the requirement that guardianship is the least restrictive alternative to achieve the State's goal of protecting a person with intellectual disabilities from harm connected to those disabilities. Further, the court must consider the availability of "other resources," like those in *Mental Hygiene Law § 81.03 (e)*, including a support network of family, friends and professionals before the drastic judicial intervention of guardianship can be imposed. Moreover, although the United Nations Convention on the Rights of Persons with Disabilities does not directly affect New York's guardianship laws, international adoption of a guarantee of legal capacity for all persons, a guarantee that includes and embraces supported decision making, is entitled to persuasive weight in interpreting our own laws and constitutional protections, and supports the application of the constitutional imperative of least restrictive alternative.

Counsel: **[***1]** *Alberto R.*, petitioner and co-guardian pro se. *Cruz Maria S.*, co-guardian pro se. *Dameris L.*, respondent pro se.

Judges: Kristin Booth Glen, J.

Opinion by: Kristin Booth Glen

Opinion

[*571] **[**849]** Kristin Booth Glen, S.

This case presents the opportunity to reconcile an outmoded,[1] constitutionally suspect[2] statute, SCPA article 17-A, with the requirements of substantive due process and the internationally recognized human rights of persons with intellectual disabilities.

History

On March 9, 2009, Cruz Maria S. filed a petition[3] for guardianship of her then 29-year- **[****2]** old daughter, Dameris L. The certifications[4] accompanying the petition showed Dameris to have mild to moderate mental retardation, and to be "functioning at the **[*572]** mental age of a seven year old." She is **[**850]** reported to "have poor receptive and expressive skills—[and, while]

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[1] In 1990, when the legislature was working on reform of the existing adult guardianship laws, then called conservators and committees, it directed the Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities (now the New York State Office for People with Developmental Disabilities) to undertake a study of SCPA article 17-A in light of national guardianship reform efforts and the "momentous changes [that] have occurred in the care, treatment and understanding of these individuals [with intellectual disabilities]" (L 1990, ch 516, § 1). Nothing ever came of that study.

[2] *See e.g. Matter of Mark C.H., 28 Misc 3d 765, 906 NYS2d 419 (Sur Ct, NY County 2010)* (holding statute unconstitutional in the absence of periodic reporting and review, and reading a requirement of same into the law); *Matter of Chaim A.K., 26 Misc 3d 837, 885 NYS2d 582 (Sur Ct, NY County 2009)* **[***2]** (criticizing procedural shortcomings of statute as potentially unconstitutional); *see* Rose Mary Bailly and Charis B. Nick-Torok, *Should We be Talking? Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 Alb L Rev 807, 840 (2011/2012) ("Because SCPA 17-A and MHL 81 had their beginnings at different times, 1969 and 1992 respectively, and with different motivations and approaches to guardianship, they are now tripping over one another. Courts are debating the constitutionality of SCPA 17-A in light of different treatment of individuals under the respective statutes").

[3] The petition was sworn to in May 2008, so presumably Cruz began the process prior to Dameris's involvement with Alberto (see below).

[4] ***HN1***[] *SCPA 1750-a (1)* requires certifications by two health care professionals, whose credentials are spelled out in the statute. In fact, in almost all 17-A proceedings those certifications—that the subject of the proceeding "suffers from" "mental retardation" or "developmental disability," that such condition began before the age of 22, and that the condition is likely to be permanent—are made by checking boxes on a form "Affidavit (Certification) of Examining Physician or Licensed Psychologist." Generally there is little or no other information from which the affiant drew her/his conclusions. ***HN2***[] The statute permits a hearing to be dispensed with if the petition is brought by a parent or parents, or if the parent(s) consents (SCPA 1754 [1]). Even where, as in New York County, hearings are held in all cases, use of the form affidavits completely eliminates any possibility of cross-examination.

ambulatory and able to care for most of her grooming needs, she is highly dependent for all other needs, including medical and financial matters." At the time Dameris was, sporadically, attending a day adult habilitation **[***3]** program run by AHRC where she was learning, and supervised in, cleaning tasks, particularly cleaning bathrooms.

On March 29, 2009, Dameris married Alberto R. at the **[***4]** Office of the Clerk in Kings County. Alberto had problems of his own, including a history of drug and substance abuse, mental illness and criminal charges.

In mid-May 2009, Cruz came to the court and requested expedited consideration of her petition because, she explained, Dameris was pregnant and due to give birth imminently. A hearing was immediately scheduled for May 20 and, on that date, Alberto appeared and informed the court of his recent marriage to Dameris. It was clear that this was now a struggle over control of Dameris between Cruz, who entirely disapproved of, and distrusted, Alberto, and Alberto, who had the same negative feelings about Cruz. Dameris, very visibly pregnant, showed flat affect, spoke haltingly and in a limited way, and, on all of the evidence adduced at the hearing, appeared incapable of caring for herself and her soon to be born baby.

None of the parties spoke English; both households, Cruz's and Alberto's, were supported entirely by government benefits including Supplemental Security Income (SSI).[5] In order to obtain more information about the living situations and caretaking capacities of the contesting parties,[6] the court hastily appointed a guardian ad litem, Raul Garcia, Esq.[7] **[***5]** **[****3]** After an extremely helpful report from Garcia, the parties returned to court with the primary issue that of responsibility **[*573]** for Dameris and the baby after she gave birth.[8] The court again benefitted from pro bono services, this time from an expert mediator, Edward Bonsignore, Esq. On June 4, 2009, after a full day of mediation, the parties reached an agreement that provided for Dameris to reside with Alberto, but gave Cruz a substantial role after the baby's birth, and continued contact and visitation at her home. The parties also agreed that, with the court's approval, Alberto and Cruz would act as co-guardians for Dameris.

The case was adjourned with the guardianship clerk and a court attorney charged with following developments and monitoring the mediation agreement. On June 10, 2009, the baby, Damaris Cruz R., was born at Brooklyn Hospital, and Dameris and Alberto returned with her to Cruz's apartment. Eventually, with some intermediate stops,[9] and with home care **[**851]** assistance from AHRC, they settled in transitional homeless housing (subsidized by Housing Stability Plus) where, with full-time homemaker services, Dameris, Alberto and the baby were doing well. They returned to court on March 19, 2010, and again on October 5, 2010, when the court formally appointed Cruz and Alberto as co-guardians with Dameris's consent.[10]

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[5] At the time Alberto was living with his mother, also on SSI.

[6] Alberto opposed Cruz's petition, but did not actually file a cross petition until much later. Dameris was, however, apparently living with him in Brooklyn, and part of Cruz's "plan" of guardianship was to bring her home to Cruz's apartment in Washington Heights.

[7] Garcia, who is Spanish speaking, served without fee and provided extraordinary assistance to the court in a very compressed period of time. He, and the firm for which he worked, O'Dwyer and Bernstien, deserve the gratitude of the court.

[8] There **[***6]** was significant concern that the baby might be taken from the hospital by Child Welfare Services, and Lynn Paltrow, director of National Advocates for Pregnant Women, attended the first two hearings as a potential resource.

[9] For a time they lived with Alberto's mother, and when that became untenable, they were temporarily placed in a homeless family shelter before obtaining a subsidized two-bedroom apartment under the Emergency Assistance Rehousing Program. The unavailability **[***7]** of affordable housing in New York City has been a continuing issue for this family which has led, on two separate occasions, to proposals to leave the city and state.

[10] At the October hearing, Dameris was considerably more engaged, perhaps as a result of the success she was experiencing as a mother. She was also much more verbal, agreed that she needed help in

Despite some intermittent problems, things were going relatively well for the R. family until, as a result of the budget crisis, the subsidy program was cancelled, and Dameris and Alberto faced eviction.[11] Cruz was visiting family in the Dominican Republic, as was her custom, and neither Alberto nor the court was able to reach her. Alberto had located rental housing in **[*574]** Pottsville, Pennsylvania, near a cousin, and needed permission to move Dameris and the baby there.

On January 17, 2012, Alberto petitioned to revoke Cruz's letters as co-guardian, returnable February 9, 2012. Cruz, who was served by substituted service, did not appear. **[****4]** At a special calendar, Alberto presented a proposed lease for a home in Pottsville, and applications for benefits and services he had filed with Service Access & Management (SAM), a case management and crisis intervention service funded by Schuylkill County.

The court was able to reach the director of SAM by phone, and to fax certain records on file here that were necessary to process the applications. With this assurance, and in the absence of any viable housing alternative in New York, the court temporarily suspended Cruz's letters and granted permission for temporary relocation to Pennsylvania. Alberto and Dameris were directed to return to court on December 4, 2012, by which time it was expected that Cruz would have returned to New York.

On December 4, 2012, all parties appeared, together with the now almost three-year-old Damaris (nicknamed Chi Chi) and Alberto's nine-year-old daughter Bianca.[12] SAM was working on obtaining services, but the family was basically **[***9]** functioning on its own, and doing well, utilizing support from Alberto's cousin, and especially his wife, Margarita, who had previously worked for a different social services agency in Schuylkill County.

Dameris appeared much more confident and dealt appropriately and lovingly with both Chi Chi and Bianca. She revealed that she was, again, pregnant, although she and Alberto also informed the court that she planned to undergo a tubal ligation immediately after the baby was born. Questioned by the court, it was clear that **[**852]** Dameris understood what she had consented to, and why; she explained that she had made her decision after consultation with Alberto, the health care professionals, and Margarita, who had fully explained the procedure to her. Concerned about the **[***10]** availability of homemaking and child care services that Dameris would surely need when the new baby was born, the court continued the hearing to December 12 in order to obtain more information.

[*575] On December 12, Cruz, Alberto, Dameris, Chi Chi and Bianca[13] appeared. Because of conflicting appointments on December 11, 2012, Alberto and Dameris had missed a meeting with their social worker, Amy Hessron, so the necessary services were not yet in place. After a call from the court, the appointment with Ms. Hessron was rescheduled for December 18. Alberto and Cruz were directed to return to the court on December 19 for the continued hearing. The now visibly pregnant Dameris was excused. There was, however, opportunity to take testimony about Dameris's

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making decisions, and stated that she was willing to have Alberto and her mother as her co-guardians. It is this court's experience that *HN3*[↑] guardianship on consent is not only autonomy-enhancing, but also generally results in greater cooperation between the guardian(s) and the "ward."

[11] The rent was $1,070 per month, and, without the City subsidy, exceeded the total benefits **[***8]** received by both Alberto and Dameris from SSI.

[12] Bianca is the child of a relationship prior to Alberto's marriage to Dameris, and initially lived with her mother, but when custody was removed she was placed with her grandmother, Alberto's mother. Subsequently the grandmother, her husband and Bianca also moved to Pottsville, but with the grandmother's worsening health and her husband's death, Alberto took custody of Bianca, and she came to live with him, Dameris, and Chi Chi.

[13] Bianca, a bright and charming child, explained that she was not missing a "real" school day, but rather a pageant, and proudly described how well she was doing in school.

current situation, which proved both enlightening and most encouraging.

Dameris had become friendly with nearby neighbors, who were assisting her in various ways, and whom she and Alberto had asked to serve as the new baby's godparents. Alberto's cousin's wife, Margarita, was **[***11]** a constant presence in the household, explaining and translating for **[****5]** Dameris, and helping her make everyday decisions, as well as more significant decisions such as the tubal ligation. With Ms. Hessron's assistance, Dameris was enrolled in a literacy class; Hessron had also become part of Dameris's support network. Cruz and Alberto had resolved most of their difficulties, and the advice and assistance Cruz offered Dameris in frequent phone calls was now welcomed and incorporated. Alberto had shown remarkable resiliency and perseverance settling his family and dealing with a number of health issues for his mother and his two daughters. His relationship to Dameris, while always loving, had clearly evolved, and they now presented as far more of a partnership than as a guardian and his ward.

Between the 12th and the continued hearing on the 19th, the court attorney assigned to the case spoke with Dameris's prenatal health care provider and with Ms. Hessron.

On the 19th, Cruz and Alberto appeared, accompanied by the prospective godfather, Raul Eusebio, who described his family's relationship with Alberto and Dameris, and the assistance they were—and intended to continue—providing. The **[***12]** court attorney testified to her conversation with Ms. Hessron, who was working diligently to get Dameris the waiver necessary for postnatal home care services, and who had also reiterated the family's **[*576]** progress despite considerable obstacles.[14] The court attorney confirmed that Dameris had executed an informal consent to the post-birth sterilization, and that the doctor who took the consent was satisfied that it was both knowing and voluntary.[15] Cruz testified that she would be going to Pennsylvania to help after the baby's birth, and that she was now satisfied with, and had no **[**853]** concerns about, the relationship between Dameris and Alberto.

Finally, Alberto spoke about what he had accomplished with Dameris over the past eight months in their new home— **[***13]** the progress she had made, what a good job she was doing now with two children, and how together they had found and utilized a support system that was helping them succeed despite all the difficulties they faced. He spoke movingly of his respect for Dameris, and how he understood his role, not as deciding for her, but in assisting her in making her own decisions. At the conclusion of the hearing, for the reasons discussed below, the court terminated the 17-A guardianship of the person of Dameris L. (now R.).

Discussion

The family is now fully settled in Pennsylvania, as opposed to the temporary move the court previously authorized. As such, with Cruz suspended, and giving consent to termination of the guardianship, the court no longer has jurisdiction over Dameris. But, even if this were not the case, I would find that guardianship is no longer warranted because there is now a system of supported decision making in place that constitutes a less restrictive alternate to the Draconian loss of liberty entailed by a plenary 17-A guardianship. ***HN4***[🡅] This use of *supported* decision making, rather than a guardian's *substituted* decision making, is also consistent with international human **[****6]** rights, most **[***14]** particularly article 12 of the United Nations Convention on the Rights of Persons with

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[14] Primary among these is the paucity of Spanish speakers in Schuylkill County, including health care providers, educators and service providers. Alberto is the primary translator, but Dameris is now learning English in her literacy class.

[15] Interestingly, the health care provider, Comprehensive Women's Health Services, did not require Alberto's consent, as guardian, to the procedure, but rather took and accepted the consent given by Dameris.

Disabilities.[16]

[*577] A. Least Restrictive Alternative

Beginning with *O'Connor v Donaldson (422 US 563, 95 S Ct 2486, 45 L Ed 2d 396 [1975])*, ***HN5***[⬆] substantive due process has been understood to include a requirement that when the State interferes with an individual's liberty on the basis of its police power, it must employ the least restrictive means available to achieve its objective of protecting the individual and the community. New York courts have embraced the principle of least restrictive alternatives (*see e.g.* *Matter of Kesselbrenner v Anonymous, 33 NY2d 161, 165, 305 NE2d 903, 350 NYS2d 889 [1973]* ***HN6***[⬆] ["To subject a person to a greater deprivation of personal liberty than necessary to achieve the purpose for which he is being confined[17] is, it is clear, violative of due process"]; *Matter of Manhattan Psychiatric Ctr., 285 AD2d 189, 197-198, 728 NYS2d 37 [lst Dept 2001]*).

The legislature, as well, has incorporated least restrictive alternative in liberty curtailing statutes including those dealing with "assisted outpatient treatment" (AOT) (*e.g.* *Mental Hygiene Law § 9.60 [h] [4]*; [i] [3] [Kendra's Law]),[18] and **[**854]** adult guardianship (*Mental Hygiene Law § 81.01* [***HN7***[⬆] "The legislature finds that it is desirable for and beneficial to persons with incapacities to make available to them the least restrictive form of intervention which assists them in meeting their needs but, at the same time, permits them to exercise the independence and self-determination of which they are capable"]; *see* Rose Mary Bailly, Practice Commentaries, McKinney's Cons Laws of NY, Book 34A, Mental Hygiene Law *§ 81.01* at 7 [2006 ed] ["The Legislature recognized that the legal remedy of guardianship should be the last resort for addressing an individual's needs because it deprives the person of so much power and control over his or her life"]).

[*578] Thus, ***HN8***[⬆] under Article 81, in determining the conditions under which a guardian may be appointed, the court is specifically directed to consider "the sufficiency and reliability of **[****7]** available resources, as defined in subdivision (e) of Section 81.03 of this article,[19] to provide for personal needs or property management without the appointment of a guardian" (*Mental Hygiene Law § 81.02 [a] [2]*). The Law Revision Commission Comments note:

> "This definition promotes the goal of the statute of requiring a disposition which represents the least restrictive form of intervention. It is incumbent upon the **[***17]** . . . court to consider voluntary alternatives to judicial intervention under [Article 81] . . . The list is not meant to be restrictive but rather set the wheels of investigation in motion for considering what possibly could be done to

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[16] United Nations Convention on the Rights of Persons with Disabilities, UN General Assembly resolution 61/611 (Dec. 13, 2006), available at http://www.un.org/disabilities/convention/conventionfull.shtml (accessed Dec. 27, 2012).

[17] Most of the early least restrictive alternative cases involved some form of involuntary **[***15]** confinement, but the more general principle applies equally to lesser deprivations of liberty, including guardianship. See discussion of Mental Hygiene Law article 81, below.

[18] *See* *Matter of Manhattan Psychiatric Ctr., 285 AD2d at 197* (noting the "underlying concern of the Legislature in enacting **[***16]** Kendra's Law, i.e., to place as few restrictions as possible on the liberty of persons who, though suffering from mental illnesses, are capable of living in the community with the help of family, friends and mental health professionals [L 1999, ch 408, § 2 . . .]" [internal quotation marks omitted]); *see e.g. Kendra's Law: The Process for Obtaining Assisted Outpatient Treatment*, OMH Q, Dec. 1999 at 4-6 (Kendra's Law requires that AOT be the least restrictive alternative); Ilissa L. Watnik, Comment, *A Constitutional Analysis of Kendra's Law: New York's Solution for Treatment of the Chronically Mentally Ill*, *149 U Pa L Rev 1181, 1199-1204 (2001)* (discussing due process imperatives incorporated in the statute).

[19] ***HN9***[⬆] *Section 81.03 (e)* defines "available resources" as meaning "resources such as, but not limited to, visiting nurses, homemakers, home health aides, adult day care and multipurpose senior citizen centers, powers of attorney, health care proxies, trusts, representative and protective payees, and residential care facilities."

> assist this person without appointing a guardian" (reprinted in McKinney's Cons Laws of NY, Book 34A, Mental Hygiene Law § 81.03 at 57 [2006 ed]).

HN10[↑] To the extent that New York courts have recognized least restrictive alternative as a constitutional imperative (*see e.g.* *Matter of Kesselbrenner v Anonymous, 33 NY2d 161, 305 NE2d 903, 350 NYS2d 889 [1973]*; *Matter of Andrea B., 94 Misc 2d 919, 925, 405 NYS2d 977 [Fam Ct, NY County 1978]* ["substantive due process requires adherence to the principle of the least restrictive alternative"]), it must, of necessity, apply to guardianships sought pursuant to article 17-A, as well as under the more recent and explicit Mental Hygiene Law article 81. Thus, proof that a person with an intellectual disability *needs* a guardian must **[***18]** exclude the possibility of that person's ability to live safely in the community supported by family, friends and mental health professionals.

HN11[↑] In order to withstand constitutional challenge,[20] including, particularly, challenge under our own State Constitution's due **[*579]** process guarantees, SCPA article 17-A must be read to include the requirement that guardianship is the least restrictive alternative to achieve the State's goal of protecting a person with intellectual disabilities from harm connected to those disabilities. Further, the court must consider the availability of "other resources," like those in *Mental Hygiene Law § 81.03 (e)*, including a **[**855]** support network of family, friends and professionals before the drastic judicial intervention of guardianship can be imposed.

B. International Human Rights **[****8]**

HN13[↑] Article 12 (2) of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." As the deliberations that accompanied drafting and passage of the CRPD demonstrated, legal capacity is not only the capacity to *have* rights, but also the capacity to *act on*, or *exercise*, those rights[21] which, the preamble to the CRPD[22] makes clear, includes the right to make one's own decisions. Recognizing that persons with disabilities may require support to exercise their legal capacity, article 12 (3) requires States Parties to provide access to those supports (*see e.g.* Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making*, 19 Hum Rts Brief [Issue 2] 8 [2012]) (Dinerstein).

The body created by CRPD to review and comment on compliance by States Parties with the Convention has repeatedly found that ***HN14***[↑] guardianship laws that impose substituted decision making on persons with mental and intellectual disabilities violate article 12, and thus the human rights of persons subjected to guardianship.[23]

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[20] There is also a potential equal protection challenge if the least restrictive alternative provisions of Mental Hygiene Law article 81 are not read into SCPA article 17-A (*see* *Matter of B., 190 Misc 2d 581, 585, 738 NYS2d 528 [Tompkins County Ct 2002]* [***HN12***[↑]] "The equal protection provisions of the Federal and State Constitutions . . . require that mentally retarded persons in a similar situation be treated the same whether they have a guardian appointed under article 17-A or **[***19]** article 81" (citing *Cleburne v Cleburne Living Center, Inc., 473 US 432, 105 S Ct 3249, 87 L Ed 2d 313 [1985]*)]).

[21] See discussion of the debates and ultimate adoption of the more **[***20]** expansive definition of legal capacity in Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar of the Future?* (34 Syracuse J Int'l L & Com 429, 442 [2007]).

[22] CRPD preamble (n) (recognizing "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices").

[23] *See e.g.* ***Dinerstein at 11-12***; Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 Colum Hum Rts L Rev 93 (2012) (collecting decisions on Tunisia, Spain and Peru).

While the CRPD does not directly affect New York's guardianship laws, ***HN15***[🡅] international adoption of a guarantee of legal capacity **[*580]** for all persons, a guarantee that includes and embraces supported decision making, is entitled to "persuasive weight" in interpreting our own laws and constitutional **[***21]** protections (*see e.g. Lawrence v Texas, 539 US 558, 576, 123 S Ct 2472, 156 L Ed 2d 508 [2003]*; Johanna Kalb, *Human Rights Treaties in State Courts: The International Prospects of State Constitutionalism after Medellín, 115 Penn St L Rev 1051, 1059-1060 [2011]*).

As Dinerstein notes,

> "The paradigm shift reflected in the move from substitute[d] to supported decision making aims to retain the individual as the primary decision maker but recognizes that an individual's autonomy can be expressed in multiple ways, and that autonomy itself need not be inconsistent with having individuals in one's life to provide support, guidance and assistance to a greater or lesser degree, so long as it is at the individual's choosing" **[****9]** (*Dinerstein at 10*).

The instant case provides a perfect example of the kind of family and community support that enables a person with an intellectual disability to make, act on, and have her decisions legally recognized as, for example, by acceptance of her "informed consent" to a tubal ligation. Because **[**856]** Dameris has such assistance, she is now able to engage in supported decision making, rather than having substituted decision making, in the form of guardianship, imposed upon her by the court.

HN16[🡅] The internationally **[***22]** recognized right of legal capacity through supported decision making can and should inform our understanding and application of the constitutional imperative of least restrictive alternative. That is, to avoid a finding of unconstitutionality, SCPA article 17-A must be read to require that supported decision making must be explored and exhausted before guardianship can be imposed or, to put it another way, where a person with an intellectual disability has the "other resource" of decision making support, that resource/network constitutes the least restrictive alternative, precluding the imposition of a legal guardian.

Based on all the evidence in this case, Dameris has demonstrated that she is able to exercise her legal capacity, to make and act on her own decisions, with the assistance of a support network which has come together for her since she first appeared in this court. Terminating the letters of guardianship previously granted to Cruz and Alberto recognizes them, instead, as persons assisting and supporting her autonomy, not **[*581]** superseding it. Terminating the guardianship recognizes and affirms Dameris's constitutional rights and human rights and allows a reading and application of SCPA article 17-A **[***23]** that is consistent with both.

End of Document

SUPPORTED DECISION MAKING PILOT:

Pilot Program Evaluation Year 2 Report

Prepared for the Center for Public Representation and Nonotuck Resource Associates, Inc.

Authors: Elizabeth Pell, MSW, LICSW, and Virginia Mulkern, PhD

Valerie Bradley
HSRI President
vbradley@hsri.org

Human Services Research Institute
www.hsri.org

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Executive Summary

The Center for Public Representation (CPR), a nonprofit law firm focusing on disability rights in Massachusetts and across the country, and Nonotuck Resource Associates, Inc. (Nonotuck), a service provider principally of shared living and adult family care residential supports, partnered to offer adults with intellectual and/or developmental disabilities (I/DD) living in western Massachusetts an opportunity to use Supported Decision Making (SDM).

CPR and Nonotuck conducted their two-year SDM pilot with a collaborative approach across development and implementation stages, from pilot design to SDM outreach and education to broader communities.

CPR contracted with the Human Services Research Institute (HSRI), a nonprofit research and consulting organization, to conduct an independent evaluation of the SDM pilot. The purpose of the evaluation was to identify challenges and recommendations to inform broader SDM adoption.

HSRI's two evaluation reports follow the sequential stages of pilot development. The first report (Year 1) examined activities undertaken to establish the pilot, select volunteers to adopt SDM, and assist SDM adopters through the process of designating decision supporters and completing SDM Representation Agreements.[1] This second evaluation report (Year 2) presents SDM pilot activity and findings regarding the experience of using SDM and an assessment of impacts. Although we refer to the implementation period as Year 2 of the pilot, the dates from SDM Agreement execution to date of HSRI's evaluation interviews, do not correspond exactly to a calendar year.

Evaluation Findings

Nine adults[2] adopted SDM and utilized SDM for 72 decisions. SDM was most frequently utilized for health care decisions (19 decisions), followed by financial decisions (15 decisions). Least frequent were SDM-arrangement decisions such as changing one's decision supporter (1 decision).

Adults with I/DD who adopted SDM ('SDM adopters') expressed satisfaction with SDM, with their selection of decision supporters, and with the ways in which decision supporters provided decision assistance. Adopters reported that their preferences and decisions were respected. Pilot participants (CPR staff, Nonotuck care managers, and individuals who adopted SDM and their decision supporters) were satisfied with the mechanics of SDM. Although SDM was only in use for a little over a year, this pilot demonstrated that when individuals with I/DD and other disabilities are given opportunities to utilize their decision making capacities with committed and trusted decision supporters, it can be a satisfying experience with positive impact on both adopters and decision supporters.

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[1] HSRI Year 1 report, Supported Decision Making Pilot: A Collaborative Approach is located online at: http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf

[2] Since the Year 1 Evaluation Report was published, a woman under guardianship adopted SDM and selected her brother (guardian), her sister-in-law, and her shared living provider as decision supporters. She and her network are trying out SDM and considering filing a petition to ask the court to discharge the guardianship.

A selection of HSRI's evaluation findings are presented below.

- Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and receiving decision help when they want help. All adopters reported that SDM is a positive experience.
- Decisions made reflected the preferences of SDM adopters.
- SDM adopters and decision supporters were satisfied with the process of providing decision assistance as well as with the decisions made.
- A variety of decisions were made—from everyday decisions to very important decisions. SDM was most frequently used for health care decisions followed by financial decisions, areas of concern that often lead to use of guardianship and conservatorship.
- Involved community members acted on the expressed preferences of SDM adopters, and did so without documentation of decisional capacity or decision supporter role.
- Having multiple supporters worked well in this pilot. Decision supporters were committed to regular and ongoing communication.
- SDM adoption and use made a definite and positive impact on the lives of adopters. One individual's right to make decisions was restored when the probate court discharged his guardianship.
- Observable differences were noticed in the personal growth of SDM adopters, along with increased self-esteem and self-advocacy, more engagement in decision making, and increased happiness.
- SDM adopters did not experience abuse, neglect or financial exploitation as a consequence of SDM. Many pilot participants believe that the structure of SDM—selecting people one trusts to help make decisions and having more than one decision supporter—reduces such risks.
- For the SDM adopters, additional opportunities for expansion of decision making authorities exist, such as utilizing the self-directed services option for services funded through the state developmental disabilities agency.
- Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision making assistance that allows people to keep their decision making rights, has a positive impact on their self-respect, and can reduce society's use of guardianship.
- Pilot participants believe SDM would be helpful for other populations whose decision making rights are often removed—specifically older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally recognized adults at age 18, an age when many families are counseled to secure guardianship.
- This pilot was faithful to the values and principles of SDM.

Introduction

In the United States, adults with intellectual and/or developmental disabilities (I/DD) are particularly at risk for losing their legal right to make decisions about their lives, including where to live, what to do during the day, and what kinds of health care they will receive. Decision making rights for adults with I/DD are often removed and awarded to a substituted decision maker as occurs under guardianship. Supported Decision Making (SDM) is an emerging alternative to guardianship which allows a person with a disability to retain his or her legal right to make decisions with the assistance of designated supporter(s).

SDM is grounded in the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD), an international disability rights treaty.[3] The CRPD asserts that people with disabilities share the same legal capacity that people without disabilities enjoy, including recognition for making decisions about their lives, and when necessary, an obligation to support a person with a disability to exercise his or her legal capacity. SDM is a mechanism for recognizing and operationalizing equal legal capacity. SDM avoids the loss of decision making rights that occur under guardianship by providing decision making support where needed.

Within the United States, the rate of guardianship for adults with I/DD receiving publicly funded services varies widely by state. National Core Indicators (NCI) data reveal the extent of this variation across 41 member states: In Louisiana, 8% of the adult service population with I/DD had court-appointed guardians; in Missouri, 84% of adults with I/DD receiving services were under guardianship.[4] This wide range signals that something other than personal characteristics of individuals influences the rate of guardianship adoption.

Guardianship laws and practices in the United States are state-specific, but in every state, guardianship tends to be a permanent loss of decision making rights for individuals with I/DD. Even in states such as Florida—where guardians are required by law to actively assist their wards to gain experience making decisions, to review the need for continued substituted decision making, and to report to the court annually—no examples of rights restored were found when studied.[5]

Loss of rights is not the only outcome that accompanies guardianship. NCI data show significantly different life experiences between adults with I/DD with and without guardians. Adults receiving publicly funded services who are not under guardianship are more likely to:[6]

- Be employed in an integrated job
- Have more extensive friendships (i.e., friends beyond family members and paid staff)
- Date without restriction (if not married or living with a partner)

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[3] CRPD located online at: http://www.un.org/disabilities/convention/conventionfull.shtml. Treaty currently signed by 166 countries. In the U.S., President Obama signed the treaty in 2009, but the Senate has not yet ratified.

[4] National Core Indicators (NCI) Adult Consumer Survey 2014-15. Located online at: http://www.nationalcoreindicators.org/upload/core-indicators/ACS_2014-15_Final1.pdf

[5] Restoration of Capacity Study and Work Group Report, Florida Developmental Disabilities Council and Guardian Trust, February 2014. Located online at: http://www.guardianship.org/IRL/Resources/Handouts/Charting%20a%20New%20Course_Restoration%20Report.pdf

[6] AAIDD National Conference 2015, *Systems Change to Promote Rights: A Supported Decision Making Initiative and National Core Indicators Data Presentation*, Located online at: http://www.nationalcoreindicators.org/upload/presentation/AAIDD_2015_SDM_Pilot_and_NCI_FINAL.pdf

- Have unrestricted use of phone and internet in their homes
- Make choices (or have more input into decisions) regarding where they live, who they live with, their daily schedules, and how to spend their personal funds.

SDM as an Innovative Practice

As a new mechanism for demonstrating legal capacity, demonstration projects are useful to inform successful wider adoption. When CPR and Nonotuck initiated this SDM pilot, there were no similar pilot projects in the United States to explore SDM implementation and determine the circumstances under which it is likely to be most successful. Since CPR and Nonotuck initiated their pilot, Texas and Delaware passed legislation enacting SDM into state law, and the U.S. Administration on Community Living funded a national technical assistance center to research and advance SDM. In 2015, five SDM projects were funded by the National Resource Center on Supported Decision Making[7] to advance SDM for individuals with I/DD and older adults in Delaware, Wisconsin, Maine, North Carolina and Indiana. Each project has a different emphasis and approach. In Wisconsin a hotline offers callers free advice about the continuum of legal decision supports available in the state, including SDM. In North Carolina, SDM is now incorporated into life planning with adults with I/DD. Separate from the National Resource Center, Disability Rights Maine initiated a project similar in many respects to the CPR and Nonotuck model, and other innovative projects are getting underway in California, Texas, New York and elsewhere.

CPR-Nonotuck SDM Pilot

The Center for Public Representation (CPR), a nonprofit law firm focusing on disability rights in Massachusetts and across the country, and Nonotuck Resource Associates, Inc. (Nonotuck), an agency principally providing shared living and adult family care residential supports, partnered to offer adults with I/DD living in western Massachusetts an opportunity to use SDM. Pilot participants were drawn from Nonotuck's service recipients: adults with I/DD and other disabilities who had involved people in their lives. This pilot was purposefully limited to a geographic area, western Massachusetts, and to those who volunteered to test the use of SDM.

CPR and Nonotuck conducted their two-year SDM pilot with a collaborative approach across all phases—from pilot design, to project management and implementation, to conducting SDM outreach and education to broader communities. The pilot had two major goals:

1. Assess the degree to which SDM can maximize independence. By directing their own decision making process and making their own decisions, pilot participants will gain confidence and become better self-advocates. They will have both a voice and a presence in the community.
2. Identify best practices and factors that can be replicated as models that advance supported decision-making as an alternative to restrictive guardianship. How can supported decision-making best be implemented to make a positive difference in an individual's life?

The formal period for this pilot partnership and evaluation was two years. However, SDM Representation Agreements are expected to continue indefinitely into the future and be modified as people's lives change. CPR and Nonotuck are discussing the pilot's future scope and possible expansion.

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[7] National Resource Center on Supported Decision Making is located online at: http://supporteddecisionmaking.org

Nine adults with I/DD and other disabilities and chronic health conditions participated in the pilot and adopted SDM with their voluntary decision supporters. During the pilot's first year, eight adults with I/DD adopted SDM and completed SDM Representation Agreements that specified areas for decision making assistance and designated decision supporters. SDM Representation Agreements were signed by adopters and decision supporters and notarized. For some adopters, health care advance directives (called "health care proxies" in Massachusetts) and durable power of attorney documents were simultaneously notarized. During the pilot's second year, an additional individual with I/DD joined the pilot and completed an SDM Representation Agreement.

The number of decision supporters selected by SDM adopters in the pilot ranged from 2 to 10. Supporters included relatives, shared living providers, and a Nonotuck care manager who is also a friend.[8] All SDM adopters selected to have decision assistance across all categories noted in SDM Representation Agreements: Finances, Health care, Living arrangements, Relationships/Social, Employment, and Legal matters.

SDM adopters represent a wide range of ages, diagnoses, and life experiences. All primarily use spoken language to communicate their preferences. Information about the personal characteristics of SDM adopters (age range, communication, diagnoses, history of institutionalization, employment status, etc.) is located in Attachment C.

Independent Evaluation Research Aims and Data Collection Methods

CPR contracted with the Human Services Research Institute (HSRI), a nonprofit research and consulting organization, to conduct an independent evaluation of this SDM demonstration pilot. HSRI conducted a process evaluation with the primary aim to tell the story of this pilot project and identify lessons learned for expanding the knowledge base of SDM in real-world situations. Evaluation reports are intended to inform a wider audience about the potential benefits of SDM adoption.

HSRI's two evaluation reports follow the sequential stages of pilot development. The first report (Year 1) examined activities undertaken to establish the pilot, select volunteers to adopt SDM, and assist SDM adopters through the process of designating decision supporters and completing SDM Representation Agreements.[9] This second evaluation report (Year 2) presents SDM pilot activity and findings regarding the experience of using SDM and an assessment of impacts. Although we refer to the implementation period as Year 2 of the pilot, the dates from SDM Agreement execution to date of HSRI's evaluation interviews, do not correspond exactly to a calendar year.

Data collection during Year 2 consisted of: 1) observation of pilot partner project coordination and events, and 2) interviews with pilot participants. HSRI evaluation staff participated in the monthly

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[8] CPR and Nonotuck considered whether people who are paid to provide care or services to the adopter should be decision supporters. The conclusion was that if, after any potential conflict of interest was discussed with the decider, he or she chose to select the paid person as a supporter, the decision was for the decider and that it would be inappropriate for the pilot project to limit that choice. Proceeding this way seems most consistent with the principles of supported decision-making. Nevertheless, see the discussion of occasional practical implications of this decision on pages 13-14.

[9] HSRI Year 1 report, Supported Decision Making Pilot: A Collaborative Approach, is located online at: http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf

meetings between pilot partners and in Advisory Council calls; they also attended pilot SDM events (a celebratory dinner in November 2015 and an SDM planning meeting in March 2016).

The second data collection method consisted of interviews with pilot participants. In-person interviews were conducted with the SDM adopters. Separate in-person interviews were also conducted with the most involved decision supporters for each SDM adopter. (All decision supporters were invited to participate in the evaluation. Nonotuck care managers arranged all meetings between HSRI evaluation staff and adopters and decision supporters.) For two adopters, a single designated decision supporter participated in the evaluation. For seven adopters, two or more decision supporters participated, sharing their views and impressions. Care managers who work with SDM adopters were interviewed either in person or by telephone, whichever was more convenient for them. The four CPR staff primarily engaged in the pilot during Year 2 were interviewed by telephone. For examining the experience and impact of using SDM, HSRI evaluators conducted 31 interviews involving 37 pilot staff and participants:

- 9 SDM adopters
- 15 Decision supporters
- 9 Nonotuck Care manager interviews with 4 care managers (1 care manager is the care manager for 5 SDM adopters and was interviewed separately for each SDM adopter.)
- 4 CPR staff

All interview protocols and procedures underwent ethical review and approval from an Institutional Review Board (IRB). Participation in this evaluation was voluntary for all pilot participants. Details regarding the IRB review are found in HSRI's Year 1 SDM pilot Evaluation Report.

SDM as a Model to Advance Human Rights

On November 17, 2015, pilot partners held a celebration dinner after the first guardianship was discharged in Massachusetts. SDM adopters, their decision supporters and family members, an Advisory Council member, and key pilot staff attended. Attendees were moved to hear how important SDM is as a mechanism to advance the human rights of persons with disabilities, to correct past harms, and to learn of the particular importance of this vanguard SDM pilot.

During the event, CPR Attorney Robert Fleischner, who represented an SDM adopter in court that day, petitioning the court to set aside a guardianship, relayed that this was a historic day. It was the first time in Massachusetts that an SDM adopter's guardianship was discharged and an SDM adopter's rights to make decisions about his life was restored. Attorney Fleischner also petitioned the court to release the legally appointed substitute decision maker for psychotropic medication decisions; the court did so, returning decision making rights to the SDM adopter. This SDM adopter's parents had been his guardians. They had reluctantly undertaken guardianship because, at the time their son turned 18, there was not an alternative. Now this SDM adopter's parents and sister are his SDM decision supporters.

As part of the celebration, Michael Kendrick, an international disability rights advocate, spoke on the importance of SDM and the values underpinning this international effort to give people with disabilities their voice when making decisions about their lives. Excerpts from Dr. Kendrick's remarks follow.

> *Everyone has the right to make the wrong decision, but if you don't have the right you can't make the right or wrong decision. In protecting them, we've taken their voice. [Adopter's name] court decision today is that he can now legally be involved in decisions about his life. Some members of society realize we didn't need to do that, to take his voice away. We need to correct, to rebalance. SDM means having a voice in decisions, standing with others. One of the great wisdoms in life is that once you've made a bad decision, not to keep making it. SDM allows us to correct our course, our mistake in removing people's voice. It's important to set things right.*
>
> *The idealism of SDM is embedded in the UN treaty. Getting SDM launched in other countries is amazing. It's given SDM a lot of legitimacy. The United Nations counts in many countries. It is a very high water mark to have SDM in this treaty and for countries to take action to get things right for people with disabilities. This project will give us lots of reasons to have done this sooner.*
>
> *SDM is tied up in "right" decision making. But we get to make decisions that some of the time are wrong, so it's not a fair standard to require right decisions be made by people with disabilities. If we do so, then when people using SDM make a decision that others don't agree with, it will be pulled back. We have corrective actions for wrong decisions, for example, divorce when marriage at the time seemed like a good decision.*
>
> *SDM is different than decision making because it gives support to make decisions. Doesn't mean the supporters are right, but means people are not making decisions alone. SDM is not about letting people sink or swim. Let's be in their corner, so they are not alone or making decisions in isolation. We can guide, correct, affirm decision making – just as we do for everyone else in our lives.*

> *Life is complicated. But the more we help one another and have people in your corner, then we are better off. The big secret is that nobody knows what they are doing. We are all just making it up every day. We are winging it. There is a big learning curve with making decisions. But we don't learn everything there is before we make a decision. Everyone is learning all the time – we are learning and growing and on a journey to figure it out. We are winging it, so we should not expect people with disabilities to be perfectionist in their decisions.*
>
> *The important questions are why are we here? Why were we born? What is the purpose of living? Life is murky, perplexing for all. We make decisions in context of pressures of living, not in a vacuum. This should produce in us a kindness and patience for others' decision making. It doesn't get easier or better. At every age of living it is complicated. For centuries humans have been on the earth with complicated lives and yet we are still surviving and having families and life goes on. Instead of asking about what decision is in a person's best interest, or what their capacity is to make decisions, the better question is why is life so mystifying?*

SDM adopters and decision supporters said this gathering was very significant. They felt part of a larger effort to advance human rights. Pilot partners marked an earlier significant date in March 2015 with a celebration as well. After many of the SDM Representation Agreements were signed and notarized, pilot staff, adopters and decision supporters marked this significant event with a special cake. These events illustrate the importance of **Practice Recommendations** outlined in the Year 1 evaluation:

- Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.
- Mark SDM adoption as a celebratory event.

Role and Ethical Responsibilities of SDM Designated Decision Supporters

PRACTICE RECOMMENDATION: Clarify the role and ethical responsibilities of decision supporters. Provide guidance in conversation with putative decision supporters as well as in written materials.

SDM is a relationship-based experience. The person with a disability may use the assistance of a person they designate to explain information, help them determine their preference on a matter, and also convey their preference to others—particularly to those who do not know the person well enough to have understood his or her preferences without translation or interpretation from a decision supporter. The role of a decision supporter thus is a weighty one.

A brochure on SDM created by the pilot partners describes the supporter role, "*The supporters assist the person so he or she can reach his or her own decisions. They help the person understand the choices at hand, and review options – the pros and the cons – of the pending issue. The supporters also assist the person in communicating his or her intention to others.*"[10]

At this time, SDM guidance for real-world applications, in general and for decision supporters, is evolving. As SDM experience grows and consensus on good practices for application with different

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[10] http://supporteddecisions.org/about-sdm/

populations evolves, additional guidance in law and standards will be available. In the meantime, using the CPRD, SDM presentations and publications posted online (including the website for this SDM pilot[11]), and the remarks of Dr. Kendrick, HSRI compiled the following list outlining the role and responsibilities of decision supporters. These do's and don'ts could supplement the pilot's SDM brochure guidance and be useful for consideration by future SDM pilot staff, adopters, and decision supporters.

a. People with disabilities have a right to make decisions about their lives and to have those decisions and their preferences recognized and honored. Decisions should reflect the will and preferences of the individual with a disability.
b. People with disabilities adopting SDM may choose one or more decision assistance persons (i.e., decision supporters) to assist them. Decision supporters can include peer support, friends, family, community members, or others.
c. People with disabilities using SDM may terminate or change decision supporters at any time.
d. People with disabilities using SDM may change the areas for decision assistance (finance, health, relationships, etc.) as well as how they prefer to access and use supporter decision assistance.
e. SDM guidance must include how to make changes to SDM Agreements.
f. Decision assistance should enable the person to understand the options available and consequences of deciding one way or another.
g. Decision support can be offered for decisions that range from everyday to more official matters.
h. People with disabilities can make "bad" decisions, decisions not in their best interest, just as people without disabilities are able to make. Decision supporters may simplify the options available, but should not limit options to only those considered "good" for a person with a disability.
i. Decision supporters should not make decisions for individuals with disabilities.
j. Decision supporters do not have to agree with a decision made by someone using SDM.
k. SDM involvement is voluntary. Adopters and supporters are free to use or withdraw from SDM at any time.
l. Anyone may object if decision supporters are not following the person's preferences and report decision supporters suspected of abuse, neglect or financial exploitation. (Information should be included in SDM rights and guidance materials on how and to whom to make complaints of concern, whether such complaints can be made anonymously, what entity will investigate the concern, the usual timelines for completing an investigation, and how a determination of findings will be communicated.)
m. Decision supporters may need to assist people who do not use speech to communicate and express their preferences and decisions. Assistance may include use of an interpreter, facilitated communication, assistive technologies or other methods.
n. A lack of resources should not be a barrier to adopting or making changes to SDM arrangements.

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[11] http://supporteddecisions.org/document-library/

Using SDM: The Decisions

Number and Type of SDM Decisions

EVALUATION FINDING: SDM decisions ranged from everyday choices to very important decisions. With decision assistance, adopters made decisions regarding their health care, dental care, mental and behavioral health care, finances, legal matters, living arrangements, work and day supports, social and leisure activities, relationships, and an SDM-arrangement decision to change a supporter.

To document adoption of SDM, CPR staff created an SDM Representation Agreement, which notes the areas for decision assistance (such as finances or where to live), and the designated decision supporter(s) for each area of decision assistance. Where there is more than one decision supporter for a particular area of assistance, the Agreement template includes the method by which the SDM adopter prefers to receive assistance from multiple supporters—either jointly (supporters confer and then present decision options to adopter) or successively (adopter first consults with decision supporter named first, and if that person is not available, goes to second supporter, and so on).

SDM adopters and designated decision supporters signed these Agreements. Agreements were notarized to mirror the legal weight afforded to other notarized agreements in common use. Additional information about the SDM Representation Agreements is found in the Year 1 Evaluation Report pages 24-27, and on the pilot website under Documents Library.[12]

Since the adoption of SDM Representation Agreements, pilot staff and participants identified 72 decisions that utilized SDM. HSRI categorized these according to decision areas in the pilot's SDM Representation Agreement form[13] but also further differentiated behavioral health decisions from the broader health care category. HSRI also added a category for SDM-arrangement decisions and examined social and leisure decisions separately from personal relationship decisions. HSRI did this to show that adopters in this pilot made decisions in all of these domains. For each SDM decision, HSRI identified one primary category. Table 1 shows the 72 decisions categorized by type from most to least frequent reported between March 2015 through July 2016.

Table 1. SDM Decision Categories and Frequency

SDM Decision Categories: Highest to Lowest Frequency	Number of SDM Decisions (3/2015-7/2016)
Health care and dental care	17
Financial	15
Social and leisure	13
Employment/ Volunteer / Day supports	10
Relationship	7
Legal matters	4
Living arrangements	3
Mental health / Behavioral health	2
SDM arrangement decision	1
Total SDM Pilot Decisions	**72**

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[12] http://supporteddecisions.org/document-library/

[13] The pilot SDM Representation Agreement form contains these decision assistance categories: Finances, Health care, Living arrangement, Relationships/Social, Employment, Legal matters, Other (please specify)

Below are examples from each SDM decision category made by adopters in their first year and a half (or less) after adopting SDM.

Table 2.   SDM Decision Examples

Category	Decision Example
Health care and dental care	SDM adopter decided after seeing a specialist and two surgeons (one for second opinion) to have surgery on foot. Surgery went well.
Financial	SDM adopter was dissatisfied with bank fees on transactions. Decision supporter advised that banks have different fee structures. Adopter decided to switch to a bank with unlimited free banking activity.
Social and leisure	SDM adopter was invited to a class reunion where alcohol was to be served. Decision supporters conveyed concern of riding in car with people who had been drinking alcohol. SDM adopter made decision to ride in car with friends who had been drinking and join them to eat at a restaurant after the reunion. (Everyone was fine.)
Employment/ Volunteer/ Day supports	SDM adopter was invited to speak at a conference on a panel with Temple Grandin. Adopter made decision to speak with support from others.
Relationships	SDM adopter's boyfriend wants to have children. Adopter discussed with decision supporter the care needs and money required to parent. Adopter has privacy with boyfriend but decided not to be a parent at this time.
Living arrangements	SDM adopter expressed preference to move out of family home to an apartment.
Legal	Legal decisions included whether to purchase a gun to protect loved ones, securing a state authorized form of ID, providing consent for image and story to be posted online, and pursuing a vehicle driver's license.
Mental health / behavioral health	SDM adopter experienced an increase in behavioral health symptoms. With a decision supporter, adopter met with treating practitioner and discussed medication options. Adopter decided to adjust medication and to add a visit with treating practitioner each month until feeling better.
SDM arrangement decision	SDM adopter changed shared living homes and providers. She asked that former shared living provider be removed as a decision supporter and replaced with current provider.

Using SDM: The Experience of Pilot Participants

Adopters' Understanding of SDM

EVALUATION FINDING: All SDM adopters articulated their understanding that SDM means they make decisions about their lives and have assistance from others. Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and receiving decision help when they want help. All adopters reported that SDM is a positive experience.

The Year 1 Evaluation Report relayed care managers' perceptions regarding adopters' understanding of SDM and what they were undertaking. SDM adopters were perceived to understand SDM. Below are several comments by care managers repeated from that report.

- *She understands the basics. She likes the idea she has a crutch and she expressed this at the first meeting. It's the first time in her life she is being told you have choice and control (she has tentativeness) and can talk about any decision. But until it's practiced it is rather nuanced.*
- *[Name] has a clear understanding of who helps him understand his decisions. He understands that there will be a team of people there to help him.*
- *We were there with the lawyers and the benefits of SDM were described. She turned to caregiver and said, "So you all will help me make decisions when I need it? We do that now."*

This year HSRI evaluators asked SDM adopters directly if they have the right to make decisions about their lives. Nearly all reported that they do (8 of 9 adopters). However, all adopters stated that they had help with making decisions when needed. And all SDM adopters named specific decision supporters who assist them with making decisions.

Decision supporters also perceive that adopters understand SDM, fully or sufficiently, to mean making his or her own decisions but also having a dependable relationship, someone to go to for input when needed. Comments by decision supporters are below.

- *That she can come to me with any questions or concerns for discussion, and that I'll support her decisions.*
- *He knows there are three people he can go to. Sometimes he asks what do you think or to confirm his decisions.*
- *She kind of knows exactly what it is. She enjoys making decisions on her own. She enjoys having this right. She's very opinionated, kind and gentle.*
- *She likes the support of other people.*
- *When she asked me to be decision supporter, she was very proud and knew who she wanted to be part of this, to be a decision supporter. I was the one who didn't understand it.*
- *Not sure she grasps the whole concept. She expects our involvement. She's always signed her own check and makes her own money and makes her own decisions. Now she reads, reads her menu and tells the waitress what she wants. Before, her family ordered for her.*

Decision Supporters' Understanding of SDM Role and Responsibilities

EVALUATION FINDING: Decision supporters understood and were able to uphold their duties to assist an individual with disabilities to understand options, help the person express preferences, and honor the person's preferences and decisions.

Pilot partners provided guidance to decision supporters on their role and responsibilities. All supporters interviewed noted that the orientation was sufficient to carry out their responsibilities.[14] Supporters interviewed were aware of their duties to help SDM adopters understand information, express preferences, and to honor the person's decisions. Decision supporters conveyed their understanding of SDM ethical responsibilities as below:

- *To understand what [name] wants, to inform her, to make sure she understands her choices, and honor those choices.*
- *I try to put myself in her position, making sure she has information as a human being. [Name] needs to make her own decisions. I am continuously helping her bring out what she thinks is important. Sometimes we take a long time talking -- me trying to understand -- then getting others to understand. For example, when she wanted to join taekwondo classes, the instructors thought that due to her disability, she should be in a child class. But [name] was thinking adult classes. I pushed adult class and that's where she is.*

Decision supporters are cognizant that they are not required to agree with a decision made by someone using SDM. Sometimes providing decision assistance and having other roles, such as a paid care provider or parent of an adopter, can get complicated. As this mother and decision supporter explained, **"***Yes, I want him to have a regular relationship with his fiancé, but I also don't want him to have children. But he wants to. I'm not comfortable with their next step."*

Decision supporters understand that SDM adopters should be able to make "bad" decisions, particularly decision supporters who attended the celebratory SDM dinner on November 17, 2015, and heard Michael Kendrick speak about the importance of not mixing SDM up with "right" decision making. HSRI asked CPR staff and care managers if they knew of instances in which adopters made decisions that their decision supporters might think were not in the adopter's best interest. CPR staff had knowledge of two decisions, and a care manager referenced a third decision, where adopters' decisions were not what others thought in their best interest.[15] For these three SDM decisions, made by different adopters, the adopters' preferences, not the decision supporters' impression of what was best, were honored.

Nevertheless, avoiding harm did occasionally influence provision of decision assistance. A number of decision supporters mentioned shaping choices in order to keep an individual safe. The duty to present decision options within a reasonable safety framework was mentioned more frequently by shared living providers serving as decision supporters than by family members in this role:

- *As long as not harmful, we are to support [name] decision. Make sure decisions are made to benefit [name]. [Shared living provider]*

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[14] At least one decision supporter was interviewed for each SDM adopter. For seven adopters, interviews included two or more of decision supporters.

[15] 1) To ride in car with friends who had been drinking after school reunion. 2) Not to get glasses. 3) Attend a day program where adopter had been wrongly treated as a troublemaker.

- *Have her best interests at heart so she is not making decisions that harm her but to enhance her life. Help you get the best care, best places to go, best docs. To have your back. [Shared living provider]*
- *Try to get to point to [name] understands, but try to leave decision alone. This is a hard question. I bring some options but do not overwhelm her. I educate and limit choices to all good, and she picks within them. [Shared living provider]*
- *Safe, better chance than she had; helping her when she needs help. [Shared living and day support providers]*
- *Morally as a family to see that [name] enjoys her life. SDM responsible for safe, right decisions. [Family]*

SDM Implementation Challenge: For both family and paid service providers serving as decision supporters, a concern with safety may occasionally limit an individual's choices. For decision supporters who are paid to provide supports to SDM adopters, state standards for service providers may influence their consideration of safety when providing decision assistance. Balancing support for some risk-taking with safety is not a new challenge for service providers. In Massachusetts, state standards require providers to promote an individual's self-determination and freedom of choice to the individual's fullest capability, and for individuals to undergo typical developmental experiences, even though such experiences may entail an element of risk. However, state standards also require that providers to ensure that an individual's safety and well-being are not unreasonably jeopardized.[16] Where there are dual responsibilities for ensuring safety and offering opportunities for risk-taking, decision supporters may limit or restrict information without advising the SDM adopter that they have done so.

Decision Making Assistance and Support Provided to SDM Adopters

EVALUATION FINDING: Decision supporters tailored decision aids and assistance to the person's needs. They did so through knowing a person well.

Supporters in this pilot did not receive training on how to provide decision assistance, but all supporters interviewed reported that they understood how to do so through knowing a person. This evaluation found a high level of confidence among decision supporters that their techniques and skills in presenting information were useful to SDM adopters. SDM adopters confirmed that decision supporters knew how to be helpful in providing decision-making assistance. As the supporter statements below illustrate, this good fit of presenting information in a way that is helpful—so the adopter understands the choices and consequences—seems to come from knowing one another and having a relationship of trust.

Typical are supporter quotes below sharing how they operationalized providing personalized decision assistance.

- *Be honest and spell out step by step pros and consequences, use words, sometimes show him on the internet.*

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[16] Massachusetts Department of Developmental Services 115 CMR 5.00: STANDARDS TO PROMOTE DIGNITY: 503(c) Self-determination and freedom of choice to the individual's fullest capability; 503(e) The opportunity to undergo typical developmental experiences, even though such experiences may entail an element of risk; provided however, that the individual's safety and well-being shall not be unreasonably jeopardized. Located online at: http://www.mass.gov/eohhs/docs/dmr/regs/reg-115cmr005.pdf

- *Now with the dementia, doctors talk above her and fast. I slow the conversation down. Repeat. Get eye contact so she doesn't "yes" you.*
- *It helps her if we research an issue together on the internet. I'm a sounding board. We're equals.*
- *If we overwhelm him he goes off topic. Then we know to make pros and cons simpler.*
- *We have a good relationship where she trusts me.*
- *I say, "Here are your choices." I ask him "What do you think?" I can tell from his answers. Can tell if he's anxious and if he needs to come back to it.*
- *You can tell when she understands. You can see confusion on her face. It's knowing her.*
- *Allow her to try and find out if she does or doesn't like it. One example is when she was on vacation in Myrtle Beach she wanted to go on the jet boat. Those gangplanks move and bounce and she fell down. She did get on the boat, but she is never going back on a jet boat again. Another thing she tried out was sitting at a bar stool. She didn't think she could do it, but she did.*
- *By her telling me that it's helping her. She confides in me. She says it's working for her.*

Summarizing the comments from decision supporters in this pilot, skills useful for providing decision making assistance can be described as:

- Be truthful
- Listen to the person
- Repeat/repetition
- Make eye contact
- Slow the conversation down
- Ask adopter to repeat back what was said or heard
- Observe body language
- Offer visual information
- Provide ideas and suggestions to inform decision making
- Conduct online searches together
- Review written information together
- Simplify and break larger concepts or abstractions into smaller, more concrete pieces
- Step away when an adopter appears confused or anxious; come back to discuss at another time
- Provide opportunities to try new things out. Experiences broaden decision making skills and preferences

These skills have much in common with the approach to supported decision making found in ASK ME, a model based on a positive, relational concept of autonomy.[17] ASK ME is an acronym for decision making steps. The following is an abbreviated description of these steps.

1. ASSESS where the person's strengths and deficits lie to determine how to best simplify/limit the task and maximize the person's understanding.
2. SIMPLIFY the task, avoid jargon, pitch information so that individual can understand.
3. KNOW the person, his or her values and what is important at that time to the person, how they have made decisions previously, and any patterns to decision making. Respect both prior decisions but also person's right to change their mind.

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[17] Peisah, Carmelle, et al., Decisional Capacity: Toward an Inclusionary Approach, International Psychogeriatrics (2013), 25:10, 1571-1579.

4. MAXIMIZE the person's ability to understand by giving enough time, modifying format, providing visual aids, creating environment conducive for optimizing decision making including best time of day for cognitive tasks.
5. ENABLE participation by tailoring the degree of support to the complexity of decision and the seriousness of decision consequences. This step also entails assisting and facilitating with communicating the decision and its implementation.

What Additional Supports Do Decision Supporters Need or Want?

EVALUATION FINDING: Even experienced decision supporters would appreciate peer support and opportunities to share experiences with other decision supporters. Establishing learning communities of decision supporters, locally and nationally, could provide for greater decision supporter awareness of issues that arise for supporters, and more comfort that SDM is a sustainable alternative to guardianship.

As noted above, decision supporters reported confidence in customizing their decision aid for adopters. They did not think they needed any assistance or training for this role. However, when asked if there had been another pilot with experienced decision supporters to speak to about the role, several supporters stated that some training and communication with other decision supporters would be helpful, "*Just having a personal conversation with other parents to talk to who have adopted [SDM].*"

Below are recommendations from decision supporters interviewed for those considering this role. Notable is the repetition of advice to let go of controlling a person with a disability.

- *Listen, know what people are capable of, guide in pros and cons, but don't decide for people. Make them feel good to be making their own decisions.*
- *Biggest advice is to separate being parent and being the supporter -- that mom is part of a team -- not the mother demanding as when he was underage or my ward. It's very important that every family that steps into SDM separates, steps out of parent role and into the job as a decision supporter. Decision supporters should know a person very well.*
- *Always remind supporters not to control people. People love titles and can abuse. Be happy that someone asks you to support them.*
- *Let go of the control that you are the only one who can do this for a person.*

How SDM Worked with Multiple Decision Supporters

EVALUATION FINDING: Multiple decision supporters worked well in this pilot—to a great extent because supporters were already committed to, and had established arrangements for, regular and ongoing communications.

EVALUATION FINDING: In this pilot, adopters utilized supporters who were available.

When SDM adopters selected multiple decision supporters (from 2 to 10), pilot staff and HSRI evaluators wondered if the arrangements would be too unwieldy. Such was not the case in this pilot even though five adopters designated three or more decision supporters. The Year 1 pilot Evaluation Report (pages 21-22) provides details about the relationship of supporters to adopters, and how long they have known adopters. Family members are the largest cohort of decision supporters; six of the nine adopters designated family members.

Decision Supporter Perspective

All decision supporters interviewed noted that communication is important and that they spend time keeping other decision supporters and involved parties up to date. Typical were supporter statements below.

- *Whoever is with him shares information. When a decision is made, we alert each other.*
- *He goes to whoever he wants to. Mom wants him to start using others more. Important for him to practice and know there are other people who he can consult.*

None of the interviewed decision supporters noted disagreement among decision supporters regarding SDM. What has occurred is decision supporters sharing different information or perspectives on an issue. This high degree of cooperation and communication across supporters seems related to having supporters who are deeply involved in a person's life. As this supporter described it,

- *We are always in agreement. Important because she likes to have independence. Are you coercing her in any way, e.g., decision re eating? No. We do stress why we think healthy are better choices, using language she understands. We get information to show her in print material and online. We do not coerce her. We make plans about future rewards for weight loss.*

Another supporter noted that having multiple people in a network was a positive because there is less dependence on one person and more perspectives on knowing a person: "*I'm cool with a group as an alternative to a guardian. What happens if something happens to guardian? Sometimes the people around you who know you, know you better than a guardian. I go to ISPs [service planning meetings] and I'm telling the guardian information*."

Care Manager Perspective

Nonotuck care managers also reported that use of multiple decision supporters in this pilot worked very well. For one adopter, communication among decision supporters is occasionally complicated, but this was described as *not* due to SDM, but a communication habit between an adopter, her mother, and the care manager that preceded SDM.

While disagreement was not reported within an individual's network of supporters, not all supporters are equally engaged, nor was this an expectation. SDM Representation Agreements prepared by CPR staff offered adopters the option to use either a "joint" or "successive" decision making approach to securing assistance from designated supporters. Noting joint or successive preference was expected to inform decision supporters on how SDM was to work in real-world application. Under joint, decision supporters are to work together to assist the individual with decision making or expressing the preference to others. Under successive, if the first supporter is not available, the adopter goes to the next supporter on SDM Agreement, and so on, until the adopter finds an available supporter.

Care managers reported that adopters consulted with the decision supporters on hand. For this pilot in which nearly all decision supporters were designated across all SDM decision categories, this practice of using the most available decision supporter worked. No one participating in the pilot was territorial or concerned with whom an adopter spoke or consulted first.

Potential SDM Implementation Challenge: This pilot showed a high level of cooperation across multiple decision supporters, but such cooperation may not always be the reality. In this pilot, where decision supporters were almost all given authority to assist an adopter in all decision areas, going to a supporter on hand worked. Future SDM pilots where there is more discrimination of supporters and areas of assistance may experience added complications when using multiple supporters.

CPR Staff Perspective

CPR staff note that having multiple supporters provides for accessibility of supporters but also for long term planning similar to when parents include siblings as co-guardian or successor guardians. One adopter's SDM Agreement includes a decision supporter, who at the time the Agreement was notarized, was younger than 18 years old. Although CPR staff viewed this supporter as in a "non-binding" role until he attained legal age, the adopter and the other supporters had confidence in his maturity and close relationship with the adopter.

CPR staff also confirmed what care managers relayed about the SDM process—that adopters went to whomever they chose in the moment to get information for a decision. *"It is really about people interacting. SDM models may need more clarity so people don't get hung up on that [joint v successive model]."*

Potential SDM Implementation Challenge: With multiple supporters, CPR staff raised a concern that a decision making process could result in the supporters discussing and making a decision and then presenting that decision to the adopter. While a risk, this evaluation did not find evidence of that kind of process.

Response to SDM Use by Community Members

EVALUATION FINDINGS: Most SDM decisions did not involve general community members. Where community members were involved, the preferences and decisions of adopters were accepted and acted upon without reviewing documentation of SDM arrangement or decision supporter's role.

SDM is not only about making decisions about one's life (with support if needed) but also having those decisions recognized and honored. This evaluation found that decision supporters had no difficulty conveying adopters' decisions to third parties or in having adopters' decisions honored.

The majority of SDM decisions did not involve community members. Twelve of the 72 SDM decisions involved community members. Where community members were involved, they included a banker, employers, day program management staff, urgent care health care practitioners, psychiatrists, surgeons, a pharmacist, an endocrinologist, a martial arts instructor, and Department of Motor Vehicles employees. These community members acted on the expressed preferences and decisions of adopters, although at times prompts were necessary from decision supporters.

Pilot participants described the interactions with all but one community member as favorable and respectful, understanding and compassionate. Some community members were respectful naturally, and others followed cues offered by decision supporters. Only one of the SDM interactions with a community member was described as "*abrasive,*" and in this case the decision supporter relayed that a surgeon's lack of bedside manner did not seem related to her daughter's disability, but to his general approach to communicating with patients and families. Examples of each type of experience follow.

Naturally positive - This interaction with a pharmacist was described by a decision supporter. The SDM adopter was experiencing hallucinations and the supporter's impression was that this distress was due to the adopter reliving buried trauma from decades of institutionalization now that she is in a safe place. A recurring visual and auditory hallucination began soon after the adopter told this shared living provider and decision supporter about abuse she suffered when she was institutionalized. The adopter's psychiatrist recommended a low dose of Risperdal, a medication with a "black box" warning due to a potential lethal side effect. The service coordinator from state agency for I/DD services was described as concerned about adopter's consent to a medication with a black box warning, and because this older adopter is diagnosed with dementia. The SDM adopter and decision supporter met with the local pharmacist who sat down at eye level with adopter and described the pros and cons in simple terms so that the adopter understood. The SDM adopter decided to take the medication. The hallucinations stopped and no side effects have been experienced.

Responsive to supporter instruction - A supporter accompanied an adopter to an urgent care center for treatment of a dog bite. The health care practitioner advised the adopter that a blood draw was necessary. The adopter refused. The supporter advised the practitioner to tell the adopter *why* a blood draw was necessary. The practitioner then explained why, and the adopter changed decision to allow blood to be drawn and tested.

Not responsive to supporter instruction - The exception to positive interactions with general community members was a surgeon who repeatedly asked the SDM adopter "why" questions even after her mother (also a decision supporter) instructed the surgeon that "why" questions are not well understood by [name]. This surgeon was described by the decision supporter as making statements that dismissed the adopter's expressions of pain and discomfort, and presented the risks of surgery to the adopter as, "You know you can die on the table." The procedure being discussed required local anesthesia. The supporter discussed the possibility of another surgeon for a second opinion and adopter decided to seek a second opinion.

The second opinion surgeon was naturally positive and described as gentle and compassionate. He acknowledged adopter's pain, and determined a less invasive surgical correction was possible. The problem was not a bone that needed fusion to straighten, but a cyst on tendon that could be removed. SDM adopter chose this surgeon and surgery. This surgeon asked the adopter what kind of music she wanted played during the procedure and made sure it was played. This adopter is recovering well and pain is eliminated.

Potential SDM Implementation Challenge: In this pilot supporters were present with adopters for interactions with community members and were able to provide instruction to enhance communication where needed. In some instances, had adopter interactions with community members not included decision supporters, the experiences and outcomes may not have been as favorable.

Use of SDM Representation Agreements

EVALUATION FINDING: Community members acted on the expressed preferences of SDM adopters without documentation of decisional capacity or decision supporter's role.

With one exception, SDM Representation Agreements were not utilized. Involved community members acted on the preferences of SDM adopters without documentation of decision supporter role. In the case where the SDM Agreement was produced, a care manager accompanied an adopter to a local

Department of Motor Vehicles (DMV) office to secure a legal form of state identification. Although SDM Agreements are not on Massachusetts' list of authorized forms of documenting a home address, a DMV supervisor agreed to accept it as proof of address and the adopter's signature, and issued the state ID with photo.

At this time, SDM Representation Agreements have no end date. They are in effect until one or another party decides to make changes or end the arrangement. A suggestion by one care manager is to make SDM Agreements time-limited, similar to other consent forms used in disability service systems. Time-limited SDM Agreements would prompt review, and create a point in time for adopters and decision supporters to re-commit or make changes. This care manager also recommended creating an SDM Agreement Fact Sheet to accompany the document.

Adding to the care manager's suggestions, HSRI offers the following list of items that could be included in an SDM Agreement Fact Sheet:

- The voluntary relationship between adopters and decision supporters, and that both parties are free to withdraw from the arrangement.
- When a decision supporter withdraws, an expected notice period so that the person with a disability has time to find new supporters if desired.
- Agreements can be modified as needed as people's lives change.
- Decision assistance instructions can be modified including who provides decision assistance, as well as how and decision domains (financial, health care, etc.).
- Instruction on what organization or person to contact to make changes to an SDM Agreement, such as add or remove a decision supporter, or add or limit areas for decision assistance.
- Whether there is any charge for making changes to the Agreement.
- Length of time the Agreement is in effect. If an Agreement extends into the future indefinitely, consider time-limits such as one or five years to build in a review date.
- How to secure additional copies of an Agreement, and that copies should be available at no cost.
- Recommendation that Agreements be signed by adopters and supporters and notarized.

SDM Implementation Challenge: Several adopters in the pilot advised HSRI staff that they did not have a copy of their SDM Agreement. In addition, not all care managers or decision supporters had a copy of their Agreement. If a copy was needed, adopters and decision supporters stated they would call a care manager, and care mangers noted they would contact their Nonotuck supervisor or CPR staff. It may be useful to periodically check, such as annually, that adopters, supporters, and service providers have copies of the most current SDM Representation Agreement.

Using SDM: Satisfaction

Adopter Satisfaction with Decisions, Supporters, and Decision Assistance

EVALUATION FINDING: SDM adopters were satisfied with making their own decisions, with the decision assistance provided, and with the outcomes of their decisions.

Adopters described themselves as very satisfied with their decisions including their selection of decision supporters. They expressed pride in making their own decisions and in having the right to make their decisions. Care managers and decision supporters confirmed adopters were satisfied with decisions that utilized SDM. For all 72 SDM decisions, the preferences of adopters were reported as being respected and acted upon.

Adopters also expressed satisfaction with their decision supporters and the ways supporters provided decision assistance. All SDM adopters reported that decision supporters treat them with respect, and are nice and polite. All SDM adopters said that their decision supporters ask what they (the adopters) want. *"Yes, she asks me what I want. She asked me if want a bed instead of pull-out sofa."* Most adopters report having decision supporters who understand what they want across the decision support areas of health care, finances, personal life, relationships, etc. HSRI asked supporters what adopters wanted in their life, their dreams. Supporters shared very specific hopes and dreams of adopters, including these below.

- To get a driver's license.
- Be married, have her own home with fiancé, and work at a radio station.
- Things she missed due to living in an institution. Things we all do in life.
- She tells us she wants to live with [shared living provider's name] until she dies. She wants to shop, go on vacation. She is completely different. She was being arrested before living with [provider], when she lived with her mother.

All supporters explain things in a way the adopters can understand in order to make their own decisions. "*She knows those hard words but she puts it into easy words for me. So the other person knows what it means."* Nearly all (8 of 9 adopters) said their decision supporters discuss both the good and bad things that could happen for a particular decision.

One of the values of SDM is that individuals have the right to terminate or change supporters. Others can verify and object if supporters are not following person's preferences. Adopters are currently satisfied with decision supporters. One adopter has already changed one of her three supporters. Two adopters who have family members in their decision support networks shared ambivalence not uncommon when family members are involved, noting satisfaction generally but not all the time. As this adopter noted on whether to change a relative who is a decision supporter, "*Sometimes, but not now, cuz we're family."* And from another adopter, "*Sometimes I'm happy with my mom."* If an adopter wants to change a supporter, most adopters (6 of 9) could name someone they would tell.

While adopters' decisions were respected and they expressed pride in making their own decisions, it does not mean their experiences were all positive or without unpleasant consequences. Adopters had negative experiences too, such as falling down while boarding a jet boat, not passing a written driver's license exam, and choosing to stay at a day program to be with friends although a program manager falsely accused the adopter of being a trouble maker.

Decision Supporter Satisfaction with Decisions and Responsibilities

EVALUATION FINDING: Decision supporters were satisfied with the SDM decisions in which they were involved, and reported they had not experienced any constraint or dilemma in exercising the role and responsibilities of supporter.

All decision supporters who were interviewed expressed satisfaction with SDM decisions to date. None of the decision supporters interviewed expressed any degree of dissatisfaction with SDM decision-making processes or decisions.

Another SDM value is that decision supporters be free of conflicts of interest. There is discussion in the international community as to whether supporters should be strictly volunteers in a person's life or if there is room for those paid to be in an individual's life, and if so, under what circumstances. This evaluation did not drill deeply into this issue, but did examine whether there appeared to be undue influence on adopters by supporters as well as any evidence of abuse, neglect or financial exploitation. (See next chapter, SDM Safeguards and Monitoring.) HSRI also asked decision supporters about any constraints or dilemmas they may have experienced themselves.

Decision supporter comments below illustrate their reflection on changing role to be a supporter and their feelings of security having multiple supporters involved.

- *No different; I was satisfied before. SDM opened our eyes to wonder are we making decisions for [name]? Make sure she has a voice. She is making her own decisions now and she is so much better in life. SDM gives her more people who know her well and also gives her voice.*
- *So far so good. Having a number of people in network is good, people who have known him for a long time. Especially if there were to be any abuse.*

While confident of their decision assistance skills and sureness that SDM is a worthwhile endeavor, decision supporters also shared examples of times when it was challenging to be a supporter. As this supporter shared, "*Sometimes he doesn't want the responsibility. An example is calling work and saying he's too anxious to come that day.*"

Using SDM: Safeguards

People with disabilities are at far greater risk of abuse, neglect and financial exploitation than general community members. A 2012 national survey by the Disability Abuse Project[18] found that more than 70% of people with disabilities have been victims of abuse. Of those who had experienced abuse, the repeated victimization is staggering:

- More than 90% reported they had experienced abuse on multiple occasions
- 57% reported they had been victims of abuse on more than 20 occasions, and
- 46% said abuse happened too many times for them to count.

Article 16 of the CRPD requires that appropriate measures to prevent all forms of exploitation, violence and abuse be undertaken, including providing information and education on how to avoid, recognize and report instances of exploitation, violence and abuse, as well as enacting legislation and policies to ensure that instances of exploitation, violence, or abuse against people with disabilities are identified, investigated, and where appropriate, prosecuted.

As SDM is a new construct, and in almost all states not yet legally sanctioned, there is concern that SDM will not sufficiently protect people with disabilities from harm. This evaluation of CPR and Nonotuck's SDM pilot examined risks and safeguards:

- Perceptions of decision supporter influence on adopters' decision making
- Any reports of abuse, neglect and financial exploitation
- Sharing information with adopters about their SDM-specific rights
- Monitoring of SDM relationships and satisfaction of adopters and supporters, and
- SDM-specific structural safeguards in the pilot's operations.

Did Adoption of SDM Place Individuals with Intellectual and/or Developmental Disabilities at Risk of Abuse, Neglect or Exploitation?

EVALUATION FINDING: SDM adopters did not experience abuse, neglect or financial exploitation through use of SDM. Many pilot participants stated their belief that the structure of SDM, selecting people one trusts to help with decisions, and having more than one decision supporter, reduces risk of abuse.

None of the CPR staff, decision supporters, or care managers interviewed think SDM increased adopters' risk of abuse, neglect or financial exploitation. There was a general understanding that all risk cannot be eliminated, and that relationships built on mutuality and voluntary choice of roles offers the potential for better outcomes.

Decision Supporter Perspective

Decision supporters interviewed acknowledged that abuse, neglect and financial exploitation are a widespread problem for people with disabilities. None, however, think adopters were at any greater risk

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[18] Report on the 2012 National Survey on Abuse of People with Disabilities: http://disability-abuse.com/survey/survey-report.pdf

due to SDM. Their collective view is that SDM, and especially SDM with multiple decision supporters, reduces risks. The supporter's reflection below was shared by many decision supporters in this pilot.

- *No more than guardianship does, especially if there is more than one decision supporter. I've seen it when a guardian sells someone's house and takes all the money. But if you have three people we can watch one another and if one of us says, "[Name] said she wants to sell her van," then there are two others to check on that.*

Educating adopters on areas of vulnerability is one of the roles decision supporters see themselves responsible for. As this supporter said, "*Educating him so that he understands people could take advantage of him and that he has to pick decision supporters well."*

CPR Staff Perspective

CPR staff reported no knowledge that risk of abuse, neglect or exploitation was either increased or decreased due to using SDM.

Care Manager Perspective

Care managers acknowledge that no system is perfect and can be manipulated. They have known people under guardianship whose families have abused, neglected and financially exploited them. The collective view of care managers is that an SDM arrangement with involved decision supporters is more protective than guardianship. Care managers also believe there is a great deal in common between the experiences of shared living and SDM.

- *Definitely reduced risk because [adopter's name] goes to [supporter's name] about everything and it is reframed. Then decision supporter asks adopter what she wants. [Supporter] never talks over [adopter's name].*
- *There's a ton of people out there to give them their voice and their power and make sure they are asked their decision. Guardians think every decision is theirs and they can approve everything. Guardians should learn about this and learn they are not the be-all-end-all, and need to respect people's preferences. Need to learn SDM does not take away a parents' voice but is a way to help their children with their own voice.*
- *This SDM team is more protective. She wasn't under guardianship before but her family was neglecting and financially exploiting her*.
- *Having a legally assigned guardian does not equate to safety and security. I have worked for Nonotuck for 25 years. There is a persistent thinking that something legally sanctioned, that the 'guardian' term is pixie dust that equates to safety and security. Real security comes through relationship. Shared living and a decision making team only enhances that. It does not make someone more vulnerable. The more centralized and controlled one's life is, that is what can lead to abuse. In shared living we see a lot of really healthy relationships and see people step into role of being very assertive advocates for people with disabilities. Care managers monitor, but we aren't there every day. Group homes may have on-site managers, but I have worked in group home settings and was a manager and money went missing, there were medication errors and missing meds, etc. Under shared living there is singular accountability having a person live in your home. There is mutuality. With SDM there is huge overlap with shared living.*

Decision Supporter Influence

Care Manager Perspective

Care managers reported that, for the most part, decision supporters have not *improperly* influenced adopters either in positive or negative ways. One care manager stated that for one SDM adopter, his parents who are decision supporters, have exerted influence so that their son has positive community experiences. One care manager interviewed did not have an opinion as yet on supporter influence.

Most care managers perceive decision supporters as sharing pros and cons with adopters and offering guidance on what is needed for a healthy life. But as trusted people, decision supporters do have influence with adopters. As this care manager noted, supporters are trying to give adopters the support they need in general, but it is complicated at times as with one adopter who wants help controlling her appetite and also wants to over-eat, *"[Adopter's name] makes major decisions. She is influenced by us for food decisions. We are* making strong *arguments for better decisions on eating. [Name] doesn't want us to step away. She still sneaks food. She knows she needs to make better decisions. Decision supporters offer opportunities to grow and learn to make better decisions."*

An example of persuasive influence involved a mother who was concerned her son was not involved in age appropriate community activities. As his care manager stated, "*His understanding is limited. Mom tries to help him understand concepts but there are instances of influence. He wanted to go to Buddy Games at his old high school and ride tricycles and obstacles for young kids... [Mother] asked the DDS Service Coordinator for help such as participating in Special Olympics and other age appropriate activity."*

In the former instance of influence, the adopter had asked her decision supporters to influence her to make better food choices. In the later scenario, it is not clear if the adopter requested that his supporters assist him with presenting as age appropriate in the community.

SDM Implementation Challenge: Decision supporters do at times exert influence on an adopter's decisions. Providing unbiased pros and cons of options can be challenging at times for decision supporters who want adopters to both enjoy new experiences but also reduce potential stigma.

Information as a Form of Safeguard: Knowing Your Rights

PRACTICE RECOMMENDATION: Where SDM is in place, require periodic review of SDM-specific rights, values and principles with both adopters and decision supporters.

One of the principles of SDM is that adopters are free to change decision supporters and areas of decision support at any time. Although pilot SDM adopters had SDM Representation Agreements for less than a year and a half, one adopter did change a SDM Representation Agreement. The adopter released one decision supporter and replaced that individual with a new supporter. In this case the adopter wanted to leave a shared living provider's home. She was assisted by her care manager to meet and visit with other shared living providers. After choosing and living with a new shared living provider for several months, the adopter asked the new shared living provider to be her decision supporter. This request was accepted and the change made to her SDM Agreement facilitated by CPR staff.

SDM Implementation Challenge: Although adopters and decision supporters were initially advised of their SDM-specific "rights", there was not a standardized list of rights or a protocol on the frequency or points in time (e.g., entrance into services, service plan review, quarterly care manger monitoring visit, etc.) care managers or other pilot staff would remind adopters and decision supporters of SDM values and principles of SDM.

In Massachusetts, the annual service planning meeting includes a review of human rights for individuals with I/DD receiving publicly-funded services. SDM-specific principles and expectations could be incorporated into state regulation and a standardized SDM rights form.

Pilot SDM Monitoring and Review

PRACTICE RECOMMENDATION: Where SDM is in place for people with disabilities receiving services, include periodic SDM-specific monitoring in service quality reviews.

SDM oversight in this pilot was primarily through monthly in-person visits by Nonotuck staff, either care managers or nurses. Nonotuck care managers know SDM adopters and supporters well. The shortest relationship between a care manager and an SDM adopter was three years. Four care managers have known participants for 11 years and longer. Such long-term relationships are one element of a safety net, as care managers can tell if a person is experiencing a problem and know how to support the adopter to share their concern.

While all care managers visited SDM adopters at least monthly and asked how things are going, not all included SDM-specific inquiry or monitoring into their visit assessment. As this care manager stated, *"I'm really not monitoring SDM. I did have a conversation with her about decision supporter. But every month I don't ask her."* One care manager has five SDM adopters on her caseload and is a decision supporter for three. This care manager did specifically inquire about use of SDM and completed an SDM tracking log created by HSRI. The tracking form had fields for noting SDM decisions and date, decision supporter(s) involved, community member involved, the circumstances or context in which decision was made, and if adopters were satisfied with the decision and outcome.

SDM Implementation Challenge: Thus far, there is not an SDM-specific assessment or monitoring instrument in use. If care managers note a problem, they stated they would explore and follow up just as they would other concerns. During the course of this pilot, no untoward problems or risks were discerned by care managers. Thus it is not clear if the typical path for problem resolution would be sufficient or require some SDM-specific adjustment.

Periodic SDM check in or monitoring could be as straightforward as the question prompts listed on the next page for individuals who have adopted SDM and their decision supporters.

Individual's satisfaction with:	Supporter's satisfaction with:
1. Selection of supporter(s)	1. Being a supporter
2. Supporter's availability to individual	2. Demands on time and activity to meet support obligations
3. Supporter's help to person to understand pros and cons of a decision	3. Feeling capable to assist person to understand pros and cons of a decision; any supporter need for assistance
4. Supporter's communication (or assistance to individual) to convey individual's preferences and decisions to others	4. Communicating (or assisting individual to communicate) individual's preferences and decisions to others
5. Representation Agreement areas for SDM	5. Representation Agreement areas for SDM
6. Other: Explain	6. Other: Explain

The Year 1 SDM pilot Evaluation Report included these **Practice Recommendations**:

- Establish a protocol with frequency and a responsible entity to periodically communicate to individuals their freedom to choose to withdraw from pilot without repercussion.
- Institute procedures to periodically remind SDM participants and decision supporters of the ability to change decision supporters, as well as change areas for decision assistance.
- Institute procedures to examine a complaint concerning a decision supporter. Institute procedures to refer investigation of complaints that rise to the level of abuse, neglect or financial exploitation.

Other SDM Pilot Structural Safeguards

Evaluation Finding: A lack of resources was not a barrier to adopting SDM for either adopters or decision supporters.

One of the values of SDM is that it should be accessible and available to all. A lack of resources should not be a barrier to adopting or using SDM. The Year 1 Evaluation Report included this **Practice Recommendation**, Incorporate safeguards into SDM initiatives such as no cost, voluntary adoption, free legal assistance, withdrawal from the pilot at any time for any reason, and care manager monthly monitoring.

All these safeguards were attended to and SDM-related activity by CPR and Nonotuck was provided without charge. There were no financial incentives to participate and no service impact for participating in the pilot or not. CPR provided for all court fees and legal representation in the court appearance petitioning the court to remove a guardianship. All SDM Representation Agreements, Health Care Proxies, and Durable Power of Attorney documents were drafted, signed and notarized without direct costs to SDM adopters or decision supporters.

Using SDM: Impact Assessment

Has SDM Made a Difference in Adopters Lives?

EVALUATION FINDING: This pilot demonstrated that positive changes occurred for individuals with I/DD and other disabilities who exercised their decision making rights utilizing tailored decision assistance from trusted decision supporters. Positive impacts included increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more.

Decision supporters, care managers, and CPR staff noted positive differences in adopters. Positive impacts included increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more. None of the interviewed pilot participants were aware of any negative impacts due to use of SDM.

EVALUATION FINDING: Using SDM made a positive difference in decision supporters too, particularly for family members.

One family that had reluctantly adopted guardianship was able to relinquish guardianship and utilize a rights-affirming option. For families that did not have guardianships, SDM made them more comfortable not going to court for guardianship and increased their feelings of security knowing decision supporters were committed in SDM Representation Agreements.

SDM Adopter Perspective

When asked what is different about their life since having SDM, adopters conveyed pride, strength, independence, helping others, and security. Adopters' responses follow:

- *It's really fun. It helps people with disabilities have their independence even though they have support through it all. It feels so much better because my parents aren't so in charge of me anymore. I have some independence now.*
- *Stronger.*
- *Feel good. Life is better. Explain to me. Have people that I trust and like.*
- *My life here is good. I'm my own guardian. [Decision supporters' names] when they are not busy they come and talk to me. They take me out, take me places, shopping.*
- *I have a new leaf on family tree.*
- *Helping people with their problems. I help my co-workers. I feel more confidence and stronger.*
- *Sometimes proud of making my own decisions.*
- *Yes, good.*
- *SDM is like a home to me.*

Decision Supporter Perspective

Almost all interviewed decision supporters (13 of 15), believe SDM has made a positive difference in adopters, primarily in empowerment, self-confidence and speaking up more about their preferences and decisions, and in some cases, speaking up on behalf of others as well. One decision supporter reported no difference because supporting their family member to make decisions was what their family was doing prior to adoption of SDM, “*I think it put a role on what was being done anyway. We didn’t know we were doing SDM with her. SDM put a title on our role.”* The other decision supporter that did not report a positive difference is not yet sure what the impact of SDM is. None of the decision supporters believe anything negative has resulted due to adoption or use of SDM.

Follows are statements from supporters who noticed positive change during the first year and a half after SDM was adopted.

- *I believe he speaks up more. Still a work in progress. Getting better.*
- *I think she feels more empowered. She has a chance to discuss, hear pros and cons and make decisions. She seems more confident.*
- *She is more confident in herself. She knows more what she wants. When I first met her she was sad due to past life experiences, and not motivated to do things she does now. SDM has helped motivate her. As things go on she is more confident that she is becoming more independent; she is more comfortable in herself. I see her blossoming.*
- *She’s happier, she has more self-esteem. People listen to her; before she was told what to do.*
- *I think she feels more empowered. She has a chance to discuss, hear pros and cons and make decisions.*
- *Yes, self-advocacy and empowerment. At one time the day program wanted to discipline her for something that was happening to her. She was responding to another woman’s aggression, but they weren’t listening to her and thought she was causing the problems. Care manager went back to day program and they looked at what happened. And [name] was right. So they apologized to her.*
- *He’s learned all about his medication. He has a lot -- from fish oil to melatonin to anti-anxiety, thyroid, and mood stabilization. I used to do it. He is now taking a more active role with his doctors and psychiatrist.*
- *Reassurance.... Her own decision making rights are important to her. This program helps her maintain that.*

Formalizing SDM relationships was also a comfort to parents and relatives. SDM commitments gave parents a sense of security that others would be involved in the life of their adult children with I/DD, even if they no longer were. And it gave adopters comfort that others had their back and they could look forward to the relationship continuing.

CPR Staff Perspective

Legal staff understand that this pilot has demonstrated positive impact, not only in the discharge of one adopter’s guardianship, but also in the changing perspectives of adopters and supporters. Regarding adopter differences, CPR staff stated that others have reported adopters now view themselves with pride for having decision making rights recognized. CPR staff also reported that SDM altered adopters’ relationships with supporters. As this CPR staff noted about the transitions initiated by SDM adoption,

- *First, we keep hearing how proud people are, how meaningful it is. This is an important contribution. Second is more practical impact, what does it mean for people in day to day life? For some, they were operating this way already and SDM formalizes an existing informal relationship without making it bureaucratic. But occasionally, when a decision has to be made and is important enough, SDM is dignifying and empowering. When that happens, it is potent. Third, for some participants that had decisions made for them, there is a learning process here. They are learning a new approach to decisions. Instead of talking in the old system, letting preferences be known but they knew their family or guardian would make the decision. This SDM pilot has reversed that and is changing the relationship of individuals to supporters.*

CPR staff stated that SDM has made a difference in decision supporters, particularly family members. Parents who had reluctantly adopted guardianship over their son were able to relinquish that role and utilize a rights-affirming option. These parents now feel empowered and part of a larger international human rights movement. For families that did not have guardianships, SDM made them more comfortable not going to court for guardianship and increased their feelings of security knowing decision supporters are committed in SDM Representation Agreements.

Care Manager Perspective

For most adopters, care managers think SDM has made a positive difference in their lives. For two adopters, care managers cannot distinguish between the positive impact of shared living and SDM. No negative impacts were known to care managers. For one adopter, a care manager noted that the process of being introduced to SDM and considering decision supporters re-engaged a former friend and advocate who had moved to another state. Now they talk weekly and this friend is a decision supporter.

Care managers reported positive impacts on adopters which they attribute to the SDM experience:

- *Yes, because focus is on him. He has to make decisions; mom can't do this for him or without him.*
- *Gives more opportunities for growth. She is more aware of decisions she is making. She has more self-esteem.*
- *She is safer. She is exposing herself as a person with Down's and having capabilities--reading, travel.*
- *Yes, she is taking leadership on her life, she wanted surgery, with work day decisions, making decisions for her life. Before SDM it would only have been mom's decisions. She has opportunities for growth with finances and compulsion to buy.*
- *Yes, because it's increased his ability to understand decisions. He is key now. He needs help and others need to give him ideas.*
- *During the process of learning about it (SDM) and going to city hall to sign document, she had a high sense of pride. When we go to the bank to open her own account she is going to be so proud. That will have her walking on air!*

Nonotuck care managers also reported a range of responses to SDM from those closest to SDM adopters, from not much has changed to very significant changes in family and provider dynamics, particularly when the family role legally changed from guardianship to SDM decision supporters.

- *SDM dovetails and formalizes legally what is already occurring through shared living.*
- *Roles are challenging. Some don't understand that SDM is not coercing. Bringing up something is not making the decision for her. Raising concern with health and letting [name] make a decision not to*

go to nutritionist, the Nonotuck care manager may see as coercing. We see that as raising her awareness and opportunities to engage in decisions about her life.

- *When mother was guardian the hardest decision she had to make was to admit [name] to [name of hospital] when [name] was not safe. [Name] was angry at mom for not asking him about it. This past March, he made decisions to increase his medication and to increase psychiatrist visits. This is a huge change for this family.*
- As this care manager noted about an adopter and her sister who is currently both guardian and a decision supporter, *SDM has made them both more standardized, more formal about decision making. [Decision supporter] knows it has to be [adopter's name] decision.*

Legally Recognized Decision Making Authorities Prior to and Post SDM Adoption

HSRI examined the impact of SDM on other kinds of legally recognized decision authorities in place prior to SDM adoption and after. One of the most profound impacts of this pilot was discharge of a guardianship and restoration of an adopter's decision making rights. The probate court judge also discharged this adopter's Roger's monitor, a court-appointed representative to make psychotropic medication decisions for those found incompetent or incapable of making these decisions. This adopter is now exercising his right to make decisions about his life and medications with decision assistance when needed from his supporters who are family members.

However, there is room for continued experience and growth both as adopters live their lives, and in other areas too. As outlined in Table 3 below, all adopters have Representative Payees for financial management of their Social Security and SSI payments, most adopters do not have their own bank accounts for personal funds, and only one is using the self-directed services option available to all individuals receiving services from the Massachusetts Department of Developmental Services. In addition, none of these SDM adopters have advanced directives for end of life care though two are older adults with advancing dementias.

Table 3. Legally Recognized Decision Making Authorities: Prior to and After SDM Adoption

Legally Recognized Decision Making Authorities	PRIOR to SDM Adoption	AFTER SDM Adoption
Guardianship	2	1*
Representative payee	9	9
Health care proxy	3	8
Durable power of attorney	0	2
Living will / directives for end of life	0	0
Using self-directed service delivery model	0	1
Bank account solo for personal funds	3	3
Bank account with representative payee	3	7

** One guardianship was discharged by court. Another guardian (who is now his sister's decision supporter), is relying on SDM for several months and plans to petition court for discharge of guardianship after an SDM testing period.*

SDM Implementation Challenge: Where SDM is in place, decision assistance and emotional support could be drawn upon to expand adopter experiences in banking, managing funds, and for those receiving publicly-funded services, to self-direct their services. The Year 1 Evaluation Report noted a less broad **Practice Recommendation**, When a representative payee and SDM are both in place for financial decision support, periodically examine the need for the representative payee. However, with the substantial changes demonstrated in adopters, and in decision supporters, self-directing services should also be considered.

SDM as a Viable Alternative to Guardianship or Conservatorship

EVALUATION FINDING: Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision-making assistance that allows people to keep their decision making rights, has a positive impact on their self-respect, gives people a voice in decisions about their lives, and can reduce society's use of guardianship.

Decision Supporter Perspective

All but one decision supporter interviewed considers SDM a workable alternative to guardianship. One decision supporter is still figuring this out. She and her husband (who continues as guardian for his sister) are currently decision supporters for an SDM adopter. At this point, the decision supporter-guardian has confidence in SDM and plans to petition to remove the guardianship after a few more months of testing out SDM.

There is a societal presumption that guardians are involved and knowledgeable about their wards. But as one supporter mentioned when sharing the benefits of SDM over guardianship, "*Sometimes the people around you, who know you, know you better than a guardian. I go to ISPs [service planning meetings] and I'm telling the guardian information."*

Below are decision supporters' opinions on SDM as an alternative to guardianship.

- *Yes, as long as there is a network, having an evaluation and being asked if it is working.*
- *Yes, some people may need a guardian, but people who can read, can understand and express themselves, they don't need guardians.*
- *SDM gives an individual more chance to express needs and wants, since there is an agency and a signed document to back it up. She has a signed, notarized document.*
- *Absolutely without question. "But you never asked me." That's what it's all about. As a parent you make decisions for them. An SDM decision support team will make sure you have what you need to progress and that you will always be asked.*
- *Yes, would be a great thing for a lot of people. There's more to people than you know; we don't share everything with everybody. We tell certain people certain things. Different people know different parts of us. This doesn't limit who we are. [Name] may tell you a story she never told*

anyone else. Everyone has a piece of her, a colorful collage that makes a beautiful woman. Can't wait 'til it sprouts out to others.

- *I like having an informal, easier flow of helping, versus formal use of guardianship.*

It is a significant role change to cease being a guardian whose primary task is to make decisions in a person's best interest, to supporting an individual to make his or her own decisions and explore preferences. As this mother and former guardian, now an SDM decision supporter, described her transition, it is challenging but carries a different sense of rewards.

- *Everyone has the right to make the wrong decision, but if you don't have the right you can't make the right or wrong decision. November 17th [court date to discharge guardianship] was also my birthday. There was a little pit in my stomach, 20 years of my life making decisions for him. But I had to have faith in the fact that he had grown enough and SDM would provide protection. I wanted him to grow to use his rights, to make mistakes and learn but never get hurt. And that's what this did. It made me feel comfortable. We had another family member who had a disability and was too dependent on the parent. When the parent died, that family member lost everything at once, and everything changed. We want [name] to have a peaceful, full life after we're gone. He'll mourn us. But that's what SDM does for me. We have ability to help him understand who that team is.*

Care Manager Perspective

Care managers involved in the pilot believe SDM is a useful alternative to guardianship for people with I/DD and believe SDM gave people a voice that guardianship typically does not allow. *"I had an individual under guardianship and the guardian made all decisions and dictated to the younger person."*

One care manager noted that SDM can be a useful alternative to guardianship when guardianship is being transferred to other relatives. A trusted family member who is guardian may die or move away and a successor guardian may not have the same bond. The preference of the person with I/DD regarding whom is appointed guardian would not typically be considered. In cases such as this, the care manager noted that SDM would be very useful. SDM would provide for selection of a trusted decision supporter.

- *Yes, because people are able to process decisions, have pros and cons, and explained in a manner they understand. And this lets them decide. Sometimes they need advice, sometimes different perspectives.*
- *Great project gives people voice they should have had all along. If it is honored by medical and bank and state officials, it is excellent. If it spares a person from being part of a clinical team review (CTR), then it's a wonderful thing. They should not have to be subjected to be in a room where people are discussing whether they are competent to make their own decisions. I sat through one a year ago and did not think this person needed a guardian. She was not fairly presented or understood that in CTR they were deciding if she was capable of making her own decisions. Demeaning. Then you go to court and they find you aren't competent. Her brother decided to go for guardianship.*

CPR Staff Perspective

CPR staff opinion is that while a small pilot, these SDM adopters and decision supporters demonstrated that SDM can be an effective alternative to guardianship.

- *Over time it has potential to reduce reliance on guardianship here and around the country.*

- *SDM may not be possible for every single person, but I hope that it is. Enough smart people are trying it out. We need to keep trying different pilots and different approaches, and seeing what works in other countries.*

Pilot Participants' View of SDM Applicability for Other Groups at Risk of Guardianship

EVALUATION FINDING: Pilot participants believe SDM would be useful for other populations whose decision making rights are often removed, particularly for older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally recognized adults at age 18 when many families are counseled to secure guardianship.

Nonotuck care managers and CPR staff were asked their opinion about applicability of SDM for other populations. All noted SDM had potential for other groups at high risk of guardianship, particularly older adults with early stage dementias and people with psychiatric disabilities. CPR staff and care managers also expressed a desire to pilot SDM with adults with I/DD who do use speech to communicate.

CPR Staff Perspective

CPR staff noted SDM applicability for:

- Transition age individuals with I/DD and/or emotional disabilities. This is a key stage when families with youth using special education services are typically steered to guardianship.
- Teens and adults with psychiatric or psychosocial disabilities whose need for support and assistance with medication decisions is typically intermittent.
- For older adults with cognitive decline, SDM could be offered early in disease progression.
- Adults with psychiatric disabilities using different approaches and strategies

Care Manager Perspective

Care managers interviewed believe SDM could be useful for:

- People do not use speech with I/DD
- Older adults with early stage dementias
- People with psychiatric disabilities. One care manager noted that SDM could be more challenging for people with some types of psychiatric disability (schizophrenia, PTSD, and personality disorders) and that for people with psychiatric disabilities, it would be important to execute SDM Agreements when an individual is in a stable mental state.

SDM Outreach and Awareness Activity

Sharing Pilot Experiences and Findings

EVALUATION FINDING: SDM outreach and awareness activity was extensive across both years of the pilot. SDM outreach and awareness activity in future can include the pilot experience and impact findings from this evaluation.

SDM, as a new way of thinking about an individual's legal decision making capacity, and as an alternative to use of guardianship, will require a great deal of awareness and education. Formal recognition for SDM will entail changes to state guardianship statutes, regulations and standards of practice.

CPR and Nonotuck expended substantial resources to getting the word out to individuals, families, and care managers supported by Nonotuck Resource Associates that a pilot using SDM was being launched for individuals with I/DD who had available and willing putative decision supporters.

Pilot partners also expended a great deal of effort and resources to share information about SDM and the pilot experience to broader stakeholders in Massachusetts, as well as nationally and internationally:

20	Conference presentations
20	Consultations (in person and by conference call) with organizations such as protection and advocacy agencies, legal aid, and Federal agencies
4	Webinars
3	Publication and resource documents
1	Website about SDM in general and this pilot. Information is presented in multiple formats (print, pictures and video).
	Regular updates about SDM on Nonotuck's Facebook page.

Pilot partners received many calls and requests for consultation and presentations. Future SDM initiatives will find it helpful to have a plan for prioritizing outreach activities and budgeting resources. Evaluation Report Year 1 **Practice Recommendations** included: Prioritize stakeholder communities for outreach activities; and Prepare for and budget to share information that an alternative to guardianship exists and pilot experience.

Pilot Resource Investment Year 2

Throughout Year 2, pilot partners again invested considerable resources to share information about this collaborative endeavor to test SDM in real-world experiences with adults with I/DD and other co-occurring mental health diagnoses. Below is a summary of outreach and awareness activity about SDM as an alternative to guardianship and the SDM pilot from September 2015 – August 2016. (The Year 1 Evaluation Report noted outreach and awareness activity from October 2013 – November 2015. Five conference presentations are found in both the Year 1 and Year 2 evaluation reports. For the combined total of outreach activity noted above, conferences in both reports were counted only once.)

CONFERENCES & PRESENTATIONS –

- Massachusetts Department of Mental Health Human Rights Officers, September 15, 2015
- Shared Living Conference, Marlborough, MA, September 30, 2015
- Americans with Disabilities Act 25th Anniversary Celebration, Farmington, CT, October 2, 2015
- Claiming Full Citizenship Conference, Vancouver, British Columbia, October 17, 2015
- Guardianship Law Series: Complexities, Challenges and Developments, Boston, MA, October 21, 2015
- Massachusetts Public Guardianship Colloquium, Dedham, MA, November 10, 2015
- National Guardianship Network: Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS), Seattle, WA, March 17, 2016
- Open Society Foundations international meeting on Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, Washington, D.C., April 10-12, 2016
- Massachusetts Continuing Legal Education, Boston, MA, May 2, 2016
- LEND Program, Shriver Center's Leadership and Education in Neurodevelopmental and Related Disabilities, Charlestown, MA, May 6, 2016
- American Association on Intellectual and Developmental Disabilities annual conference. HSRI presented in person using videos created for the conference of two SDM pilot participants, Atlanta, GA, June 6-9, 2016
- National Disability Rights Network, Baltimore, MD, June 13-16, 2016
- Reinventing Quality, conference of the National Association of State Directors of Developmental Disabilities Services, Washington, D.C., August 1, 2016
- Ability Beyond Disability, Bethel, CT, January 20, 2016

WEBINARS –

- American Bar Association sponsored presentation on guardianship termination. Webinar open to ABA members and non-members, March 1, 2016

CONSULTATIONS –

- University of Massachusetts, teleconference with students regarding Massachusetts Uniform Probate Code (Estate and Administration of Probate and Family Court), September 22, 2015
- Confer with Disability Law Center regarding guardianship appeal sought by private attorney, September 29, 2015
- SDM group from international conference Claiming Full Citizenship, teleconference, November 23, 2015
- ACLU Disability Rights Office, phone call, December 15, 2015
- MA Department of Developmental Disability Services, meeting with Commissioner and General Counsel, December 17, 2015
- National Consumer Law Center phone consult regarding SDM for elders, January 21, 2016
- Quality Trust, D.C., teleconference on SDM collaboration, February 9, 2016
- Community Legal Aid in Worcester, MA, teleconference on SDM and transitional planning, March 23, 2016
- Federal Administration on Community Living (ACL) teleconference on SDM, guardianship, and guardianship abuse, May 4, 2016
- New York CUNY Project, teleconference regarding SDM project, May 4, 2016
- New York CUNY Project, skype call, May 23, 2016

- ASAN (Autistic Self Advocacy Network) and TASH, teleconference regarding Administration on Community Living SDM projects, June 1, 2016

PUBLICATIONS –

- National Guardianship Association newsletter article, August 2016

While there were no direct costs to individuals or decision supporters associated with adopting SDM, CPR and Nonotuck committed fully, investing financial, staff and other resources to support this SDM pilot. To provide other organizations with an estimate of investment activity, the partners shared information for the pilot establishment year and do so again for this implementation year. CPR staff hours and Nonotuck direct costs do not reflect the full investment of partner organizations, for example, travel time is not included and Nonotuck staff time for SDM activity is not separable from regular care manager monthly visits with SDM adopters. However, many of the investments made by these partners are expected not to be incurred by organizations initiating future SDM pilots. In Table 4 below are CPR staff hours dedicated to SDM activity during Year 2, September 1, 2015 through August 31, 2016.

Table 4. SDM Investments Year 2: CPR Staff Hours

SDM Implementation Activity: September 1, 2015 - August 31, 2016	**CPR Staff Hours**
New pilot participant & decision supporter orientation: Meet with new SDM pilot candidates to discuss SDM, specify areas for decision-making support, identify supporters, review Representation Agreements, HCPs and DPOAs. Draft, revise documents as needed. Monitor pilot, update forms, orient new supporters as needed.	27
Guardianship discharge for one individual: *work already in progress* Court preparation, document filings, court appearance *(11/17/2015)*	37
Research SDM legal issues, analyze proposed and enacted SDM legislation in multiple venues for possible replication; review and comment on Massachusetts proposed legislation	84
Research on possible pilot expansion options to other sites or other populations	40
SDM educational print materials: Update brochure; review guidebooks	6
Grant development for SDM funding	30
SDM training, public outreach & education: P&A presentations, lawyer trainings, conference presentations & webinars	130
Website - Ongoing development, maintenance, adding video stories	18
Project coordination: Includes monthly CPR-Nonotuck meetings, HSRI communication, and quarterly Advisory Council meetings	33
Evaluation activities: Includes communications, CPR staff interviews, reviewing draft evaluation report, gathering time invested information	56
Pilot internal gathering and celebration November 2015:	22

SDM Implementation Activity: September 1, 2015 - August 31, 2016	CPR Staff Hours
Secure venue, invite participants, engage speaker. Purpose to share SDM advancement globally, note pilot history and accomplishments, and bring together pilot participants and network supporters for celebratory dinner after court discharge of first guardianship.	
Pilot national planning meeting in March 2016: Draft agenda; engage speakers, secure event venue; extend invitations to judges, advocates, people with disabilities, attorneys, providers; present, moderate and facilitate day-long forum (4 CPR staff)	100
Open Society Foundation international SDM conference in Wash. DC: Prepare for and participate in four-day event (3 CPR staff). Time does not include travel.	93

Nonotuck pilot expenses other than staff and travel over the SDM implementation project Year 2 are below. As in the first year of the pilot establishment, staff hours for SDM could not be separated from the regular monthly care manager visits and communication. As noted in the Year 1 Evaluation Report, Nonotuck's CEO George Fleischner conveyed, *"We spent hours on this. We might not want to chase people away but we also want people to understand the reality of the work. ... [T]he beauty of using Nonotuck has been that SDM folded so sweetly into the Project Director and the Care Manager roles. It became just part of their job. A part that Nonotuck staff took seriously and with great desire."*

Table 5. SDM Investments Year 2: Nonotuck Resource Associates Direct Expenses

SDM Implementation Expense: September 1, 2015 - August 31, 2016	Nonotuck Direct Costs
SDM pilot website, http://supporteddecisions.org/	$1,732.50
SDM Celebratory Meeting and buffet dinner, November 17, 2015	$1,107.00
Pilot national SDM planning meeting, Smith College, Northampton, June 2016	$1,632.60
Copies	$ 264.00

Future Training and SDM Guidance

Although pilot partners provided extensive education and training on SDM, care managers suggested creating additional SDM informational materials, with quick reference information on why SDM exists, SDM resources, and where to find more information and education. These suggestions by care managers add depth to Year 1 Evaluation **Practice Recommendations**:

- Educate project staff about the legal and social foundation and constructs for SDM.
- Prior to meeting with putative SDM adopters, prepare plain language educational materials. Include a brief explanation of what SDM is, why it is an important rights issue, and what the practical impact is expected to be if adopted.

Reflections on SDM Pilot Experience

What Would You Do Differently If Initiating SDM Pilot Today?

CPR staff were asked, “If you were initiating this pilot today, what would you do differently?” CPR staff stated they would allocate more effort to outreach and education in the local communities where SDM adopters live and interact. Outreach would focus on landlords, bankers, and doctors, etc., and ways to let general community members know what SDM is, that an alternative to guardianship is being piloted, and to expect that some of their customers or clients would be using SDM.

CPR staff also would request a formal announcement of support from the state agency (in Massachusetts, the Department of Developmental Disabilities Services). A formal show of support for SDM would help families feel comfortable trying this model of support.

CPR staff reported learning that having an SDM orientation packet with some standardized materials about SDM would have been useful from the beginning. But they also recognized that it was important not to overwhelm people with paper, to keep it simple, and to focus conversation on exploring people’s ideas and questions about SDM.

CPR staff also noted how important the SDM pilot website is as a resource for families and others. The website with videos and SDM resources made the concept of SDM real to people not involved with disability rights on a daily basis. One staff mentioned that it would be useful to create and post short videos illustrating the SDM process in action.

A powerful learning experience was the celebratory dinner after discharge of the first guardianship. SDM adopters, decision supporters and pilot staff attended and were moved to hear how important SDM is to correct past harms against people with disabilities, and how important this pilot is. This celebration was the only time pilot staff, SDM adopters and decision supporters were together. Bringing all the pilot participants together led to feeling part of a larger effort that gave meaning to participants. Offering more networking experiences for the pilot participants is a useful strategy for future SDM initiatives. This pilot-informed opinion mirrors the reflection of pilot participants who attended the pilot’s initial planning retreat in October 2013, and adds weight to the Year 1 Evaluation Report **Practice Recommendation**, Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.

Did Pilot Partners Meet SDM Pilot Goals?

Pilot partners, CPR and Nonotuck, met their goals for this demonstration project. Pilot goals are noted below in Table 6. The strategies undertaken by the partners allowed people with I/DD to regain and retain decision making rights, to exercise their will and preferences with support, and to have their decisions recognized by others. CPR and Nonotuck’s pilot provides a model for reducing inequality between people with and without disabilities. Pilot evaluation findings and recommendations offer guidance for broader SDM adoption in the U.S.

Table 6. Examination of Pilot Partners' Goals and Strategies for SDM Demonstration Project

Pilot Partners' Goals and Strategies for SDM Demonstration Project	Met / Not Met
Goal 1. Maximize individuals' independence: By directing their own decision-making process and making their own decisions, pilot participants will gain confidence and become better self-advocates. They will have both a voice and a presence in the community.	Met
Goal 2. Identify best practices and factors that can be replicated as models that advance supported decision-making as an alternative to restrictive guardianship. How can supported decision-making best be implemented to make a positive difference in an individual's life?	Met
Strategy 1: Assist a small number of individuals with intellectual and other disabilities to test SDM	Met
Strategy 2: Establish SDM only for individuals whose families and support network are supportive of SDM adoption	Met
Strategy 3: Make a difference in people's lives; move away from substituted to shared, supported decision making	Met
Strategy 4: Establish and utilize an advisory group	Met
Strategy 5: Provide for an independent evaluation	Met
Strategy 6: Model SDM for use by Protection and Advocacy agencies	Met
Strategy 7: Report/publish/share experience and lessons learned	Met

Limitations of Pilot

This pilot was not undertaken to demonstrate the utility of SDM across all people and situations where an alternative to guardianship could be conceived. Pilot limitations were purposeful and structural -- limited to adults with I/DD who wanted to try SDM and whose family members, putative decision supporters, and guardians also wanted to test out SDM. It was important to pilot Advisory Council members and pilot partners that this pilot limit participation to consenting guardians.

Another form of the collaborative approach is that all SDM adopters are supported by Nonotuck Resource Associates, a provider principally of shared living and adult foster care residential supports. Shared living and adult foster care residential service models offer a likely decision supporter(s) for a person with a disability, particularly those without involved family members. For some pilot participants, SDM mirrored their experience of relationship and support found in the shared living and adult foster care models, and could not be separated.

Although some may view piloting with one provider a limitation, for project start up, communication and figuring things out as one goes, beginning with one provider made sense. One CPR staff opined that one provider allowed for making changes on the fly. Additional partners or providers at the outset would likely have reduced flexibility and responsiveness.

Additional limitations of this pilot relate to adopters' personal characteristics. All adopters use spoken language, and none are considered to be severely or profoundly intellectually disabled, although two have advancing dementias and several have serious co-occurring behavioral health diagnoses. These "limitations" mean further SDM experience with those who do not use spoken language or who have more profound intellectual challenges will still be required to demonstrate SDM as an alternative to guardianship for adults with I/DD who do not use speech and those with more significant intellectual disabilities.

Independent Evaluation Contributions and Limitations

Although SDM was in use for a little over a year, this pilot demonstrated that when individuals with I/DD and other disabilities are given opportunities to utilize their decision making capacities with committed and trusted decision supporters, it can be a satisfying experience with positive impact on both adopters and decision supporters.

HSRI's evaluations shared the story of a collaborative, intentional SDM pilot and distilled the experiences of participants, lessons learned and implementation challenges. Attachment A to this report lists the pilot-informed recommendations from both years of the pilot. Attachment B lists Year 2 evaluation findings related to SDM use and examination of impacts.

HSRI had planned to include the first-hand impressions of general community members with whom SDM adopters interacted around decisions in this evaluation. However, for most of the 12 community members reported as involved in an SDM transaction, there was insufficient contact information. Also, there was an extended lag time between the evaluation staff learning about an SDM decision with an involved community member and the event. Another barrier to surveying community members were addressing privacy matters. Thus this evaluation does not report the impressions of community members directly. HSRI collected the response of community members indirectly from decision supporters and care managers. None of the 72 SDM decisions were challenged. Nine of the ten involved community members were reported as treating SDM adopters and their decisions respectfully and professionally.

Next Step Considerations

One of the challenges of a pilot initiative is determining what happens after the time set aside for the pilot ends. For the nine pilot SDM adopters in this pilot, their relationships with decision supporters will continue indefinitely and alter as needed. However, for a number of pilot participants interviewed, there is uncertainty about next steps. Going forward, partners may find it helpful to clarify the following:

- Care managers occasionally leave their positions and also use medical and family leave time. How will SDM training for new care managers be accomplished for those with SDM adopters on their caseloads?
- Will SDM monitoring continue as a care manager responsibility?
- Will there be periodic meetings of pilot SDM adopters, decision supporters, and care managers to sustain their commitment to SDM and to share developments, problem solve, and mentor new decision supporters?

- Will SDM be offered to adults supported by Nonotuck at risk of guardianship in future? If legal representation to advise a court of SDM option, will legal services be made available? If yes, from CPR or another organization with experience representing people with disabilities without cost to person with a disability?
- Will SDM be offered to other adults supported by Nonotuck who are not under guardianship and have people interested in serving as decision supporters?
- Will SDM be offered to adults who do not use spoken language to communicate, or to adults with more significant intellectual disability?
- How do partners plan to parlay the experience and outcomes to date for SDM as a model to limit the use of guardianship? Are there plans to update the Massachusetts' guardianship statute to legally recognize SDM? To advocate with state agencies to formally recognize SDM?

In March 2016, CPR organized an all-day SDM discussion meeting. National and international disability rights advocates and legal thinkers met to explore and discuss strategies for advancing SDM as a mechanism to promote equal rights for individuals who are, or might be exposed to, compromised participation in society due to guardianship. In addition to CPR staff and Nonotuck leaders, participants included SDM pilot Advisory Council members, CPR Board members, SDM adopters, a care manager who is also a decision supporter for several adopters, and an Advisory Council member who is a self-advocate. Representatives from organizations included the Open Society Foundations, ASAN, the Massachusetts DD Council, the Maine and New York Protection and Advocacy agencies, elder law experts, and the National Resource Center for Supported Decision Making. HSRI's evaluation team attended.

The day was thought-provoking and the discussion informed CPR's and Nonotuck's planning of next steps to advance supported decision-making. HSRI's evaluation reports will be shared with the SDM pilot's Advisory Council so that members can contribute to the ongoing conversation about SDM. Activities under discussion include expanding the pilot beyond Western Massachusetts and publishing SDM resources, such as a white paper or research article, based on pilot experiences and evaluation findings.

Attachment A. Pilot-Informed Guidance for Establishing SDM Initiatives in the U.S.

Practice Recommendations were drawn from both pilot years.

SDM Pilot Establishment

Partnership Practice Recommendations

Partnership between a legal advocacy and a service provider organization are useful for establishing SDM.

Partnership and collaboration is facilitated when organizations share values.

Pilot Staff Orientation to SDM Practice Recommendations

Educate project staff about the legal and social foundation and constructs for SDM.

Initial SDM Planning Meeting Practice Recommendations

Set aside time to discuss SDM initiative framework, resources needed, and foreseeable implementation issues.

Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.

Pilot Team Communication and Project Management Practice Recommendations

Establish a clear pilot project team and clarify roles.

Schedule regular in-person meetings with agendas to update one another and jointly plan next steps.

Clarify how problems will be resolved.

Advisory Council Formation and Role Practice Recommendation

Establish an Advisory Council to provide multiple perspectives on implementation.

Independent Evaluation Practice Recommendation

Early pilot initiatives should establish an independent evaluation to safeguard SDM adopters with external review of implementation and to share lessons learned.

SDM Participant Selection

Identify SDM Participants Practice Recommendations

Prior to meeting with putative SDM adopters, prepare plain language educational materials. Include a brief explanation of what SDM is, why it is an important rights issue, and what the practical impact is expected to be if adopted.

Where legal staff do not have regular communications with people with I/DD, consider utilizing an expert to role model SDM introduction conversations. Review interviewing guidance for conversations with people with I/DD such as *Disability Etiquette* located online at: https://www.unitedspinal.org/disability-etiquette/

Prior to meeting with a person with I/DD find out about a person's life and communication style.

Allow extra time for individuals with I/DD and their family members and care givers to get comfortable so they can freely express reservations and ask questions.

Expect to meet more than once with individuals with I/DD to present and discuss SDM.

Create a script for pilot staff to guide SDM conversations.

Establish a protocol with frequency and a responsible entity to periodically communicate to individuals their freedom to withdraw from pilot without repercussion.

Participants Select Decision Supporters Practice Recommendations

Provide opportunity for staff participating in selection discussions to debrief following sessions to insure consistency with respect to assurance of individual's choices and how any persuasion or disagreements might best be handled.

Shared living appears to offers a community-member to provide those with and without involved family members a decision supporter they trust. (Next year HSRI will track satisfaction with decisions.)

Even when well-known to one another, SDM conversations can lead to case managers learning something new about people they support.

Participants Select Areas for Decision-Making Assistance Practice Recommendations

When more than one decision supporter is chosen, describe in the SDM Agreement how multiple supporter consultation is to work.

Take precaution so that individuals with I/DD understand they can specify which types of decisions they want to use support from designated people, and which types of decisions they want to make on their own. Legal staff should minimize the influence of others (family, guardian, staff, etc.) by meeting with individuals without others present when possible.

Institute procedures to periodically remind SDM participants and decision supporters of the ability to change decision supporters, as well as change areas for decision assistance.

Institute procedures to examine a complaint concerning a decision supporter. Institute procedures to refer investigation of complaints that rise to the level of abuse, neglect or financial exploitation.

SDM Adoption

SDM Documentation Practice Recommendations

Create plain language SDM Agreements. Avoid legal language where possible.

Require decision supporters to sign SDM Agreements to ensure they understand the commitment, freely consent, and know the agreement is flexible and can be changed as people's lives change.

Notarize SDM Agreements to convey a formal document with legal stature.

Mark SDM adoption as a celebratory event.

When a representative payee and SDM are both in place for financial decision support, periodically examine the need for the representative payee.

Even when uncontested, discharging a guardianship is complicated and time consuming. Allow sufficient time to insure that all requirements can be met.

Structure Safeguards Practice Recommendations

Incorporate safeguards into SDM initiatives such as no cost, voluntary adoption, free legal assistance, withdrawal from the pilot at any time for any reason, and care manager monthly monitoring.

Clarify the role and ethical responsibilities of decision supporters. Provide guidance in conversation with putative decision supporters as well as in written materials.

Where SDM is in place, require periodic review of SDM-specific rights, values and principles with both adopters and decision supporters.

Where SDM is in place for people with disabilities receiving services, include periodic SDM-specific monitoring in service quality reviews.

SDM Outreach and Awareness Activity

Raise Awareness about SDM Practice Recommendations

Prepare for and budget to share information that an alternative to guardianship exists and pilot experience

Prioritize stakeholder communities for outreach activities

Provide for Sufficient Resources Practice Recommendations

Prepare for and budget for additional staff time and resources to carry out SDM activities, coordinate activities, and share pilot experience.

Attachment B. Pilot Evaluation Findings Related to Use of SDM

Number and Type of SDM Decisions

Evaluation Finding: SDM decisions ranged from everyday choices to very important decisions. With decision assistance, adopters made decisions regarding their health care, dental care, mental and behavioral health care, finances, legal matters, living arrangements, work and day supports, social and leisure activities, relationships, and an SDM-arrangement decision to change a supporter.

Adopters' Understanding of SDM

Evaluation Finding: All SDM adopters in this pilot articulated their understanding that SDM means they make decisions about their lives and have assistance from others. Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and receiving decision help when they want help. All adopters reported that SDM is a positive experience.

Decision Supporters' Understanding of SDM Role and Responsibilities

Evaluation Finding: Decision supporters understood and were able to uphold their duties to assist an individual with disabilities to understand options, help the person express preferences, and honor the person's preferences and decisions.

Decision Making Assistance and Support Provided to SDM Adopters

Evaluation Finding: Decision supporters tailored decision aids and assistance to the person's needs. They did so through knowing a person well.

What Additional Supports Do Decision Supporters Need or Want?

Evaluation Finding: Even experienced decision supporters would appreciate peer support and opportunities to share experiences with other decision supporters. Establishing learning communities of decision supporters, locally and nationally, could provide for greater decision supporter awareness of issues that arise for supporters, and more comfort that SDM is a sustainable alternative to guardianship.

How SDM Worked with Multiple Decision Supporters

Evaluation Finding: Multiple decision supporters worked well in this pilot—to a great extent because supporters were already committed to, and had established arrangements for, regular and ongoing communications.

Evaluation Finding: In this pilot, adopters utilized supporters who were available.

Response to SDM Use by Community Members

Evaluation Findings: Most SDM decisions did not involve general community members. Where community members were involved, the preferences and decisions of adopters were accepted and acted upon without reviewing documentation of SDM arrangement or decision supporter's role.

Use of SDM Representation Agreements

Evaluation Finding: Community members acted on the expressed preferences of SDM adopters without documentation of decisional capacity or decision supporter's role.

Adopter Satisfaction with Decisions, Supporters, and Decision Assistance

Evaluation Finding: SDM adopters were satisfied with making their own decisions, with the decision assistance provided, and with the outcomes of their decisions.

Decision Supporter Satisfaction with Decisions and Responsibilities

Evaluation Finding: Decision supporters were satisfied with the SDM decisions in which they were involved, and reported they had not experienced any constraint or dilemma in exercising the role and responsibilities of supporter.

Did Adoption of SDM Place Individuals with Intellectual and/or Developmental Disabilities at Risk of Abuse, Neglect or Exploitation?

Evaluation Finding: SDM adopters did not experience abuse, neglect or financial exploitation through use of SDM. Many pilot participants stated their belief that the structure of SDM, selecting people one trusts to help make decisions, and having more than one decision supporter, reduces risk of abuse.

Other SDM Pilot Structural Safeguards

Evaluation Finding: A lack of resources was not a barrier to adopting SDM for either adopters or decision supporters.

Has SDM Made a Difference in Adopters Lives?

Evaluation Finding: This pilot demonstrated that positive changes occurred for individuals with I/DD and other disabilities who exercised their decision making rights utilizing tailored decision assistance from trusted decision supporters. Positive impacts included increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more.

Evaluation Finding: SDM made a positive difference in decision supporters too, particularly for family members.

SDM as a Viable Alternative to Guardianship or Conservatorship

Evaluation Finding: Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision-making assistance that allows people to keep their decision making rights, has a positive impact on their self-respect, gives people a voice in decisions about their lives, and can reduce society's use of guardianship.

Pilot Participants' View of SDM Applicability for Other Groups at Risk of Guardianship

Evaluation Finding: Pilot participants believe SDM would be useful for other populations whose decision making rights are often removed, particularly for older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally-recognized adults at age 18 when many families are counseled to secure guardianship.

SDM Outreach and Awareness Activity

Evaluation Finding: SDM outreach and awareness activity was extensive across both years of the pilot. SDM outreach and awareness activity in future can include the pilot experience and impact findings from this evaluation.

Attachment C. Demographic Information Regarding SDM Adopters

Category	SDM Adopter Information
Age	24 to 79 years. When pilot initiated, age range was 23 to 78 years.
Gender	6 females, 3 males
Primary means of communication	9 (all) use speech but there is vocal expression range, specifically: • 1 primarily uses “yes” and “no” with facial expression • 1 relies heavily on text messaging • 1 needs a lot of time to process information and respond
Intellectual disability diagnoses	2 Mild intellectual disability 6 Moderate intellectual disability 1 Not diagnosed with intellectual disability
Developmental disability diagnoses	4 Down syndrome 3 Other developmental disabilities
Behavioral health diagnoses	1 Borderline personality disorder, history of suicidal preoccupation 2 Bipolar mood disorder 4 Anxiety disorder 2 Depression/dysthymia 1 ADHD (attention deficit hyperactivity disorder) 1 Psychotic disorder 1 Post-traumatic stress disorder (PTSD)
Significant medical conditions	2 Dementia 1 Seizure disorder 1 Obesity 1 Incipient cataracts 2 Hypothyroidism 1 Pre-diabetic 1 Congestive heart failure 1 Congenital heart defect 1 Asthma
Living arrangement	5 live with family (Adult Family Care) 4 live with non-relative care providers in care provider’s home (Shared Living)
Employment status	1 retired (used to own a house cleaning business) and attends a day program 3 have part time community jobs with small groups of people with disabilities 3 have individual jobs in their communities 1 volunteers in a couple of community locations
Risk of guardianship	2 older women with dementia would be at risk if not using shared living service model. (1 experienced a change of home and live-in caregiver due to behavior related to dementia progression.)
History of institutionalization	6 have never lived in an institution for persons with disabilities. 2 lived for decades in different state institutions for people with I/DD. 1 resided in residential schools between ages 9 and 22, then lived in group home until her late twenties.

Supported Decision-Making New York: Evaluation Report of an Intentional Pilot

"This is not just signing a piece of paper. It's about a real transformation, that we have now seen over and over, in which people with IDD become real agents of their own lives." SDMNY staff

Prepared for Hunter College/The Research Foundation CUNY
August 2019

Elizabeth Pell
INDEPENDENT CONSULTANT | EPELL@COMPORIUM.NET

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Executive Summary

In 2015, the New York State Developmental Disabilities Planning Council (DDPC) issued a Request for Proposals for a five-year Supported Decision-Making Pilot Grant. The purpose of the project was to develop and distribute educational materials and to pilot supported decision-making with people with intellectual and developmental disabilities (IDD) in locations throughout New York State. DDPC expected the grantee to work closely with the state's Protection and Advocacy agency, Disability Rights New York (DRNY), to perform the work. Narratives and data from this supported decision-making initiative would inform reforms to state law to advance the use of supported decision-making as an alternative to guardianship.

"Supported Decision-Making New York" (SDMNY), a consortium of collaborating institutions, was awarded the grant. Hunter College/CUNY serves as the lead agency for the consortium, which also includes the New York Alliance for Inclusion and Innovation (formerly the New York State Association of Community and Residential Providers, or NYSACRA), and The Arc Westchester.

SDMNY partners developed educational information about supported decision-making (SDM) and have presented to a wide variety of stakeholders. By the end of the third year of the grant, the partners had conducted over 90 awareness and outreach sessions utilizing an array of platforms, from in-person presentations to podcasts to webinars. SDMNY partners also designed a facilitation model offering SDM to two groups of people with IDD: the **Diversion** pilot offers SDM to divert those at risk of guardianship away from guardianship whereas the **Restoration** pilot offers SDM to those with guardianship orders with the aim to restore their decision-making rights by terminating the guardianships. The DDPC grant requires SDMNY recruit a minimum of 90 persons in the Diversion pilot and a minimum of 45 persons in the Restoration pilot.

Diversion and Restoration SDM pilot sites have been established in five geographic locations around the state, first in New York City, then in Westchester County, followed by the greater Rochester area, Long Island, and the Capitol region. By the end of the third year of the grant, 79 people with IDD had enrolled in an SDMNY pilot; 8 had completed the facilitated SDMNY process and held executed SDM Agreements with supporters.

During the third year of the grant, Hunter/CUNY subcontracted with an independent consultant to conduct the one-year focused process evaluation reported here, related to SDMNY Restoration and Diversion pilot activity. This evaluation was not a comprehensive evaluation of SDMNY activities to date. Instead, it was an inquiry into selected pilot activity with regard to four research areas:

- What concerns or advice led family members of people with IDD to consider or to become a guardian?
- What influenced family member and guardian adoption of SDMNY?
- Has the SDMNY process in this pilot addressed or reduced concerns that led family members to become or to consider becoming a guardian?
- Has participating in the SDMNY pilot affected or changed the individual with IDD?

This evaluation also provided key Hunter/CUNY staff an opportunity to reflect on their experiences to date and identify challenges and recommendations useful to sustain and broaden SDMNY adoption after grant funding concludes.

In addition to interviews and surveys conducted for the purpose of this evaluation, the evaluator also reviewed background papers, SDM pilot evaluation reports in the U.S. and around the world, and other publicly available materials.

Evaluation Findings

A selection of evaluation findings follows.

Model

- The SDMNY model utilizes trained volunteer facilitators who develop a relationship with the person with IDD and assist with creating a Supported Decision-Making Agreement. Recruitment of volunteer facilitators has been challenging. Initial attempts to utilize social work students posed problematic as the timing of SDM facilitation meetings did not sufficiently align with clinical practice requirements. Facilitator recruitment through provider agency personnel was attempted but deterred due to the absence of an available funding stream for facilitation activities. SDMNY staff continue to explore renewable sources of volunteer facilitator pools with academic professional programs—including occupational therapy assistants and graduate students in special education—as well as court-affiliated mediators.
- Developing a Supported Decision-Making Agreement using the SDMNY facilitation process takes at least twice as long as originally planned. The three-stage facilitation process was designed to occur over 6 to 9 months. Completed and signed agreements have taken a year to 18 months.

- Mentors provide oversight of, and assistance to, facilitators, and quality review of Supported Decision-Making Agreements. SDMNY began with staff serving as mentors. With geographic expansion and the growing number of facilitators, the need for paid mentors has become apparent. Additional development is needed to secure and expand a paid professional mentor pool.
- SDMNY staff reflected that people with IDD could have been more consistently involved as full partners—from the establishment of the pilot, to research, training, recruitment, and planning expansion and system change strategies.
- SDMNY has established important initial safeguards. For long-term SDM sustainability, additional safeguards are needed related to the use of Supported Decision-Making Agreements—including reporting and examination of complaints and concerns (e.g., undue influence by a facilitator, mentor, or supporter, or a third party not honoring a decision), and for reporting and investigating possible abuse, neglect, or financial exploitation.

Outreach and Recruitment of People with IDD

- Recruiting people with IDD to engage in SDMNY takes more time and effort than expected, particularly for those under guardianship orders. Significant challenges to recruitment are a lack of legal standing for SDM and a widely held belief that guardianship is necessary in order for family members to be involved in decisions, particularly in a crisis or urgent situation.
- Recruitment was most successful when SDMNY staff developed a relationship with an organization (a school) over time and engaged in ongoing conversations with school personnel, both administrators and teachers, in order that all school staff, not just transition coordinators, understood the potential benefits of SDM for persons with IDD.

Pressures Toward Guardianship

- Guardianship is not well understood. Most guardians and potential guardians (60%) reported awareness of but not a clear understanding of the specific loss of rights that accompanies guardianship in New York.
- Family members, both guardians and potential guardians, are advised that guardianship is necessary, most persuasively from other parents with children with disabilities, from schools, and from health care providers.
- Many family members are not fully cognizant that alternatives to guardianship exist; as a result, they are unable to make informed decisions about guardianship or alternatives.

Family Members Are Interested in SDMNY Values

- Family members participated in SDMNY because supported decision-making aligns with their values and expectations of how to treat their adult family members with IDD:

respecting their voice, encouraging them to advocate for themselves, and supporting them to have more control over their own lives.

- Family members found SDMNY information sessions very impactful. In particular, they found the following information persuasive: limits of guardianship, removal of rights, evolution of best practices to SDM, and how deeply it matters to allow people to experience risk-taking and decision-making in their own lives.
- Legal recognition of SDM would increase guardian and potential guardian confidence in SDM viability, providing them assurances that decision-makers' rights would be protected in the future, that third parties would accept decisions made using SDM, and that SDM will continue even after parents and other family members become unavailable or pass away.

SDMNY Early Impacts

- Facilitators who participated in this evaluation reported that the SDMNY training and experience changed their perspective and removed some stereotypes about people with IDD.
- For most potential guardian family members, participating in SDMNY reduced concerns that may have led to guardianship petitions. For guardian family members, participating in SDMNY has yet to reduce the concerns that led them to petition for guardianship.
- Positive impacts reported for people with IDD participating at this early stage of SDMNY engagement included increased self-advocacy, greater self-confidence, a wider array of experiences and trying new things, reduced anxiety, and greater happiness.

Introduction

At its core, supported decision-making (SDM) is the normal human activity of consulting other people and sources to inform a decision. In the context of disability rights, there are numerous descriptions of SDM. The National Council on Disability—an independent federal agency that advises the president, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities—uses the following description:[1]

> There is no singular definition or model, but this generally means an individual choosing one or more people to assist that person in understanding the nature and consequences of potential personal and financial decisions, supporting the individual in making their own decisions, and then communicating decisions as needed. It generally occurs when people with disabilities use friends, family members and professionals to help them understand the everyday situations they face and choices they must make, allowing them to make their own decisions without the need for a substitute decision maker such as a guardian. This process works in the same way that most adults make daily decisions – by seeking advice, input and information from trusted knowledgeable others.

SDM is also derived from an international human rights treaty, the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD asserts that people with disabilities share legal capacity on the same basis as people without disabilities—that is, they have the right to make their own decisions and have those decisions legally recognized. Article 12 of the treaty affirms the equal recognition before the law and legal capacity of persons with disabilities. Countries ratifying the UNCRPD commit to "…provide access by persons with disabilities to the support they may require in exercising their legal capacity."[2] SDM is recognized as a mechanism for operationalizing equal legal capacity.

Nearly every country has ratified the UNCRPD.[3] The United States, North Korea, and Sudan are among those countries that have yet to do so. Former President Barack Obama signed the UNCRPD in 2009. In the U.S., however, a two-thirds majority Senate vote is also required for ratification of an international treaty. The UNCRPD has made it to the Senate floor, but the majority vote has yet to be achieved.

Even so, there is much interest and progress underway to advance SDM here in the U.S. SDM is emerging as self-direction, person-centered planning, and service choices that include integrated, non-disability options are becoming the norm. And SDM is advancing quickly in the U.S. At the time SDMNY launched, just two states (Texas and Delaware) had revised their guardianship law to recognize SDM Agreements (SDMAs) and advance SDM.

Now eight states and the District of Columbia have passed legislation recognizing SDM agreements: Texas, Delaware, Wisconsin, Alaska, North Dakota, Indiana, Nevada, and Rhode Island.[4]

Prevalence and Outcomes of Guardianship for Adults with IDD

In the U.S., guardianship is a legal process. A state court appoints a guardian, a substitute decision-maker, when a judge determines a person lacks capacity to make important decisions regarding his or her own life or property. A guardianship order removes a person's right to decision-making about her or his own life, including decisions such as where to live, whether to work, whether to have an intimate relationship, what medical care to receive or refuse, and how to spend money. Guardianship can also, depending on the state law, remove a person's right to vote, to marry, to drive a car, and other forms of engagement in community life. Young adults with IDD are particularly at risk of guardianship and losing their legal right to make decisions about their lives.

The use of guardianship in this country has been promoted and adopted as a protective measure, primarily for older adults with dementias and for people with IDD, to reduce perceived or experienced risk or vulnerability. But best practices evolve and are changing to affirm rights. People with disabilities have been demanding their full human and legal rights. Civil and human rights protection for people with disabilities is steadily gaining legal footholds and social acceptance. The UNCRPD and SDM are real drivers for change here in the U.S. and around the world.

While a dearth of data on guardianship means exact numbers are unknown, the number of people under guardianship is still on the rise in the U.S. Since 1995, the estimated number of older adults and adults with IDD under guardianship in the U.S. has tripled, from 500,000 to 1.5 million.[5] And according to the National Council on Disability, actual guardianships may be much higher.[6] Since the late 1990s, the National Core Indicators™ (NCI) has been collecting data on guardianship rates among adults with IDD who are receiving publicly funded services. While the rate of people who have IDD across the country is the same, the rate of guardianship for adults with IDD receiving publicly funded services varies widely by state. Data from the most recent NCI™ dataset (2017-2018) found that adults with IDD reported to have full or partial guardianships ranged from 5.5% in one state to 89% in another.[7] Such variation indicates that something other than the personal characteristics of adults with IDD influences guardianship rates within state service systems.

Guardianship is correlated with negative impacts for people with disabilities beyond a loss of rights. Adults with IDD under guardianship have different life experiences than those not under guardianship. A new National Core Indicators™ Data Brief, *What Do NCI Data Reveal*

About the Guardianship Status of People With IDD?, examines the data from a 2016-2017 NCI survey of 25,671 adults with IDD who are receiving publicly funded services and compares the lives of those who are under guardianship with those not under guardianship.[8] According to the report, those not under guardianship were more likely to:

- Be employed in a community-based job
- Live in their own home or apartment (and less likely to live in a group residence)
- Be involved in making decisions about their lives
- Be included in their communities
- Receive preventative health care screenings, if female (mammograms, Pap test)

In addition, guardianship can place people at risk of victimization. Although guardianship is presumed to provide protections, there are some cases where guardians (both family member and professional guardians) take advantage of their authority and victimize their wards. The extent to which people with IDD and older adults are victimized by guardians is not known as our government has not collected this information in a systematic way. The Government Accountability Office conducted an examination into the extent of abuse by guardians for older adults and, in its 2016 report, confirmed abuse and financial exploitation by guardians occurs; and in the same report, the GAO reiterated the dearth of national data.[9] Efforts are underway to collect accurate national data on the exploitation and abuse of older adults and adults with disabilities through state Adult Protective Services.[10] Information on perpetrators including guardians will be available through the National Adult Maltreatment Reporting System which began collecting data in 2016.

Paradigm Shift Underway: Recognizing SDM and Renewed Guardianship Reforms

As previously mentioned, SDM is advancing quickly in the U.S., and eight states have passed legislation recognizing SDM Agreements (SDMAs). Some state statutes require the use of a standard form for SDMAs whereas others do not. And while statutory requirements vary across jurisdictions, SDMAs generally include statements that a person is voluntarily adopting SDM and identify areas where decision support is desired, who provides the support, and how support is to be delivered. SDMAs are meant to be living documents that extend indefinitely into the future and can be modified or terminated at the decision of the person with a disability.

Alaska has a novel approach to SDM. The state's new statute offers SDM to all citizens, those without and with disabilities, as well as people under guardianship. If a part of the SDMA has to do with decisions under the guardian or conservator's domain, then the guardian must consent and sign the agreement acknowledging others are involved.[11]

The Uniform Law Commission, a national group of lawyers appointed by their state governments who provide states with nonpartisan, uniform draft legislation in areas of state law, has recommended major changes to guardianship law at several points, beginning in 1969.[12] Over time, states have adopted important recommended procedural provisions, including a right to notice, to object to the guardian and guardianship, and preference for limited, tailored guardianship over plenary guardianships. In 2017, the Uniform Law Commission approved the *Uniform Guardianship, Conservatorship and Other Protective Arrangements Act* (UGCOPAA) that presents SDM as a less restrictive alternative that must be considered before guardianship can be imposed.

The American Bar Association (ABA) is also a proponent of attempting SDM before guardianship. In 2017, the ABA adopted Resolution 113 urging state, territorial, and tribal legislatures to amend guardianship statutes to require SDM be identified and fully considered as a less restrictive alternative before guardianship is imposed. This resolution also urges judges to consider decision-making supports, including SDM, that would meet the individual's needs as grounds for termination of a guardianship and restoration of rights.[13] Prior to passage of Resolution 113, the ABA published guidance for attorneys, in its *PRACTICAL Tool for Lawyers: Steps in Supported Decision-Making,* that also proposes consideration of less restrictive options, including SDM, before proceeding with a guardianship petition.[14]

Other professional associations have published policy and practice recommendations favoring SDM. In 2016, the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc published a joint policy statement in support of guardianship reform and the importance of individual autonomy for people with IDD, *Autonomy, Decision-Making Supports, and Guardianship.*[15] An excerpt from that statement reads:

> The personal autonomy, liberty, freedom, and dignity of each individual with IDD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with IDD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

The federal government is also promoting SDM. In 2014, the Administration for Community Living, Department of Health and Human Services, funded a national technical assistance center to research and advance SDM for older adults and people with IDD. The National Resource Center on Supported Decision-Making has been collecting and sharing stories of those using SDM and has funded 18 SDM projects around the country to advance the SDM knowledge base and encourage states to recognize SDM in many forms—from an alternative to guardianship to reducing disability discrimination in organ transplantations. For more information about the Center visit: http://supporteddecisionmaking.org.

The U.S. National Council on Disability 2018 report, *Beyond Guardianship: Towards Alternatives that Promote Greater Self-Determination of People with Disabilities*, presents the civil rights implications of guardianship and alternatives and recommends expansion of SDM at state and local levels.[16]

Pilot programs (in this country and around the world) are contributing to the advancement of SDM. These pilots are demonstrating the positive impacts of assisting people to retain their rights and receive support with decision-making. Evaluations of pilots that examined impact to date have found SDM to enhance self-esteem, self-confidence, and decision-making skills of SDM adopters. SDM pilots have demonstrated that SDM is a viable alternative to guardianship. Bulgaria's SDM pilot even demonstrated that service costs were lower for those using SDM, including reduced hospitalizations and reduced social welfare costs due to an increase in competitive employment. As retired Surrogate Judge Kristin Booth Glen stated at the 2019 National Supported Decision-Making Symposium, "SDM pilots around the world demonstrate that SDM is a process that changes learned helplessness to people becoming agents of their own lives, and repositions those around them to stop being fixers and, instead, to become true supporters."[17]

Supported Decision-Making in New York

In New York, the guardianship law for people with IDD (Surrogate's Court Procedure Act Article 17-A) is separate from and provides less due process protections than the general adult guardianship statute (Mental Hygiene Law Article 81). There is no requirement for a hearing, and no requirement for specific evidence about a person's capacities or need for support (i.e., a functional assessment). Instead, the legal criterion is simply a diagnosis of intellectual or developmental disability, without examination of how a person operates in the world or evidence about supports in place or that could be accessed related to areas of vulnerability, and the judge's determination that guardianship would be in the person's "best interest."

This evaluation found that in New York, schools, health and behavioral health care providers, and other parents with children with IDD tend to guide families toward guardianship. The path to guardianship is compelling, as according to the most recent National Core Indicators™ (NCI) data, 41% of adults with IDD receiving publicly funded services in New York have guardians and most of these guardians (82%) are family members.[18] As NCI does not capture information about adults with IDD who are not receiving publicly funded services, data about those with guardians is likely underreported.

The use of SDM in New York has the potential to make a significant difference in reducing dependence on guardianship and increasing the quality of life of adults with IDD. Recognizing this, in 2015, the New York State Developmental Disabilities Planning Council (DDPC) awarded a five-year grant to Supported Decision-Making New York (SDMNY), a consortium of collaborating institutions, to develop and distribute educational materials and to pilot SDM for people with IDD throughout New York State. Narratives and data from the SDMNY educational and SDM pilot activities are intended to inform any law reform initiatives to advance the use of SDM as an alternative to guardianship.

SDMNY Partners

The SDMNY partners are Hunter College/CUNY, the New York Alliance for Inclusion and Innovation, and the Arc Westchester. Disability Rights New York (DRNY), the state Protection and Advocacy agency, serves as the legal resource. More information about this partnership can be found on the SDMNY webpage: https://sdmny.org/who-are-we.

In addition to providing information about SDM to a wide variety of stakeholders, SDMNY partners designed pilots offering SDM to two groups of people with IDD: The SDMNY Diversion pilot seeks to divert those at risk of guardianship whereas the Restoration pilot aims to restore decision-making rights by terminating guardianships. Grant deliverables require that SDMNY recruit at least 90 persons with IDD for the Diversion pilot and at least 45 persons under guardianship for the Restoration pilot.

Hunter/CUNY is the direct contract grantee, charged with overall administration of the project and the grant funds through the Research Foundation of CUNY. Hunter/CUNY took the lead in developing the three-phase SDM facilitation model utilized in the pilots and operates the SDMNY pilot project site in New York City. The Arc Westchester established the first site expansion into Westchester County, and, in Project Year 3, the New York Alliance for Inclusion and Innovation began overseeing expansion to three additional sites—in Long Island, Rochester, and the Albany/Capitol region.

Independent Evaluation

DDPC contracted with an independent evaluator to begin work in SDMNY's fourth year, with reports due after the end of the grant. However, Hunter/CUNY staff wanted evaluation information that could guide project activity in Years 4 and 5 and subcontracted with another independent evaluator in Year 3 to conduct a one-year targeted process evaluation. This focused evaluation gathered information from family members of individuals with IDD primarily involved in the SDMNY New York City site to explore four research questions:

1. What concerns or advice led you to consider guardianship, or to become a guardian?
2. What led you to become involved in Supported Decision-Making New York "SDMNY"?
3. In what ways has the SDMNY process in this pilot addressed or reduced concerns that led you to consider guardianship or to become a guardian?
4. From your perspective, how has participating in the SDMNY pilot affected or changed the individual with IDD?

Approach

SDMNY staff anticipated the evaluator would conduct telephone interviews with 30 to 35 family members from the Diversion and Restoration pilots. This evaluation report refers to family members involved in the Diversion pilot as "potential guardians" and family members involved in the Restoration pilot as "guardians."

Additionally, this evaluation report refers to SDMNY Diversion and Restoration pilots as one pilot (as "SDMNY") because decision-makers across both pilots use basically the same facilitated process and agreement template. Presentation of the family member evaluation data, however, retain their affiliated pilot distinction to examine areas of commonality and divergence.

The scope of this evaluation was expanded in February 2019 to include the experience of key Hunter/CUNY staff and those serving in the role of "Facilitators." This information will serve to document specific areas of SDMNY development, to inform and guide next steps, and to compare SDMNY with other SDM pilots. Online surveys were conducted to collect key SDMNY staff reflections (from the Project Director, Senior Project Coordinator, NYC Site Coordinator, and Faculty Associate) and reflections from facilitators. Questions for staff covered the development of the SDMNY model, outreach and recruitment, challenges and strategies, and thoughts for sustaining SDMNY initiatives after grant funding ends. (See Attachment D for the SDMNY Key Staff Online Survey.) Given that the role of facilitator is a volunteer position, the facilitator survey was very short and focused on facilitator impressions regarding training and perceived impacts of SDMNY. (See Attachment E for the Facilitator Online Survey.)

For more information in general on the approach and methodology for this evaluation, please refer to Attachment A: Evaluation Background, Methods & Approach.

Limitations of the Evaluation

This evaluation was both time limited and limited in scope. It does not include the experiences of people with IDD directly—experiences that may provide additional evidence of the importance and life-changing nature of having one's decision-making rights upheld. Nor does this evaluation include the perspective of other SDMNY partners or Advisory Council members. This evaluation also does not examine the facilitation process, the types of decisions made using SDMNY, satisfaction with decisions, or third-party acceptance of decisions.

SDMNY Staffing & Roles

SDMNY staff for the New York City (NYC) site are affiliated with Hunter/CUNY and include the Project Director, Senior Project Coordinator, NYC Site Coordinator, Faculty Associate, and Project Assistant. The DDPC grant requires a matching resource contribution from grantees. In 2017, the Project Director published an article describing SDMNY's development, noting the need for additional staff support to supplement grant-funded positions: [19]

> SDMNY's core staff was painfully small, considering the project's ambitious goals and the "deliverables" required under the grant. Housed at the Silberman School of Social Work at Hunter College in East Harlem, the staff consisted of a project director whose salary was contributed by CUNY, a project coordinator, and a half-time office assistant. As it became clear that the staff was inadequate to fulfill the grant's several missions, Hunter College generously added to the team by providing two years of funding for a full-time coordinator of facilitation and education, a position essential to the project's success.[20]

SDMNY Core Staff

Project Director

The Project Director notes that an important role she plays is to remain focused on, and bring the team back to, the "big picture" as there are many competing demands on staff every day. The Project Director oversees all SDMNY initiatives which includes a myriad of activities. These include but are not limited to:

- Review reports prepared for grant funder
- Serve as Principal Investigator
- Liaison to Hunter and CUNY university system
- Raise funds for project expenses not covered by the grant (e.g., NYC Site Coordinator position; small individual external contracts, etc.)
- Write articles for publications (law review, etc.)
- Present at professional conferences and symposia
- Develop and review content for SDMNY website
- Participate in SDMNY outreach and training presentations

Sixty percent of the Project Director's time (salary and fringe) are provided by CUNY to meet the grant requirement for matching funds.

Senior Project Coordinator

The Senior Project Coordinator is a full-time, 100% grant-funded position with these responsibilities:

- Coordinate implementation of grant activities and ensure quality
- Periodic reports to funder and tracking progress toward project goals
- Recruit and hire paid project staff and subcontractors
- Budget management including processing invoices and reimbursements
- Plan and carry out strategic initiatives
- Serve as a facilitator for the NYC site
- Develop training and informational materials
- Train and mentor facilitators, primarily at the NYC site, with supervisory responsibilities over the other sites
- Manage the SDMNY website: https://sdmny.org/
- Participate in SDMNY outreach presentations
- Liaison with the independent evaluator

NYC Site Coordinator

The NYC Site Coordinator is a full-time position whose salary is contributed by Hunter College (through the Hunter College Foundation) to meet the grant requirement for matching funds. (From October 2018 through March 2019, however, this position was grant funded.) The NYC Site Coordinator's responsibilities include:

- Co-create training materials for facilitators
- Conduct facilitator trainings throughout the state
- Coordinate recruitment of prospective facilitators, mentors, and collaborating organizations
- Participate in SDMNY presentations to prospective expansion site facilitators, mentors, and collaborators
- Collect satisfaction and demographic data from participants as required by funder
- Pair decision-makers with facilitators and facilitators with mentors

Faculty Associate

The Faculty Associate served an important role in writing the grant proposal, designing the SDMNY model, and currently recruits graduate students as facilitators. Currently the Faculty Associate also serves as a mentor for facilitators. This position is grant funded for 17% of faculty time.

Project Assistant

The Project Assistant is a grant funded, part-time (57% of full time) administrative position that supports the SDMNY team by:

- Assisting the Project Coordinator and Site Coordinator with facilitator trainings
- Social media updates (Facebook and Twitter)
- SDMNY information and outreach session demographic and satisfaction data collection
- General administrative and office management tasks as requested

Recommendations

SDMNY staff offer the following recommendations to enhance the contributions from staff.

SDMNY Recommendations: Staff Resource Considerations

- Staffing plans frequently change due to turnover and changes in project activity. Where additional staffing resources are necessary, seek additional resources as soon as possible.
- Consider staff technological capability and time for website design, construction, maintenance and updating.

SDMA Facilitators and Mentors

Volunteer Facilitators

The SDMNY model uses trained volunteers called "facilitators" to assist decision-makers to develop SDMAs that identify trusted people to provide support and map out specific areas for support, the kinds of support desired, and the methods for providing support. Using volunteer facilitators was important to the design of a sustainable model.

Some SDM models have used paid staff to assist people with disabilities to craft an SDMA. For example, in two Australian SDM pilots, paid independent professionals guided the development of SDMAs and ensured supporters were able to meet the support requirements of the decision-maker and were open to coaching.[21]

Mentors

Facilitators are assigned, and have ready access to, persons experienced in the facilitation model called mentors. SDMNY staff report that mentor support and supervision provide skill development and confidence for the facilitator, and a degree of quality control for pilot operations.

Mentors meet with their designated facilitators upon a facilitator's assignment with a decision-maker, and at least monthly thereafter, typically around a facilitator's meeting with a decision-maker. Meetings are generally by phone. Mentors are also available for coaching and problem-solving as needed. Mentors review and approve SDMAs prior to signature by parties.

For the first two years of active SDMNY facilitation, paid staff served as mentors. But as the number of decision-makers and facilitators increased, mentoring facilitators became too great of a time demand. So in Year 3, SDMNY began supplementing the mentor pool with modestly paid mentors drawn from facilitators with successful facilitation experience.

Evaluation findings related to Volunteer Facilitators and Mentors are found in the next section, "SDMNY Pilot Model Development."

Advisory Council

The use of Advisory Councils to guide SDM initiatives is a common and useful practice. DDPC's grant required an Advisory Council with representation from a variety of stakeholders: people with disabilities, parent and sibling groups, special education system, the state Protection and Advocacy agency, attorneys, and members of the court system. Not specified were the number of representatives or how they were to be utilized. SDMNY's Advisory Council has 54 members from diverse stakeholder groups (a complete list is shown on the SDMNY website at: https://sdmny.org/who-are-we/). Advisors met in person for a one-day conference to kick off SDMNY in March 2017 and will meet in person again at the conclusion of the five-year grant. Interim communication is at least quarterly and occurs via teleconference.

This evaluation explored with key pilot staff their assessment of Advisory Council guidance and contributions. Pilot staff report that they value and rely on Advisors, both individually and collectively, for guidance and advice, and touch base frequently for feedback. Advisors also contribute by extending SDMNY reach, spreading the word and conducting outreach into different communities throughout the state.

Asked what would strengthen the role or impact of this Council, pilot staff mentioned funding to offer more frequent in-person meetings. The Project Director, who served on the Advisory Council with CPR-Nonotuck's SDM pilot, opined that the annual in-person Council meetings for that pilot were "incredibly valuable," and that an annual in-person meeting with the SDMNY Advisory Council (in addition to periodic teleconferences) would be more constructive than relying only on teleconference engagement.

Recommendations

SDMNY staff offer the following recommendations to enhance the contributions from the Advisory Council.

SDMNY Recommendations: Advisory Council

- Fund an annual in-person meeting with Advisory Council.
- Create an online discussion forum organized by topics on the SDMNY intranet portal for Advisors to engage as issues arise, as well as over time.
- Share quarterly project narrative reports submitted to the funder with Advisors to convey progress in more detail.
- Develop small, subject matter work groups to utilize Advisor expertise more effectively. Work groups would report back to the full Advisory Council.

SDMNY Pilot Model Development

SDMNY was designed by a planning group that reviewed SDM experiences in the United States and other countries—specifically Bulgaria, the Czech Republic, Kenya, Australia, and Israel.[22] Significant SDMNY model design elements are noted in Project Director Kristin Booth Glen's 2017 law review article, including:[23]

- The person with IDD is at the center of the process, even if under guardianship. The term "decision-maker" is used to refer to a person with IDD, reinforcing the person's central role.
- The facilitator works with the decision-maker and the decision-maker's chosen supporters to create a written agreement, the Supported Decision-making Agreement (SDMA). The SDMA reflects the understanding between decision-maker and supporter(s) of the process they will utilize going forward.
- Decision-makers always have the right to remove or add supporters, as well as change or cancel the agreement.
- The SDMNY model and facilitation process should be replicable and sustainable on a state-wide basis. The facilitation process will need to be paid for through existing or repurposed sources or have minimal or no cost.

Two pilot program experiences were particularly useful to the development of the SDMNY model. One was an early SDM pilot in the U.S., undertaken by the Center for Public Representation (CPR) and Nonotuck Resource Associates in Western Massachusetts; the other, an early Australian SDM pilot spearheaded by the Office of the Public Advocate in South Australia. SDMNY planning team members spent considerable time communicating with developers of these pilots.[i] Table 1 is a crosswalk of key structural components across the three SDM pilots: SDMNY, CPR-Nonotuck, and the South Australian Office of the Public Advocate.

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[i] The first Australian pilot was substantially modified for subsequent Australian pilots. Significant was refinement of the facilitated process for assisting an individual with disability to consider and establish decision support. This crosswalk is not an examination of the facilitation processes used to develop an SDMA.

Table 1. Structural Elements of SDM Models: SDMNY, CPR-Nonotuck, South Australia

Element	SDMNY	CPR-Nonotuck	South Australia
Funding	New York State Developmental Disabilities Planning Council (DDPC) competitive grant award	Primary funding contributed by partner agencies with evaluation funding support from Open Society Foundations	M.S. McLeod Benevolent Fund and Office of the Public Advocate
Timeframe	5 years (2016-2021)	2 years for initial pilot (2015-16); expansion ongoing	Almost 2 years, Dec. 2010 to Oct. 2012
Independent Evaluation	Focused independent 1-year evaluation of NYC site (report 2019). Second, project-wide evaluation funded by DDPC for years 4-5 and one subsequent year.	Independent 2-year evaluation (reports in 2015 and 2016)	Independent evaluation aligned with project timeframe (report 2012)
Advisory Council	Yes, includes individuals with IDD	Yes, included individuals with IDD	Yes, included individuals with IDD
Recruiting Individuals with IDD	Initial outreach to special education schools, self-advocacy organizations, provider agencies. Open to all individuals with IDD expressing interest.	Adults served by provider agency (Nonotuck) with cooperative social networks including guardians and family members interested in trying SDM.	Outreach via information sessions to service providers at work sites. Outreach to guardians via public guardian office. Open to people with IDD, acquired brain injury, or neurological disease.
Person with Disability Legal Status	At end of Year 3: Without guardian = 58 With guardian = 21 (1 guardianship discharged before person enrolled in SDMNY)	Without guardian = 8 With guardian = 1 (1 guardianship discharged during pilot)	Without guardian = 24 With guardian = 2 (1 guardianship discharged during pilot)
SDM Adopters "Decision-makers" Info	79 adults at end of Year 3 with primary diagnoses IDD and autism. (10 decision-makers withdrew by end of Year 3.)	9 adults with primary diagnosis IDD, age range 24-79, most with co-occurring behavioral health conditions including dementias	26 adults, age range 18 to between 70-79, with acquired brain injury, IDD, autism. Excluded those with primary diagnosis of dementia or behavioral health, those in significant conflict with friends or family, those experiencing abuse or neglect.

Element	SDMNY	CPR-Nonotuck	South Australia
Decision Supporters	• Identified by person with disability • Voluntary role • Family members, guardians, staff, neighbors, friends	• Identified by person with disability • Voluntary role • 2-10 supporters including family members and guardians, as well as current and former paid staff who are also friends	• Identified by person with disability • Voluntary role • Family members or friends with 1 exception (project coordinator served as supporter as social network depleted) • Supporter criteria: expected to be well informed about a participant's goals and commit time needed for support role and assist participant to make a decision known.
SDMA Development Guided by	Trained volunteer and paid staff guide decision-maker and supporters through SDMA development	Paid pilot staff (CPR attorneys with provider care managers) partnered to guide decision-maker and supporters through SDMA development	Paid pilot staff guided decision-maker and supporters through SDMA development
SDMA Legal Status	• No legal recognition in New York • Notarized when signed by individual, facilitator, and supporters At decision-maker's election, health care proxies have also been signed.	• No legal recognition in Massachusetts • Notarized when signed by individuals and their supporters • Other legal documents often notarized as well such as Power of Attorney, Health Care Proxy	• No legal recognition in South Australia, informal agreement • SDM decisions limited to where to live, lifestyle and health. Excludes finances and asset decisions.
Ongoing SDM Monitoring & Complaint Protocol	• DRNY provides free legal representation for rights restoration. • During grant period, Project Coordinator addresses concerns or complaints with developing an SDM agreement. • Procedures to address complaints or concerns re: SDMA use are not yet in place but planned for year 4.	• CPR free legal representation for rights restoration as well as SDM-related complaints. • Nonotuck care managers provide oversight of SDM monthly monitoring. During initial pilot, monitoring was formal, now informal as per service provider case management.	• SDMAs lapsed at project end, Oct. 31, 2012.

When developing SDMNY, a foundational decision was whether SDMNY would be housed in an existing provider agency or be a freestanding entity that could be incorporated into different kinds of settings. Key SDMNY staff surveyed for this evaluation expressed concern that if housed within provider agencies, SDM could become diluted—that is, with lip service to voice and choice but bereft of the true experience of legal personhood. Thus, SDMNY's facilitated SDM process was designed as separate from, but available to, service providers.

Facilitated Development of SDM Agreements

Key pilot staff consider SDMNY's structured facilitation process to develop an SDMA distinct from other SDM endeavors in the U.S. because SDMNY's process focuses on decision-making as an ongoing process, and not just on completing the SDMA:

> "I think it's because we are focused on the PROCESS by which the decision-maker makes decisions and uses support. We see ourselves not as getting an agreement signed, but as creating a lasting, viable process that the decision-maker and her/his supporters, who almost certainly will change over time, can use throughout her/his life." –SDMNY staff

SDMNY's facilitation model identifies three stages of development. The following excerpt from the SDMA template describes the activity within each stage. (The full SDMA template is available at https://sdmny.org/wp-content/uploads/2019/08/SDMA-draft-3.5.pdf.)

> ***Phase 1*****:** The facilitator works with decision-maker to learn about how s/he communicates, makes decisions, what kinds of decisions are likely to arise in the long and short term, and who are the important people in the decision-maker's life from whom s/he may choose trusted supporters.
>
> ***Phase 2***: The facilitator works with the supporters the decision-maker has chosen, educating them about SDM, and helping them "reposition" from people who make decisions for the decision-maker to supporting her or him in making her or his own decisions, including consideration of the "dignity of risk."
>
> ***Phase 3*****:** The facilitator works with the decision-maker and her/his chosen supporters to negotiate the SDMA, to ensure that all parties understand their roles, obligations and responsibilities; prepares a draft of the SDMA that all parties review and may alter; and oversees the signing of a final version.

Setting the Stage for an Evolving Decision-Maker

A distinctive SDMNY design component is the expectation that facilitators begin working one-on-one with decision-makers, free from the influence of others. This provides decision-makers an opportunity to share their stories free of input from others. It highlights for the decision-maker, and for others, that the decision-maker is the locus of control for SDM meetings and the resulting agreement.

Several family members interviewed for this evaluation suggested that more information at the outset of the facilitation process about the first phase of facilitation would be helpful. The following statements from family members represent these sentiments.

> "I'm not sure what the process is, how it works. Not sure what they are talking about when they meet. What are they really trying to do? What is the process? She [the facilitator] just called me and asked for [name's] number. I know they want him to make his own decisions. I don't know what they are doing, but I would like to know what all this process is and how it is going to help him." –Potential guardian

> "Well, I'm still learning about it. Only went to one session. A written agreement comes, right?" –Potential guardian

> "I think the family could be brought in a little earlier, brought in some of their concerns. I could have let them know her go-to is to say, 'I forgot.' To involve the family a little earlier in the process to discuss their concerns with the person and their decision-making capabilities. I understand the one-on-one. But have family voice concerns about decision capabilities before going forward. People believe in it [SDMNY] and think it would be good." –Guardian

> "He goes to so many different activities, appointments, it's getting to be a little too much with all the activity. He feels he is able. I don't know because he is talking to people and they may be agreeing with him but not know the state of his mental capacity. He is a young man who agrees with a lot of things. They are telling him he can do certain things on his own but when it comes to it, he is not as able. He has someone coming to teach him how to cook but that is not happening."
> –Potential guardian

For Consideration – Initiating meetings between facilitators and people with IDD without others does place the individual at the center of the process. It also has raised anxiety for some family members. It may be useful to explore if guardians and potential guardians who attend an SDMNY information session and learn about the process experience reduced anxiety or concern compared to those who first learn about SDMNY by receiving a packet of materials from the decision-maker.

SDM Agreement Design

Supported Decision-Making Agreements (SDMAs) are documents that describe and formalize the SDM process to which the parties have agreed. SDMNY developed their SDMA template after comparing more than a dozen available formats. Planners felt it was important to craft a template where:

- Decision-making areas for support were open, not prepopulated with common decision areas of support (for example, health care decisions).
- Decision-makers could prescribe the kinds of support from different supporters (for example, gathering information, explaining information, communicating decision to a third party).

On the advice of DRNY, the template was designed to resemble the New York State statutory Power of Attorney form to appear more familiar to courts and judges.

After several revisions, a working draft was presented for feedback and comments to a focus group of self-advocates from the Self-Advocacy Association of New York State (SANYS) and shared with Advisory Council members with legal experience. A significant change to the template suggested by self-advocates was to enlarge the font size identifying the decision-maker's name on the first page to powerfully communicate whose SDMA it is. A revised draft incorporating feedback was then presented to facilitator training participants and has remained the template to date. SDMNY participants in both the Diversion and Restoration groups utilize the same SDMA template.

The final SDMA template identifies the person with IDD as the decision-maker and sets out the rights and responsibilities of the decision-maker and supporters. Explicit is that the decision-maker is responsible for his/her decisions and is free to amend or end the agreement at any time. The template provides four areas for specifying individualized decision support, which SDMNY staff refer to as the "Big Four":

1. ***Which*** areas a decision-maker wants decision support in (i.e., financial matters, health care, living arrangements, etc.)
2. ***Who*** is chosen to provide that support (trusted persons in the decision-maker's life)
3. ***What*** kinds of support (gathering information, helping to weigh alternatives or possible consequences, communicating decisions to others, etc.);
4. ***How*** support will be provided (face-to-face conversation with individual supporters for individual areas, group meetings, text, telephone, Skype, etc.).

The SDMA template includes other administrative information including how to make changes to decision support, to supporters, and how to revoke the agreement.

Comparison of SDMA Templates

A number of SDMA templates are in use in the U.S. These have been developed by advocacy organizations, as per SDM pilots, and in some states that have modified law to incorporate SDM. Table 2 below shows a comparison of SDMAs (two from pilots, including the Center for Public Representation (CPR) and Nonotuck pilot mentioned previously, and one from state law) by key domains.

Table 2. Comparison of SDM Agreement Template Design and Development

Domain	SDMNY Pilot Form	CPR Pilot Form	Alaska Statute H.B.336
Assistance with SDMA development	Trained volunteer meets solely with person with IDD (decision-maker) to facilitate SDMA development at the beginning; later brings in supporters	Paid staff (attorney & care manager) facilitate SDMA development with person with IDD and anyone else the person chooses to participate	Options for development: • Self-guided without professional assistance • If person has a disability, some service provider and legal service agencies will help • If eligible for low-income legal services, Legal Services Corporation will help • Lawyers can be hired privately
Supporter	Provides for multiple supporters. No supporter inclusion or exclusion criteria. Each supporter signs declaration to provide the assistance described, to not exert undue influence, and to avoid conflicts of interest.	Provides for multiple supporters. No supporter inclusion or exclusion criteria. Each supporter signs declaration that it is their job to honor and present the person's expressed wishes.	Provides for multiple supporters. Inclusion criteria: should clearly understand and communicate with person to be supported. Each supporter signs declaration to provide the assistance described. Supporter exclusions: • Person with court order prohibiting contact • Person paid to provide a single service cannot be a supporter for choices re that service (unless a family member) • Person you work for or who works for you (unless a family member)

Domain	SDMNY Pilot Form	CPR Pilot Form	Alaska Statute H.B.336
Areas for Decision Support	Person with IDD identifies areas for decision support. SDMA form does not include decision area prompts.	Form prompts areas for decision support and allows for identifying other kinds of decisions. Person with IDD identifies which supporter provides assistance by decision type.	Form in statute but use of a substantially similar format is accepted. Statutory form prompts areas for decision assistance. Includes prompt to exclude any supporter from helping with decisions the person notes. Allows people under guardianship to use SDM; for decisions designated to the guardian, guardian consent is required. Includes worksheet with ideas (e.g., staying safe, education) plus write-in areas.
Method of Decision Assistance	Prompts method of decision assistance. Prompts noting areas where decision assistance is not wanted.	Prompts method of decision assistance. Prompts person with IDD to inform supporter how he/she expresses preferences in each decision area. Indicates if supporters act jointly or successively within each decision area. Allows excluding any supporter from helping with specified decisions.	Prompts method of decision assistance and frequency.
Routine oversight of SDMA	Oversight by Mentor during development. Planning underway for complaint and concern reporting and review to be in place during Year 4 and post-pilots.	Monthly visits by Care Manager. During initial pilot, monthly meetings between partner agencies.	For financial decisions, Decider must choose a Monitor, a non-supporter to ensure supporter(s) are honest and use good judgment.
Complaints	During SDMA development complaints are directed to Project Coordinator. After SDMA signing ceremony, no complaint entity or process in place. To be developed Year 4.	Until state passes law with complaint procedures, CPR offers pilot participants free legal resources to address SDM-related complaints. Other complaints follow provider and state agency policy. Abuse, etc. is reported to state agency.	Relies on complaint procedures already in place for reporting abuse, neglect, exploitation such as mandated reporting for vulnerable populations and court oversight of guardianships.
Notarized Signatures	Yes	Yes	Yes

Domain	SDMNY Pilot Form	CPR Pilot Form	Alaska Statute H.B.336
Changes/ Revocation	Changes expected. SDMA attachments provide format for decision-maker to revoke or make changes. Revised SDMA is notarized.	Changes expected. By statement or expression of preference of person with IDD at any time. Revised SDMA is notarized.	Changes expected. Revised using same format with supporter attestation and notarized.
Expiration	Active until decision-maker revokes.	Active until person with IDD revokes.	May include an end date. If no end date, active until the Decider revokes. Expires if guardian or conservator is ordered.
Liability of Third Parties	Not yet established. SDMA is not yet legally recognized.	Not yet established. SDMA is not yet legally recognized.	Third parties are not legally liable when acting in good faith on the SDMA.

Creating an SDMA Takes Time

SDMNY's three-stage facilitated SDMA process was designed to occur over 6 to 9 months with an expectation of monthly in-person meetings, lasting no more than an hour, between facilitators and decision-makers. However, facilitating development of an SDMA has taken much longer, typically over a year and often up to 18 months.

> "Initially, the facilitation process was anticipated to last 6 to 9 months, in part so that the process could be completed within the span of two semesters. Over time, the facilitation process generally seems to require at least 12, and often up to 18 months of once-a-month meetings. Generally, phase 1 seems to last 5 to 7 months, phase 2 lasts 3 to 4 months, and phase 3 lasts another 4 to 6 months."
> –SDMNY staff

Delays occur when there are not trained facilitators to match with a decision-maker, or when facilitators cease their volunteer commitment before completion of an SDMA. In addition, meetings rarely occur monthly, and both facilitators as well as decision-makers initiate postponements. One- to three-month gaps in meetings were noted by pilot staff as "not uncommon."

Although in-person facilitation meetings are the expectation, pilot staff report that "more often than not, phase 2 meetings do not occur in person but over the phone." And phase 3 meetings "frequently" occur via videoconference due to the logistical challenges of finding meeting times and dates that accommodate all attendees (supporters, the facilitator, and the decision-maker). Once an SDMA is prepared, a signing ceremony is scheduled, which adds another month or two to the process.

SDMA Signing Ceremony

Signing ceremonies are the final stage of creating an SDMA and are important occasions, providing meaning and significance to the achievement of a negotiated support agreement. Decision-makers, their supporter(s) and the facilitator meet to sign and have the agreement notarized. For an original SDMA or a modification, the signing parties are the decision-maker, facilitator, supporter(s), as well as a Notary Public.

Signing ceremonies are personalized. The facilitator may share a few words of congratulations, followed by remarks from the decision-maker and/or a supporter. It is up to the decision-maker to determine who, if anyone, speaks. Next, the facilitator goes through the “Notice to Decision-maker” section of the SDMA, and the decision-maker checks off his/her rights and responsibilities with regard to the agreement. If satisfied with the provisions, the decision-maker signs the agreement, followed by the supporter(s). Signatures are notarized. Supporters unable to attend in person may send digital signatures in advance of the event, which are incorporated into the agreement but are not notarized. The decision-maker keeps the original document and copies for each supporter are made at the time of the ceremony. Everyone receives a folder with FAQs regarding the agreement and a congratulatory letter from the SDMNY Project Director. Health care proxies have also been executed as part of the SDMA signing ceremony.

Most decision-makers have chosen to have group ceremonies located at an organization (i.e., a school or a self-advocacy group). For group ceremonies, SDMNY staff may invite a guest speaker. Past speakers have been a school principal and the Commissioner for the Mayor’s Office for People with Disabilities. Refreshments are served so that the attendees can mingle after. One decision-maker, who preferred a private ceremony, requested his ceremony attendees wear green and that key lime pie be served.

Signing ceremonies affirm decision-maker and supporter courage and their important role in advancing human rights. At the first signing ceremony on September 25, 2018, Kristin Booth Glen, SDMNY Project Director and Former Surrogate Judge of Manhattan, addressed decision-makers in this way:

> By signing your agreement, you are letting others know that you are capable of making decisions with support. Your agreement will serve as a guide for you and your supporters as you navigate life’s many challenges… By being a part of SDMNY’s pilot project, you and your supporters are pioneers in demonstrating how SDM can work as a better alternative to guardianship. And, as well, you are part of a worldwide movement that honors and respects the rights of persons with intellectual disabilities to make decisions like anyone else. That deserves our thanks at SDMNY, and our deepest congratulations.

Additional signing event information and photos are posted on the SDMNY website: https://sdmny.org/news/.

Modifying or Revoking an SDMA

Modifying the SDMA is considered a normal, expected future event as decision-maker capabilities change, as decision-support areas alter based on life experience, supporter commitment changes, or as a decision-maker changes his or her mind regarding a supporter. Facilitators are expected to convey this to decision-makers. The SDMA template provides a mechanism for the decision-maker to initiate modification. Attachment C to the SDMA provides for a decision-maker to revoke the agreement, while Attachment D is for making changes. Both revocations and modifications require two witnesses, their signatures, as well as a Notary Public signature that the decision-maker authorized the changes.

At this stage, SDMNY focus is on recruiting decision-makers and facilitating their completion of an SDMA. Having the instruction on how to make a change to an SDMA is an important step in laying the foundation for a living, flexible document. But actually making changes and checking on how an SDMA is working in real life are also important for SDM sustainability and retaining trust of SDMNY participants. One of the potential guardians interviewed for this evaluation shared his concerns as to whether someone would check in and assist his son to make changes after grant funding ends:

> “Big concern of mine is the way it’s set up now, there is a neat plan and it looks good on paper, but as his plans and goals shift and change, how does that support change? Who will help him with that? How will [name] know ‘I need to modify this’? When the pilot funding is not in place, who will be monitoring? We think there should be another layer to check that his plan is working for him. Now it’s a very specific plan, but is not specific in making changes to plan such as who will take over [facilitator’s name] role when she is not there any longer? To transition supporters and roles, who is there to help him change this document?” –Potential guardian

Evaluation Findings: SDMA Facilitation Process

- Completing an SDMA using the SDMNY facilitation process typically takes twice as long or longer than expected, from a year up to 18 months.
- Although in-person meetings between a facilitator and decision-maker were the expectation, meetings in later stages often occur by phone or video conference.
- For SDM sustainability, identify a responsible entity to check on how SDMAs are functioning for decision-makers and supporters and identify a responsible entity to assist decision-makers with SDMA changes after grant funding ends.

For Consideration - Pilot staff may find it useful to explore whether facilitator retention is impacted by:

- Holding facilitation meetings more often than once a month, reducing time to complete an SDMA and the volunteer commitment.
- Explicitly advising potential facilitators on how long the facilitation process can take.
- Having back-up facilitator plans in place for each decision-maker so that substituting a new facilitator does not lead to delays in SDMA completion.
- Where logistics complicate in-person meetings, it may be useful to explore the extent to which virtual meetings meet expectations and serve both SDMNY's and the decision-maker's goals.

SDMNY Roles: Decision-Maker, Facilitator, Mentor, Supporter

Decision-Maker Role

Adopting the term "decision-maker" to refer to an individual with IDD engaged in SDMNY was important to key staff. The term decision-maker sets the stage and expectations, both for the individual with IDD as well as supporters and third parties. Decision-makers drive the process. They voluntarily adopt SDM, identify areas where decision support is welcome, identify and invite supporter involvement, and advise supporters how to provide decision support.

Facilitator Role

Facilitators are trained volunteers who assist decision-makers to develop SDMAs. Facilitators assist decision-makers to consider what kinds of decisions they may want help with making, who they want decision assistance support from, what kinds of support they want, and how support should be provided. Facilitators also assist decision-makers to reach out to potential supporters and negotiate the terms of their SDMA with supporters. The NYC Site Coordinator matches facilitators with decision-makers with matching largely determined by geography.

SDMNY staff consider the work that facilitators undertake as powerful and empowering:

> "On a more profound level, the facilitators act as Virgilian guides for decision-makers navigating vexing issues surrounding their decision-making futures. Some of the questions that facilitators help decision-makers address are difficult and anxiety-inducing, for example, who a decision-maker might want to support her when a loved one passes away? In this way, facilitators are agents of self-discovery,

> empowerment, and relational transformation that may affect the decision-makers beyond what is reduced to writing in their SDMAs." –SDMNY staff

> "At the same time that the 'end' of the facilitation is the SDMA, facilitating the development of the process, by which the decision-maker will use support throughout her/his life, is equally important, as is helping the decision-maker to see her/himself as a decision-maker, and to empower her/him to be an agent in her/his own life." –SDMNY staff

Facilitator Qualifications

The SDMNY model purports no required facilitator qualifications (such as education degree, language fluency, experience with individuals with IDD, knowledge of developmental disabilities system, etc.). Facilitators do not know individuals with whom they are matched and thus spend time developing their relationship while facilitating progress toward an SDMA. When recruiting facilitators, what matters to key staff is:

- Belief in the value of people with IDD making decisions about their own lives
- Respect for the SDMNY process and completion of the 2-day SDMNY facilitator training
- Computer skills sufficient for reporting and communicating with SDMNY staff

Effective Facilitator Characteristics

Asked what characteristics or traits are found in the most effective facilitators, all surveyed SDMNY staff noted commitment to a person's right to make her/his own choices, SDM, and the SDMNY facilitation model. Other important characteristics mentioned were:

- Good listener
- Flexibility and diligence
- Patience with process
- Being comfortable with potential conflicts that may arise with supporters
- Ability to put other roles aside to focus on SDM facilitation
- Have an open mind (one staff added: an open heart as well)
- Enthusiasm and personal satisfaction for the work

An insight from one staff was that the most effective facilitators are those who see themselves as benefiting from the experience:

> "Facilitators who believe they are benefiting from the facilitation process and their interactions with decision-makers seem to be the ones who remain the most engaged and committed throughout the process."

Facilitator Recruitment: Unexpected Bumps in the Road

From the outset, the plan was to create a sustainable, low-cost facilitator model for eventual expansion. Toward this goal, SDMNY staff explored securing volunteer facilitators from various organizations. The predominant effort has been directed toward students in professional programs, but recruitment efforts have also included volunteer organizations, provider agency staff, and trained volunteer mediators from court-affiliated Community Dispute Resolution Centers (CRDC).

Facilitator recruitment began with graduate professional university students. Between CUNY and the State University of New York (SUNY), there are campuses in every county in New York State. The influx of new students was viewed as a potential sustainable source of facilitators.

Students pursing their Master of Social Work (MSW) degrees, whose code of ethics embraces client self-determination, were first explored. The SDMNY NYC site is located in the building that houses the Silberman School of Social Work at Hunter College. SDMNY staff anticipated that MSW students would use work as facilitators to meet part of their clinical practice requirements. SDMNY staff also anticipated that MSW graduates would find the experience so rewarding that they would continue as volunteers after graduation. This effort was initially less successful than planned because the timing of facilitation meetings was not compatible with the routine hours and supervision required for MSW credentialing. Even so, some MSW students were recruited to volunteer as facilitators outside of their clinical practice requirements.

Next, staff tried recruiting Bachelor of Social Work (BSW) students as clinical practice requirements are more flexible. Staff collaboration with BSW faculty and administration has been time-consuming but is expected to result in a structure for BSW facilitators that can be replicated in BSW programs across the state.

A promising collaboration is underway with the Occupational Therapy Assistant (OTA) program at LaGuardia Community College (part of the CUNY system). As with social work ethics, SDM philosophy aligns well with occupational therapy values to identify ways to enhance client autonomy. SDMNY staff report that OTA facilitators have demonstrated great interest, commitment, diversity, and high energy. At this stage, however, there is much work to be done to formalize the administrative structure.

Facilitator recruitment was also explored with service provider agencies but was less successful than anticipated. SDMNY staff report a significant deterrent for providers is the lack of clarity regarding billing for the time that staff engage in facilitation as a reimbursable service under the Medicaid Home and Community-Based Services waiver program. Even so, some SDMNY facilitators are employed by service providers. The SDMNY Project Director noted that The Arc Westchester, an SDMNY partner organization that received grant funding, allows staff to use work hours to engage in facilitation activities. And some provider staff have volunteered on their own time. However, with the complications of reimbursable time and a workforce shortage of direct support professionals, SDMNY staff turned to other potential facilitator pools.

Outreach was made to volunteers with Re-Serve, an organization that places retired professionals and others with nonprofit organizations. Several Re-Serve members took the facilitator training but only one followed through to become a facilitator. More recently, facilitators were recruited from the volunteer mediator program at the CDRCs, affiliated with the New York State court system's Office of Court Innovation.

In addition to continuing to develop facilitator opportunities with social work and OTA college students, future facilitator recruitment plans include exploring graduate students in special education as well as non-professional volunteers connected to other community organizations (churches and other faith-based entities, union retirees, civic groups, etc.). And, as in the Bulgarian SDM pilot, SDMNY is exploring the idea of using parents and others who have experienced the transformation of SDM in their own families as volunteer facilitators for non-related individuals.

What Attracts Facilitators to SDMNY

Each of the four facilitators participating in the evaluation survey reported being drawn to this volunteer relationship for a different reason: to assist individuals with varied abilities to be as independent as possible; to comprehend their rights; to support making decisions; and to establish an alternative to guardianship.

Facilitator Training Evolution

SDMNY staff describe a very thorough training development process that entailed numerous brainstorming sessions, examining other pilot models (including Bulgaria, Israel, CPR-Nonotuck), and hosting Cher Nicholson to present for four days on the facilitation method she refined from experience with Australian SDM pilots and consulting with SDM initiatives around the world.[24]

Though much up-front work was done to develop the training, SDMNY staff have continuously modified it based on actual experience and feedback from training participants and others. Facilitator trainings are in English and are multi-modal, utilizing in-person presentations, written materials, role-playing, and video instruction. Major modifications have included:

- Expanding the training from one day to two consecutive six-hour days
- Establishing goals and objectives for each phase of facilitation
- Stressing the aim of facilitation before discussion of facilitator skills
- Consolidating into one module the skills and strategies involved in facilitation

- Adding a module on the SDMA design and creation
- Adding emphasis on dignity of risk
- Adding video simulations, one for each of the three facilitation phases, in collaboration with Outside Voices, a theater group of people with IDD

Over time, SDMNY staff gained insight that the original training videos and in-person role play simulations inadvertently conveyed supporting a decision-maker to reach a goal rather than supporting the decision-making process.

> "For example with decision support around money, the video and the in-person simulations frequently ended up with helping a decision-maker open a bank account or learn to budget rather than how to make decisions, and use support to do so, about finances." –SDMNY staff

> "Trainings now stress that facilitators are not decision supporters; their role is to assist decision-makers to make decisions with the kinds of support they desire. Training now directs the facilitator to reflect on the decision-making processes rather than engage in directly supporting decision-makers to make decisions about their lives" –SDMNY staff

SDMNY staff remark on how challenging it is to be a facilitator and not someone who makes things happen or fixes problems:

> "How hard it is to get everyone involved (staff, facilitators, etc.) to move from thinking about facilitating decision-makers to reach their goals to facilitating how they make a decision. We are all basically problem solvers, and it is really hard to get off this, as witnessed by our training videos, and even the revised facilitators' manual, which still has instances of focus on goals rather than the decisions necessary to attempt/reach them. It comes up in the facilitator training all the time."

> "Be clear, from the beginning, internally and in training, etc., that we are not, nor can we facilitate decision-makers to reach goals or accomplish things they want to do (open a bank account, find an apartment, get better services, etc.) and that we are solely engaged in facilitation (with trusted supporters) of DECISIONs!"

As there was initially neither money nor time to remake the videos, trainers critiqued videos and simulations probing whether a facilitator over-stepped her/his role. SDMNY staff anticipate the next iteration of the training manual and videos will clarify and reinforce the distinction between creating the process for the decision-maker to utilize decision support and making a decision to achieve a goal.

Facilitator Perspective on Training

Each of the facilitators surveyed for this evaluation stated that they found the training useful. One described it as "intensive and thought-provoking." Another stated it was "…providing a road map process for guiding and assisting the decision-maker through the SDMA process." For one facilitator, training was transformative:

> "I did not realize that it would change my perspective on how to approach working with adults in general with different abilities. The training allowed me to reflect on how we structure and execute programming here, and how SDMNY/empowering our individuals towards independence can be interwoven through all of the work that we do."

To enhance the training, facilitators suggested including real case scenarios that convey the experiences of facilitators and decision-makers, issues or problems, and how these were addressed or resolved. SDMNY staff note that with the increasing number of decision-makers with SDMAs, case scenarios now reflect lived experiences.

Facilitator Issues and How Pilot Staff Addressed

Facilitator continuity and attrition have been the significant challenges for the SDMNY pilot. Utilizing volunteer facilitators, and particularly students, entails attrition after graduation, downtime between semesters, and during semesters, students finding time for SDMNY amid competing priorities. When facilitators have not been able to continue the SDMNY process to its completion (e.g., through the signing ceremony), either the assigned mentor or Site Coordinator has stepped in, or the mentor secured another facilitator.

An unexpected challenge that SDMNY staff worked through was that not all facilitators who completed a training subsequently agreed to volunteer their time. Some people participated in the training only because they were interested in learning about SDM. To address this, staff initiated a signed commitment form which specifies the time commitment expected of those who complete a facilitator training to complete an SDMA (3 to 4 hours per month for 12 months). Since instituting this commitment form, facilitator uptake has increased.

Another challenge was timing a facilitator's training to align with being matched to an available decision-maker. When lag time occurred between training and a decision-maker assignment, the impact of training diminished, and facilitator availability reduced. To retain commitment of a trained facilitator, staff realized it was preferable to have decision-makers wait to be assigned a facilitator rather than have trained facilitators wait for months for a decision-maker assignment.

Evaluation Findings: Facilitator

- Facilitator recruitment and attrition have been significant challenges to establishing a sustainable volunteer pool. Given recruitment strategies and organizational hurdles cleared to utilize professional students and other potential volunteer pools, going forward, SDMNY staff are confident that using volunteer facilitators is viable and sustainable.
- Facilitator training has evolved with substantial changes. A fundamental change was stressing the distinction between helping a decision-maker develop his/her support for decision-making rather than support in achieving a goal.
- Facilitators found the training useful. For some, the training altered their personal values and beliefs about people with disabilities and deepened their understanding that all people want to make decisions about their lives.

Mentor Role

From the outset the mentor role was devised to provide guidance as well as technical and emotional support to facilitators. Mentors and facilitators typically check-in via a monthly phone call after the facilitator and decision-maker meet. Mentors review facilitators' draft SDMAs, which are also reviewed by the Project Director and Senior Project Coordinator. Thus mentors, as monitors of the SDMA process and development, serve an important oversight role.

> "Mentors are a crucial source of guidance and both technical and moral support. They also serve as backup facilitators if, for whatever reason, a facilitator becomes unavailable. Increasingly, the project has come to view them as an important mechanism for quality control in the future, in order to preserve the integrity of the three-phase facilitation process developed by SDMNY beyond the grant period."
> –SDMNY staff

In response to the increasing number of decision-makers with completed SDMAs, the mentor role has expanded. SDMNY staff initiated SDMA user focus groups facilitated by mentors. Decision-makers have the opportunity to meet in person once a month to review the content of SDMAs, share experiences, practice problem-solving and provide mutual support.

Mentor Qualifications

The NYC Site Coordinator matches mentors with facilitators; each mentor oversees multiple facilitators. Mentor qualifications are twofold: first, completion of the SDMNY facilitator training, and second, successful facilitation experience with at least one decision-maker through the creation of an SDMA. Queried about which characteristics are present in the most effective mentors, SDMNY staff specified effective mentors are those who:

- Value facilitators as change-makers in the lives of decision-makers
- Impart to volunteer facilitators their important role and retain volunteers
- Possess strong listening, and probing skills, as well as skill running meetings
- Are flexible and available to facilitators, willing to give additional time and energy to help facilitators navigate challenges

Beyond the facilitator training and expectation to have guided at least one decision-maker through completion of an SDMA, there currently is no additional training specific for mentors. Developing a training and resource manual for mentors is planned for Year 4.

> “Throughout the project it has become ever more compelling how important the mentor is to the success and integrity of the process. I've insisted, often with a lot of pushback, that as we have expansion sites, there should be at least one person who has already done at least one facilitation and is otherwise appropriate to mentor the facilitators at that site.” –SDMNY staff

Paid v. Volunteer Mentors

The SDMNY design plan to recruit volunteer mentors from experienced facilitator volunteers was not realized. Thus far mentors have been drawn almost entirely from paid pilot staff. One explanation put forward by pilot staff is the length of the facilitation process:

> “There was an expectation among SDMNY partners that strong facilitators would later go on to serve as mentors, but the length of many facilitation processes has delayed the anticipated development of mentors for both the NYC site and expansion sites in Westchester, Rochester, Albany, and Long Island.”

As SDMNY expands, additional mentor positions for facilitator supervision and support and SDMA quality oversight need to be established. Three of the four SDMNY staff serve as mentors in the NYC area and co-mentor at SDMNY expansion sites. As staff explain, planning is underway to expand the mentor pool, but funding is not yet in place for additional mentor positions:

> “It became increasingly clear the significant role that mentors play in ensuring quality control and model fidelity, especially as the New York City pilot program site grew. To promote post-project sustainability, we considered it advisable that high-quality mentoring be available and that mentoring experience not be the exclusive purview of the grant’s core staff. Therefore, we plan to contract in Y4 two outside part-time mentors to provide mentoring to our growing corps of facilitators.”

> "Increasingly I think, as the role and importance of mentors grows, and as the need for mentors to serve a significant number of facilitators becomes clear for administrative and quality control reasons, there will need to be a funding source for these crucial participants as, by and large, volunteers are unlikely to be willing or able to take on the workload that mentors will need to undertake to make the work successful."

To sustain and support mentors into the future, staff envision establishing facilitator and mentor learning communities.

> "I think it is important to cultivate and nourish a dedicated professional community of facilitators and mentors who take pride in their role in increasing decision-makers' autonomy. I believe that facilitators and mentors must feel not only committed to this cause but also, they must have a way to support, sustain, and learn from each other's endeavors in their own lines of work. Especially because I view current facilitators and mentors as crucial future resource persons for decision-makers who may seek to modify their SDMAs or to reeducate their supporters about their decision-making preferences, they need to be invested in the cause itself so that today's decision-makers will have persons to go to when they face challenges in getting recognition of their SDMAs from third parties or holding their supporters accountable."

Evaluation Findings: Mentor

- Several factors have contributed to the need for additional mentors: the time investment to develop SDMAs, SDMNY geographic expansion, and utilizing SDMNY staff solely as mentors to support facilitators.
- The mentor position entails supervisory and quality monitoring responsibilities and should be a paid position. With expansion of SDMNY, additional development efforts are needed to secure funds for, and expand the paid mentor pool.

SDMNY Recommendation: Mentor and Facilitator Mutual Support

- To sustain mentors and facilitators, establish and support professional networking forums (such as a learning community) for mutual support, problem-solving, and sharing resources and ideas.

Supporter

In Phase 1 of the facilitation process, decision-makers identified family members—usually parents, but also grandparents, siblings, friends, and paid service provider staff—as supporters. During Phase 2 meetings, supporters meet with the facilitator and decision-maker to learn about SDMNY and their role as defined by the decision-maker's preferences.

This is a negotiated voluntary undertaking with supporters free to offer the requested support, negotiate the delivery of support, as well as decline to participate. The SDMNY model does not require supporters commit to a term of service.

Supporters who sign SDMAs pledge to provide support as described in the agreement, to refrain from acting as a substitute decision-maker, to avoid conflicts of interest and not to exert undue influence. After signing the SDMA and pledging their assistance, no additional training or coaching is planned for supporters.

In the first Australian SDM pilot undertaken by the Office of the Public Advocate, proposed supporters were expected to meet two expectations:[25]

- Be well informed about the participants' goals
- Affirm they would offer the time needed to undertake the support role and assist participants to make their decision known.

Evaluation recommendations for the CPR-Nonotuck SDM pilot included providing supporters opportunities to share their experiences with other supporters.[26] SDMNY supporters may welcome the opportunity to participate in a learning community of other supporters to learn about issues and complicated situations and strategies undertaken. Sharing experiences may also increase supporter confidence in SDM as a sustainable alternative to guardianship.

The extent to which decision-makers are utilizing friends and other non-relatives as supporters was not examined in this evaluation. SDMNY staff opined that the SDMNY model has thus far only been accessible to those with natural support networks. Extending the supporter role beyond relatives, particularly parents, would:

- Allow aging relatives to pass on or "retire" from their role as supporters with less anxiety;
- Broaden access to SDM for people who may not have involved family or who are socially isolated; and
- Reduce vulnerability to abuse, neglect and exploitation by having wider social networks.

> "I don't believe that as currently designed, the SDMNY facilitation process can have a major impact on the lives of persons with IDD without preexisting natural support networks. To address this limitation I would personally recommend that, just as we have secured OPWDD's approval for decision-makers to use self-direction funds to finance facilitation services to develop SDMAs, we should also work towards finding ways for future decision-makers without natural supports to use either self-direction or traditional funding streams to hire (and fire) persons specifically tasked with providing decision-making support. Especially since many prospective

> decision-makers without natural supporters reside in restrictive or under-inclusive settings, I believe that they should have opportunities to hire peers (i.e., self-advocates) as supporters. This possibility would enable them to have regular contact and form meaningful relationships with experienced self-advocates who could not only support their decision-making but also foster their empowerment. In this way, SDM might become a vehicle for enhancing the interconnectedness and autonomy of both persons with IDD." –SDMNY staff

SDMNY Recommendations

Find ways to offer SDM to decision-makers who do not have trusted people in their lives available to take on the role of supporters. Test using self-direction or other funding streams to finance paying for decision-making support, particularly other people with IDD (e.g., self-advocates) as supporters.

SDMNY Pilot Safeguards

Abuse, neglect and financial exploitation are a widespread problem for people with disabilities. A 2012 national survey by the Disability Abuse Project found that more than 70% of people with disabilities have been victims of abuse.[27] The CPR-Nonotuck SDM pilot evaluation examined whether use of SDM instead of guardianship had increased decision-maker vulnerability to abuse, neglect, or exploitation. Evaluation respondents (including decision supporters, family members, and provider case managers) viewed SDM as reducing risk and vulnerability, especially where multiple decision supporters were utilized.[28]

Stressing Best Practices Through Outreach

SDMNY outreach and educational sessions are, according to staff, an avenue for discussing concerns regarding potential abuse, neglect, and financial exploitation. During information sessions, the Project Director, a retired judge who reviewed guardianship petitions while on the bench, asks audience members if guardianship truly protects individuals from exploitative experiences. Then she notes, "*the incredible persistence of the belief, with no empirical evidence, that only guardianship protects*," and shares information on the abuse, neglect, and financial exploitation of people with disabilities, including those under guardianship. Audience members are advised that court oversight of guardianships, which many believe protects the person under guardianship, is minimal if not nonexistent.

During information sessions, the Project Director places guardianship in historical context, as the most recent form of protective intervention after institutionalization was rejected as the professionally recommended form of protection for people with IDD. She describes the evolution of best practice thinking which now embraces legal personhood and full citizenship of people with disabilities.

> "People have found the historical information especially useful and compelling, especially as it allows us to not blame anyone who thought about, or actually did guardianship. It was the only alternative they were given to protect their kids or loved ones. It's also great now to have supporters and parents who have been through the SDMNY process give their heartfelt testimonials." –SDMNY staff

SDMNY information and outreach sessions also stress the dignity of risk as a critical dimension of SDM and an important human experience. Presenters advise that decision-making is a skill, and that practice leads to increased skill, as does having input from others to help inform decisions.

> "Rather than focus on proving that SDM makes decision-makers less vulnerable to certain risks, SDMNY has endeavored to convince those it has reached that SDM makes decision-makers better equipped to face and avoid those inevitable risks." –SDMNY staff

Important to SDMNY viability is instructing audience members to anticipate decisions they do not agree with:

> "SDMNY in various ways encourages those it reaches to embrace the "dignity of risk." It helps reduce the likelihood that program participants become disillusioned with the facilitation process." –SDMNY staff

SDMNY sessions educate the public to consider SDM as a means for individuals with IDD to be empowered to make decisions and steer their life paths, and to cultivate relationships that will make them less vulnerable to abuse, neglect, and exploitation.

SDMNY Facilitation Process as Safeguard

SDMNY staff consider the SDMA facilitation process and the SDMA to provide foundational safeguards. People with IDD and supporters learn to speak up should abuse, neglect, exploitation occur, be threatened, or suspected. In this and other SDM pilots, people with IDD who learn about their human rights, receive coaching on speaking up, and experience their decisions respected by others, have experienced greater self-advocacy and speaking up. (This evaluation provides evidence of positive impacts in the section entitled "SDMNY Impact").

Supporters as Safeguard

SDMNY information sessions convey that a risk factor for being taken advantage of is social isolation and that reliance on fewer people puts people with IDD at higher risk for abuse, etc.

Safeguards for Supporters

In terms of safeguards for supporters, the SDMA template informs the decision-maker that she has responsibility for decisions. Should a third party accept an SDMA decision and something untoward result, supporters should be free of any liability. However, in the absence of statutory guidance, potential liability remains uncertain.

Another SDMNY initiative planned for Year 4 is the creation of online forums for decision-makers, and separately, for supporters, to assist one another by sharing experiences, resources, and problem solving.

Concerns, Complaints, Disputes Among or Between Supporters and/or the Decision-maker. During this pilot stage, SDMNY-related dispute resolution is through the Senior Project Coordinator. Decision-makers and supporters are given the Senior Project Coordinator's telephone and email for raising concerns about the facilitation process. For concerns or problems after SDMAs are signed, there is not yet an established complaint resolution process or responsible entity, though planning is underway to establish these resources. To date, SDMNY staff are not aware of any issues or problems after an SDMA has been signed.

To compare, in Alaska, concerns and complaints related to SDM are directed to the adult protective services agency. For the South Australia pilot, all participants in the pilot were given information about the Office of the Public Advocate's Complaint Policy. In the CPR-Nonotuck SDM pilot in Massachusetts, those who adopted SDM were advised that they would be able to utilize the legal services of CPR to resolve SDM-related legal problems. For non-legal problems that did not rise to the level of suspected abuse, neglect, or exploitation, SDM complaints were to be worked out by the care manager, individual with IDD, supporters, and service providers. Abuse and neglect concerns were to be reported to a state agency, the Disabled Persons Protection Commission.

Additional Safeguards Planned

Professor Rebekah Diller, of the Benjamin N. Cardozo School of Law, presented at the 2019 National SDM Symposium hosted by the National Resource Center on Supported Decision-Making. Her remarks primarily addressed consideration of SDM for older adults and included a list of protective components built into various statutes and pilots.[29] These included:

- Voluntariness

- Eliminating conflicts of interest
- Accountability
- More than one supporter
- Monitors of the SDM arrangement
- Facilitators for developing an SDM agreement
- Education and training of SDM participants
- Responsibilities and fiduciary duties of supporters
- Recordkeeping
- Reporting and administrative oversight

SDMNY staff are cognizant that while some safeguards identified by Professor Diller are in place (i.e., voluntariness, facilitated SDMA development, education of SDM participants, etc.), more structure is needed to fully operationalize appropriate protections and buttress permanency and sustainable safeguards into the future.

> "If and when there is legislation, it should include a provision similar to that in the SDMA laws of states that have passed them, that third parties who have reasonable cause to believe that the agreements are being misused or there is abuse, neglect or undue influence can and should report it to the appropriate adult protection agency. In terms of safeguards for the supporters, the SDMA provides that the decision-maker takes responsibility for her/his decisions, so if a third party accepts the agreement, and things go South, the supporters should be free of any liability."

SDMNY is creating a mediation protocol for resolving conflicts between decision-makers, supporters and/or third parties in collaboration with the Mediation Clinic at CUNY Law School during the fourth year of the grant. For dispute resolution after the grant ends, staff report that SDMNY is forging a partnership with the state's court-affiliated but independent CRDCs. These Centers exist in every county and provide trained volunteers for dispute resolution and conflict coaching. SDMNY staff envision that challenges related to SDM will be handled by CRDC volunteers who will receive additional training on SDM.

Evaluation Finding: Safeguards

- SDMNY has established important initial safeguards. For long-term SDM sustainability, additional safeguards are needed related to use of SDMAs including reporting and examination of complaints and concerns (e.g., undue influence by a facilitator, mentor, or supporter, or a third party not honoring a decision), and for reporting and investigating possible abuse, neglect, or financial exploitation.

SDMNY Outreach & Decision-Maker Recruitment

To recruit people with IDD, SDMNY initially planned outreach to students transitioning out of special education programs in NYC schools as well as to service providers, and referrals from Disability Rights New York (DRNY), the state Protection and Advocacy agency.

As mentioned, the five-year grant requires SDMNY to recruit at least 135 people with IDD for its pilot programs. The Diversion pilot aims to avoid guardianship for 90 people, and the Restoration pilot to recruit 45 people under guardianship. Between January 2017 and March 2019, 79 individuals with IDD signed up for one of the SDMNY pilots, 58 in Diversion and 21 in Restoration; however, 10 withdrew after signing up. As of May 2019, 8 decision-makers have fully executed SDMAs (7 Diversion, 1 Restoration). None have yet experienced a restoration of rights, although one decision-maker is represented by DRNY in potentially pursuing that goal, and another decision-maker began the SDMNY facilitation process after his guardianship was discharged.

Surveyed SDMNY staff note that outreach has been directed to a more diverse pool of individuals with IDD than other SDM pilots in the U.S. They report that SDMNY recruitment was aimed at people with more significant impairment, including those who communicate without using words, and to those with diverse ethnic and racial identities, socio-economic backgrounds, and experiences.

> “No model to date caters to such a diverse audience, and the challenges and successes of this model will influence the development of models elsewhere.”

> “We also go beyond what might be seen as a willingness to confine supported decision-making to the ‘highest functioning’ people with IDD, insisting on the right to legal capacity for all, and working with people with more significant impairment, non-verbal decision-makers, etc.”

Although this evaluation did not examine the personal characteristics of decision-makers, demographic information was requested of guardian and potential guardian evaluation respondents. (See page 43 for information about family member evaluation respondents.)

Staff report it has been more difficult and time consuming to recruit decision-makers than expected:

> “It can often take 2-3 months from the time of an info session for recruitment of DMs until sign-ups actually take place. People need time to think about and process the information before agreeing to participate.”

From January 2017 through March 2019, SDMNY held over 40 in-person decision-maker recruitment events for audiences of persons with developmental disabilities, family members, and professionals (e.g., lawyers, educators, and service providers). In-person information sessions reached over 700 attendees. SDMNY staff also conducted education and outreach, including webinars and conference presentations, to educate stakeholder groups about SDM as an alternative to guardianship. Through Year 3 of the grant, SDMNY information and outreach sessions reached over 4,250 people.

SDMNY staff prioritized recruitment activity across three stakeholder groups: prospective decision-makers, family members, and professionals in the IDD community. As necessary as it is to educate the public, resources are limited, and outreach energies need to be strategically planned. One-time sessions, SDMNY staff realized, were, "…next to useless in generating decision-makers." More success recruiting decision-makers resulted from developing relationships with organizations over time. "Building relationships and trust takes a lot of time but turns out to be really necessary."

Most successful was building a relationship with the Cooke School, a special education school for youth through age 21. Although here too recruitment was slow and time consuming. SDMNY staff initiated ongoing, continual conversations with school personnel, both administrators and teachers, in order that all school staff, not just transition coordinators, understood the potential benefits of SDM for persons with IDD. Once awareness of SDMY philosophy and its importance for self-determination was conveyed to educators, SDMNY staff held information sessions for parents and, simultaneously, for students. As students enrolled and passed through the facilitation process, word spread, and more parents and students learned about SDMNY and were interested. A helpful strategy to increase recruitment was when a school invited SDMNY to present and, after the presentation, school personnel reached out to encourage attendees to follow up with SDMNY. Where there was personal encouragement, sign-up rates were higher.

Outreach to self-advocacy groups is considered moderately successful by staff, with at least one person signing up per session:

> "That has been an important lesson and suggests (gratifyingly) that SDMNY has designed a process and developed a message that is readily understandable by and attractive to self-advocates, our primary stakeholder group." –SDMNY staff

SDMNY staff report that the presence of people with IDD in the room is helpful when illustrating the utility of SDM:

> "Many times, the folks in the room don't actually understand the concept of decision-making, so opportunities to brainstorm about easy decisions, hard decisions, everyday decisions and creating a conversational dialogue are appealing."

Staff realize the contributions of people with IDD at information sessions; at the time of writing, however, outreach and recruitment sessions had yet to include a paid self-advocate presenter.

Referrals for those with guardianships have been rare:

> “Those referred by the court system in some cases appear to be frustrated with the project, as they have interpreted the project as being a reason for why their 17-A guardianship petition was denied.” –SDMNY staff

Somewhat successful were presentations to lawyers, through the bar association, and to judges, through the Surrogates' Association. Future outreach plans include court clerks who are responsible for processing guardianship applications, as clerks are often an initial source of information about guardianship for potential petitioners.

SDMNY also conducted outreach to service providers throughout NYC. Provider information sessions did spread the word to staff but did not yield SDMNY referrals.

> “When we delivered info sessions to agency providers, often the personnel viewed the presentation as professional development, and did not lead to direct results for recruitment of decision-makers.” –SDMNY staff

The 20 family members (potential guardians and guardians) interviewed for this evaluation described how they (or the decision-maker) first learned about SDMNY. Potential guardians reported that school and self-advocacy organizations presentations were the more frequent path to SDMNY enrollment. For guardians, presentations to self-advocacy organizations (i.e., direct presentations to people with IDD) yielded the greater number of signed up decision-makers. Table 3 below displays the outreach events where evaluation-involved family members learned about SDMNY.

Table 3. Decision-Maker Recruitment

Outreach Method	Potential Guardians (Diversion pilot)	Guardians (Restoration pilot)
School presentation	7/15 (47%)	0
Self-advocacy organization presentation	5/15 (33%)	3/5 (60%)
Other presentation venue	2/15 (13%)	1/5 (20%)
Person assisting with guardianship	1/15 (less than 1%)	0/5
Do not remember	0/15	1/5 (20%)

Primary Barriers to Outreach and Recruitment

According to SDMNY staff, the most significant challenges to recruitment are a lack of legal standing for SDM, belief that guardianship is necessary, and a sign-up procedure.

Lack of Legal Standing

SDMNY staff view the absence of legal recognition for SDM and SDMAs in New York State as a primary factor that discourages prospective potential guardians and guardians. State agencies such as the Office for People With Developmental Disabilities (OPWDD) and the Department of Education (DOE) also have yet to officially recognize SDMAs. Without legislative or policy grounding in New York, a doctor or banker or landlord, etc., could refuse to accept a decision made using SDMA. This is a deep concern to parents.

Without statutory authority SDMNY may not offer enough practical value, as highlighted in this staff quote:

> "Although I believe that the facilitation process and SDMAs occasion important conversations and yield unique understandings about decision-makers' relationships with supporters that inhere regardless of the legal weight afforded an SDMA, many service providers and some family members seem primarily concerned with the day-in and day-out of supporting persons with IDD in other more concrete ways, such as obtaining and maintaining benefits and services, whereas investing time and energy in enhancing more abstract aspects of a person's life, such as autonomy, can take a backseat in their minds."

Belief That Guardianship Is Necessary

Another significant barrier to SDM adoption that staff identified is the belief that guardianship is necessary, and a wrap-around protective intervention:

> "Parents and other potential guardianship petitioners, and guardians themselves, have been told this over and over, by multiple sources, over many years. It's hard to break through. But as we have a growing number of success stories, and parents and decision-makers who can attest to the process, we are beginning, just beginning, to break through."

SDMNY staff address these challenges by laying out the need for SDMA legislation and legal standing for the process and the signed agreement. They explain that the experience and successes of SDMNY will be used as evidence to secure legislative recognition. And as mentioned in the prior section, information sessions share the history of various methods society has used to protect people with IDD, including placement in institutions, to guardianship, to SDM. Sessions present examples of guardianship as an imperfect form of protection, explaining the risks for abuse, neglect and financial exploitation that can and do occur under guardianship, and in some instances, by guardians.

Surveyed SDMNY staff understand that there is more work to do to inform the public about the existence of a robust alternative to guardianship and to engage people with IDD and their families in SDMNY. To sustain SDMNY into the future, SDM must be taught and utilized at various points in school, starting in elementary school and building SDM into transition programs and curriculum. Educators and others need additional information to understand what guardianship entails: a permanent loss of rights and legal personhood, and potentially limiting the development of a person with IDD's sense of self and full community membership.

SDMNY Procedure

The other primary recruitment barrier identified by staff stems from a sign-up process. Following information sessions, interested individuals are not signed up on the spot. Instead, SDMNY staff schedule a one-on-one meeting with each prospective decision-maker, and in many cases, with one of the decision-maker's family members. Staff report that often, "life seems to get in the way" of arranging the follow-up one-on-one meetings. And even after one-on-one meetings occur, there have been significant delays in retrieving the consent forms to complete sign-up.

For Consideration - Consider SDMNY sign-up immediately after an information session. One-on-one meetings to discuss details can still be part of the process and provide an opportunity to withdraw.

Evaluation Findings: Outreach and Decision-Maker Recruitment

- Recruiting people with IDD to SDMNY required more effort and time than anticipated. Referrals for those with guardianships have been rare.
- The most significant challenges to recruitment are a lack of legal standing for SDM, a widely held belief that guardianship is necessary, and the SDMNY sign-up procedure.
- More successful decision-maker recruitment resulted from developing relationships with an organization over time. SDMNY and a special education school formed a successful partnership that utilized these strategies:
  - First, educate and inform school administrators and teachers about SDM.
  - Host separate but contemporaneous information sessions with family members and students.
  - After an information session, school personnel reach out to encourage specific people to follow up with SDMNY.

Guardian & Potential Guardian Experience

Participating in this evaluation was voluntary and open to all family members with an SDMNY-enrolled decision-maker between December 2018 and May 2019. Family members of decision-makers participating in the Diversion pilot are referred to as "potential guardians." Family members of decision-makers participating in the Restoration pilot are "guardians." Potential guardians are being diverted away from guardianship through adoption of SDM, and guardians, it is hoped, will find confidence in SDM and be willing to petition the court to relinquish guardianship and restore decision-makers' rights.

This evaluation explored the opinion and experiences of SDMNY-involved guardians and potential guardians regarding the following research areas:

1. What concerns or advice led you to consider guardianship, or to become a guardian?
2. What led you to become involved in SDMNY?
3. In what ways has the SDMNY process in this pilot addressed or reduced concerns that led you to consider guardianship or to become a guardian?
4. From your perspective, how has participating in this SDMNY pilot affected or changed the individual with IDD?

Evaluation respondents were potential guardians (n=15) and guardians (n=5) of decision-makers involved in SDMNY. Telephone interviews took place from Feb. 1, 2019 through May 5, 2019.

This evaluation presents quotes from potential guardians and current guardians who gave specific consent to use their words in this evaluation report. Many gave permission to use their names as well. For consistency, however, the evaluator chose not to identify respondents by name. Additionally, when respondents mentioned a decision-maker's name, that identifier has been removed.

Personal Characteristics of Guardians and Potential Guardians

One of the funder's expectations for SDMNY was that people with IDD adopting SDM would be from various walks of life and demonstrate the use of SDM for those with diverse backgrounds and abilities. While this evaluation did not collect demographic information about decision-makers, guardians and potential guardians were requested to disclose personal demographic information about themselves. Demographic information was voluntary to disclose; all participating guardians and potential guardians were advised of this and provided additional consent to share their personal information for this evaluation report.

Guardians and potential guardians identified predominately as: parents of the decision-maker, White/Caucasian, as non-Hispanic or Latino, English as primary language, and currently living with the decision-maker. Potential guardians were nearly twice as likely to live with a spouse or partner and almost three times more likely to live with both the decision-maker and other children. While more diversity is demonstrated in the potential guardian pool than those serving as guardian, three times more potential guardians than guardians participated in this evaluation. Information collected about the personal characteristics of guardians and potential guardians is displayed in Table 4 below.

Table 4. Personal Characteristics of Guardians and Potential Guardians

Characteristic	Guardians (n=5)	Potential Guardians (n=15)
Age	Range: 33 to 77 years old Average age: 57 years old	Range: 40 to 70 years old Average age: 55 ½ years old
Race	White 100% (n=5)	White 64% (n=9) Black 7% (n=1) Hispanic 14% (n=2) Mixed race 14% (n=2) 1 declined
Ethnicity	Not Hispanic or Latino 100% (n=5)	Not Hispanic or Latino 71% (n=4) Hispanic or Latino 29% (n=10) 1 declined
Primary Language	English 100% (n=5)	English 93% (n=14) Spanish 7% (n=1)
Legal Status/Relationship to Decision-Maker	Guardian 100% (n=5) - Parent n=4 - Sibling n=1	Parent 73% (n=11) Sibling 13% (n=2) Other Relative 13% (n=2)
Lives with Decision-Maker	40% (n=2)	79% (n=11)
Lives with Spouse or Partner	20% (n=1)	71% (n= 10)
Lives with Other Children (excludes Decision-Maker)	20% (n=1)	57% (n=8)
Works Outside the Home	60% (n=3)	60% (n=9)

Pressures to Pursue Guardianship

One of the principal evaluation research areas was to explore the concerns and influences that lead parents and other family members of individuals with IDD to consider guardianship or to become a guardian. While not all family members are persuaded to secure guardianship or to seriously contemplate guardianship, all conveyed that guardianship is presented as the recommended path by multiple sources. Most influential in guiding family members toward guardianship are other parents of children with disabilities, schools, and health care providers.

Guardian’s Reasons for Pursuing Guardianship

Guardians stated that they understood it was their responsibility to protect their adult children or relatives once they became legal adults and were advised guardianship was the way to accomplish this. Guardians did not understand there was a choice not to become guardian. Concern about not being able to help make medical or financial decisions steered some family members to secure guardianship. One family member secured guardianship to keep the State out of her family member’s decision-making.

> “Yes, 10 years ago, when [name] turned 18, it’s what people did. When you turn 18 you get guardianship. There was no gray area. No one said, hey [name] might not need a guardian. Now we know differently.”

> “There was not a viable choice at that time. It was sort of a package, all or nothing. We’ve tried to look at things and be proactive and this was one more thing to be proactive about. We’ve had very good support from our service provider, CFS. And this was just one of those things, we were aware of, so that when he was suddenly 18. Probably what drove it was access to medical information. [Name] could not make medical decisions and we didn’t want him to be in a situation where he couldn’t give consent. And we wanted to have access to his medical information. There was also concern that he wouldn’t have made good decisions in some financial decisions.”

> “I didn’t want the State to have control over him. He is a vulnerable person. He doesn’t use verbal language and he’s someone who, without someone overseeing, would be vulnerable. I am not an immensely trusting person of the State.”

Potential Guardians Who Did Not Consider Guardianship

One-third of potential guardians stated they have not considered guardianship (n=5/15, 33%). Their reasons are varied but have in common a theme of not hindering their family member’s independence or the learned experience that comes from making one’s own mistakes. Below are some of their comments.

> “No, we are working so hard to make him independent, to cut off his rights is not right for us. And the other thing is that we are a family of three; we don’t have more family. That is why we are working hard to make him as independent as he can be.”

> “We always were very protective of him. We like him to have his independence. Unless something goes wrong with him, if he can’t speak for himself, if he needed one of us to do something for himself, then we allow him. We treat him as if he doesn’t have a disability. He can manage his own decisions. If we disagree, we let

> him know we disagree; we tell him. We allow him to make mistakes. You learn from mistakes. We let him handle it. He is very stubborn when his mind is made up. We let him learn from his mistakes, because the same thing keeps happening over and over, because he wants his independence. If we mentioned guardianship to him, it would be like we're taking things away from him. In contract (SDMA), whatever decision he makes no one can interfere with it. If he doesn't like it, he'll call me, he'll call one of us."

> "I could not accept the thought of him having to ask his guardian for every little thing he wanted or needed, knowing he is capable of making his own decisions. Couldn't swallow thought of him asking for money."

Potential Guardians Who Considered Guardianship

Most potential guardian family members stated they have considered guardianship (10/15 respondents, 67%). They described being influenced by:

- Advice that guardianship ensures involvement in medical care or financial affairs.
- Advice that guardianship is necessary should an emergency or crisis occur.
- Advice from schools, health care providers, and other parents with children with disabilities to secure guardianship when youth with IDD become legal adults at age 18.

Guardianship is only presented as a helpful intervention, a step to adulthood, devoid of negative consequences.

Potential guardians reported the recommendation for guardianship is often framed as necessary to be involved in medical or financial decisions, as well as to be involved in the case of an emergency. They are told scenarios that scare family members. Below are statements by potential guardians illustrating these pressures.

> "Because all the people in school system advised that. Some of the doctors like the neurologist also advised us. We initially thought we would do this because of things they made you think about. They say scary things like what if a medical issue comes up and something needs to be done, but she doesn't understand and doesn't want the care. She could jeopardize her health. Or that someone could take advantage of her by selling her a service. The idea was guardianship would protect."

> "I knew [name] would need support in making decisions for himself and thought guardianship was the way to go about it. When we had an evaluation done, the GAL was respectful, but she never said we are taking rights away. We were told this is the only way we could help him make decisions. There is misinformation out there about guardianship. One thing you hear is that if you don't have guardianship then

> you won’t be able to participate in your son’s care or life decisions such as in an emergency. If there is an emergency and you aren’t guardian, then there is nothing you can do. I’m a nurse. I know that’s not the standard of care. I don’t think I wouldn’t be included. Information about guardianship was attached to very emotional, extreme situations. You hear about your child being preyed upon and taken advantage of if you don’t get guardianship. It was like one of the 5 things to do, check the box.”

Potential guardian family members report receiving recommendations from multiple sources to secure guardianship: “Everyone saying the same thing: the school, SSI, other parents.” As shown in Table 5, pressure from other parents with children with IDD, health care providers, and schools are the primary external sources of influence. Service providers and financial institutions rarely if ever recommended guardianship to these family members.

Table 5. External Sources of Influence Toward Guardianship

Sources of Guardianship Recommendations	Yes Recommended
Other parents with children with IDD & from one’s own family	7/15 (47%)
Health care providers	6/15 (40%)
School, teacher, transition coordinators	6/15 (40%)
Disability service providers	0
Banks / financial institutions	1 (less than 1%)

Influence of Other Parents with Children with IDD

Most commonly mentioned was the influence of other parents who have children with IDD. However, their influence is not unidimensional but comes in many forms. The comments of potential guardians below illustrate some of the permutations.

> “I have two groups of parents. A group of urban, well-educated parents with children the same age. We have discussed this. Some are doing guardianship for medical care, but of very high functioning young adults. So I was surprised. I was thinking, “Am I slow? Am I missing something?” In another parent group, of suburban parents, one parent told me the guardianship process was upsetting. She said, “I was crying. I felt terrible; but I did it.” So I have learned little by little. I just learned guardianship is reversible. And they are growing. At 20 years old I’m not sure what she is capable of yet. She is showing promise. Why do guardianship at a young age when they are becoming a person in society? Why not wait until they are 25 or 30? They start talking about this when 15 years old. It’s too early.”

> “Yes, other parents were definitely guiding you, in support groups, in workshops. As a parent you are trying to digest your child’s disability. You are absorbing information from other parents to understand your child. It’s so overwhelming. You want what’s best, so yes, you are going to accept guidance from other parents who have already gone through this.”

> “In general, it’s the ‘You have to have guardianship,’ and ‘You have to take care of them.’ Other parents were not pushing me, but in conversation it’s the expectation. When I learned about guardianship I thought, ‘I can’t do it,’ and thought I was that terrible mother, and would sit there quietly.”

> “Everyone thought guardianship was what we had to do. There was no other conversation about decision specific capacity; it was an all or nothing. I felt we needed to do guardianship as there were no alternatives. It was the next step. We have parents with children who were a bit older in school for special ed, and we got the message from them guardianship was the next step. When [name] was turning 18 we pursued guardianship. We found out what was needed, got a lawyer, had a guardian ad litem and evaluations to get guardianship. Then, right around the same time, I went to a SDMNY presentation and put everything guardianship on hold and started SDM.”

> “Some families did it themselves and others said you have to have a lawyer. So many questions about the process. Did child need to be in court or not? Person really doesn’t know; it is just the next protective step. Never expect people to talk to their child about it; just did it. No one said we are going to take away your rights; not that we are taking your rights away. No push back when we went SDMNY and changed minds and it was just okay. Especially as this was the only thing to do.”

School Influence

Schools convey a wide array of—and sometimes conflicting—messages to family members, from promoting self-determination to guardianship. One potential guardian mentioned that the school her child attended promotes self-determination and retaining rights:

> “No, they (school transition coordinator) said he can make his own decisions. The more he tries, the more experience he gets, and the more responsible he’ll be. We hope he will be fully independent with assistance.”

More typical for evaluation respondents were school recommendations to secure guardianship. Forty percent of potential guardians stated they had been advised by school personnel to secure guardianship. The recent National Council on Disability report, *Turning*

Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities refers to the critical role schools play in promoting guardianship. Called the 'school-to-guardianship' pipeline, the report conveys that states' educational systems actively encourage guardianship and do not advise of less restrictive alternatives.[30]

Potential guardians stated the influence of schools comes in many forms. Guardianship is listed as a step on a transition checklist and schools host workshops advising family members on how to secure guardianship. Examples of school influence toward guardianship that potential guardians experienced is shared below.

> "Didn't say you have to but gave you a checklist from age 14 to 21 and guardianship is on it as a step. They were adamant that this is what parents do."

> "The transition process is for guardianship."

> "I had applied for guardianship and 5 days before court date, I ended up going to an SDM workshop. I didn't know the option existed. I had done all the guardianship evaluations, petitions, and taken the day off work. I pulled the petition and entered the project. Because I was misinformed. When [name] was a child, I was not in the mental health field then, I was always told in order to protect your child when she turns 17, I had to start the guardianship process. But I didn't understand the ramifications, that I was removing or eliminating her constitutional rights. That was not explained to me. It was always in my mind. When you meet other parents at workshops, they are mingling, talking, saying, "Yes, I started the process." Every year District 75 in NYC, they have a guardianship workshop and I started attending when [name] was 15 so I could be ahead of the game. They bring in a guardianship lawyer who gives you the how-to on guardianship and all the steps. It's very instructional. I just followed the steps."

> "Cooke (school) is wonderful sharing information with parents and students. We had been to workshops on guardianship a couple of times."

> "Parent workshops from age 5 at school, at public schools, District 75 school for autistic kids."

Health Care Provider Influence

Forty percent of potential guardians reported being advised by health care practitioners to secure guardianship. These family members conveyed that health and behavioral health care providers sometimes see themselves as being helpful when determining a person with

IDD is incompetent for a guardianship petition. As described in the stories below, accommodations to assist the person with IDD in understanding the assessments and engaging in due process before their rights are removed appear to be absent. Health care providers appear to be motivated to help secure a guardianship and may not understand that a lack of notice regarding assessment and lack of communication accommodations are forms of discrimination.

> “For the guardianship, we had an evaluation, a psychological, and they never met person before and do it in an hour and are not interested in best response. We lined it up with YAI. Actual psychiatrist came in and asked [name] about health care decisions and life support and would that be something he wanted. These questions were out of the blue, with no context and no accommodation. Practitioner did not try to help my son understand, so of course they could say he couldn’t understand a living will and so couldn’t make decisions, and this would surely support our guardianship application. One of the many examples of ways things are not constructed to help him be whole, be supported. No one is acknowledging the limits of the assessment; it’s not about helping him flourish. Questions are out of the blue. A discombobulated exam to show he doesn’t understand. They’re not looking for him to understand. So when I heard about SDMNY—I have a background in patient self-determination and decision-specific abilities and honoring participation and agency and autonomy—we pulled guardianship and pursued this. And it has been fantastic. Helped turn our mind and heart for him. So much on our minds of what we needed to do for him instead of what we need to help him do for himself. He needed practice to think about his preferences and his responsibility. Guardianship did not include him much. That is about us [parents] being scared—focusing on dependence, transition. Guardianship lens is different than shared decision-making and SDM. SDMNY is resource intensive and coaching repetition over time. To help person see themselves as a decision-maker and integrate that in their lives.”

> “We had one doctor, a neurologist who worked with [name] since she was a baby. When [name] was younger, this neurologist was so positive about our daughter. But as she got older, we were turned off with the neurologist. We had paperwork for the guardianship and gave it to her. Part of the papers are about going to court, and neurologist said, “Oh no, she is not going to understand anything, and it would just make her anxious.” I looked at this doctor in a new way. She is a well-known neurologist working with autism. We went to a special needs attorney who did some paperwork, including a Will, and he mentioned guardianship, and said, “You have to do that.” He has children himself, but he doesn’t know my daughter. He never met her, and he also said, “She won’t understand.” So I had my doubts that it was a good idea. But when I thought about it, I thought mitigating factors would lessen those scary things from occurring. Such as right now, I’m involved in her life. She is not

> one to ignore our advice or guidance. I thought we'd be involved. She would trust our advice to some degree. And there are other documents that one can do, a health care proxy, where we can be involved, and she would trust our opinion."

As this last quote illustrates, health care providers may not be aware of alternatives to guardianship or know how to respond when families advise that supported decision making is being utilized:

> "When our old pediatrician retired and we went to the new one, the first thing he asked was 'Do you have guardianship?' I tried to explain that we were trying something different, SDM, but felt he wasn't interested in hearing about it at that time."

Guardianship as a Prerequisite for Service

This evaluation examined whether potential guardians experienced pressure from health care providers, school systems, disability service systems, or financial institutions to secure guardianship in order for a decision-maker to receive a service. Although guardianship was not presented as a condition for service delivery, several potential guardians reported being urged to secure other decision-making arrangements—one a health care proxy to proceed with a surgery, and two to become representative payees for SSI benefits. A potential guardian shared this experience: "No, not guardianship. But they wanted to assign a payee because she's in a wheelchair and not able to use her hands. People are judged by the way they look."

Costs Are Not a Factor

Guardianship is a legal process that can entail financial costs related to hiring an attorney, securing assessments, and filing documents with a court. SDMNY staff wanted to know if potential guardians were influenced to adopt SDMNY and not pursue guardianship due to costs. None were. All 15 potential guardians reported that costs were not an influential factor, though for different reasons. Potential guardians either knew ways to self-file (without using an attorney), viewed petition-related costs as just another cost of having a child with a disability and something you must do, or did not know there were costs associated with filing a guardianship petition. Several potential guardians stated that in New York there are institutions that aid family members with filing a petition, including school systems and local Arcs.

> "No, cost consideration but didn't drive our decision, and there was a way to do it without attorney. But it was another reason not to do it. Also you hear all these stories about going for guardianship and the judge may turn you down, or if you get a certain judge you won't get guardianship or you'll get a different type, or if your

> name falls at a different end of alphabet, you will get a judge that may or may not have your child's interest. It didn't sound like [name]'s interest were of concern. SDM is in the center of what is in [name]'s interest." –Potential guardian

Evaluation Findings: Pressures to Secure Guardianship

- Guardians did not understand there was a choice not to become guardian.
- While not all family members were persuaded to secure guardianship or to seriously contemplate guardianship, all conveyed that guardianship was presented as the recommended path by multiple sources.
- Most persuasive in guiding family members toward guardianship are other parents of children with disabilities, schools, and health care providers.
- Family members are advised that guardianship is necessary to be involved in medical and financial decisions and to help in the rare case of an emergency. Family members report that stories they are told are intended to instill fear and are effective.
- School pressure toward guardianship appears pro forma and not an individualized recommendation. Some schools list securing guardianship as a step in transition to adulthood and host workshops that teach parents how to secure guardianship.
- Health care professionals and special needs attorneys may recommend guardianship without knowledge of an individual, conduct assessments without accommodation, and dismiss the capability and rights of a person with IDD.
- Guardianship was not presented as a condition for service delivery by health care providers, school systems, disability service systems, or financial institutions. Several potential guardians were pressured to secure less restrictive decision-making interventions (health care proxy, representative payee).
- Costs related to guardianship are not a significant factor for family members deciding whether to pursue guardianship.

Guardianship Is Not Well Understood

For many families, guardianship is not a thoroughly understood undertaking. What is and is not covered by guardianship is not clear. A number of evaluation respondents shared their frustration with the lack of concrete, daily life distinctions between what guardianship can and cannot address, as well as what SDM can and cannot address. Below are statements illustrating the confusion, discomfort, and frustrations that family members experience trying to navigate the challenging landscape that is guardianship.

> "Because my understanding, what was explained to me, was that if she could not advocate for herself, and if I wasn't guardian, then I could not make decisions for her. So I needed guardianship to assist her with medical care, income, with decisions. As a parent I am to advocate for her. You are being told this since your

> child was 5 years old. My daughter has progressed. Her IQ is still within 50 but she has developed a personality. It's a skill set to make decisions and her preferences have been cultivated. And no one has told us this is what you have to cultivate." –Potential guardian

> "What is and is not covered by guardianship is raised through the SDMNY process. Now I am much less concerned than I was. I had a very good lawyer who got to know [name], and if I were to do this again, it would have been good to understand breaking those things [less restrictive options] out separately. It would have made sense in conjunction with the SDM process. In world of best practices all the options would be given to you when your kid was 15 and we could have involved future agents in our place and involved them in the process. Our process would have been very different if more comprehensive pieces earlier on. So many parents haven't planned, and kids get to 18 or 19 or 21 and the easiest thing to do is to get guardianship as they are frightened of not getting medical information. We were proactive and we still ended up in this guardianship process. One of the problems is the education system being the locus for disseminating information about transition. People get pushed off a cliff as there is no consistency from school to school or to foster independence and skills people will need to use. You get a medical diagnosis, they may send you to social services, then to the educational system, and it keeps going on. There's no connection between creating jobs and supporting people or those going on to higher education. It's not just job skills, it is also social skills that aren't taught along the line. SDM is just one piece of a much bigger pie. People should be getting prepared for SDM all along. It's self-advocacy preparation." –Guardian

Guardianship Removes a Person's Rights – News to Me!

Guardianship entails removal of the person with disability's legal rights. Guardians and potential guardians participating in this evaluation were asked if they were aware that imposing guardianship entailed loss of rights for the decision-maker. The majority of both groups (60%) reported awareness but not a real understanding of what loss of rights means in daily life.

In New York State having a guardian means a person with IDD loses all legal capacity to make decisions about their life, including decisions about their health and health care, their finances, what kind of education, who to associate with, where to live, who to live with, and where to work.

Potential Guardian Awareness That Guardianship Removes Rights

More potential guardians said they were aware that guardianship entailed a loss of rights than those who did not (62% v 38%). But even those who knew that rights would be removed did not fully realize what the removal of rights meant. Some potential guardians, aware of the loss of rights, felt they had no choice. Typical were these expressions of frustration with the lack of reliable, thorough information including that guardianship entails removal of the ward's rights:

> "No, they don't tell you. I slowly learned that myself. I heard a person say you can't vote if have a guardian. They use a fear tactic and they don't tell you all the negatives."

> "It's never part of the conversation. It's not the definition that is given. It's because he has difficulty you need to do this to protect him. Protective intervention. When I read guardianship documents, I learned that I am speaking for him. And then after I die, his brother would make decisions for him. As a parent, you give up on things, and with guardianship, it's here is another not right thing that I have to settle with. Five years of panic for when school stops; so you plan for adulthood, but there is nothing to plan for. Planning and the anxiety is not helpful. Only guardianship is firm. There is misinformation about guardianship and about SDM. Information is still very unclear."

> "Any attorney you ask will suggest that guardianship is the way to go. But then talking to parents, talking to Matt (Senior Project Coordinator), just going to seminars, when they compared what guardianship is and what it might become, I had a bad taste in my mouth about doing it. I had concern about doing it now, right now. I didn't see it as a necessity. From my viewpoint, we'd only heard of guardianship until several months ago. And what we didn't realize until digging deeper was the complete annihilation of [name]'s rights. The way we looked at the guardianship was the opposite of what we've been trying to do for [name] his whole life; it didn't philosophically align."

> "When he was 17, no one ever put it that way. Parents say, "This is what we're doing. This is what we are thinking." We were all concerned about some of his decision-making rights were going to be taken away and trying to think if there were any other options. I remember really questioning the whole guardianship thing when I learned he may lose his right to vote. And he really wanted to participate in that. That was the first time for me that guardianship was not the right path for him."

Guardian Awareness That Guardianship Removes Rights

Three of the five interviewed guardians understood at the time they petitioned for guardianship that loss of rights was a consequence, but they undertook guardianship because they did not perceive an alternative. Guardians believed guardianship was necessary to be involved and make decisions in an emergency or crisis. (SDM was not an option when these guardianships were ordered.) Guardians experienced the quandary of striving for both independence of their family members with IDD and emergency protection.

> "Good question. I don't think we had considered that. We were only thinking in terms of our own philosophy which is to promote self-advocacy and independence. There was no choice. It was the whole enchilada or not. We didn't know there was another choice. People we selected as back up guardians were people who shared our philosophy. We did understand, but our thinking was probably to have guardianship for extreme situations, for the long run, and support our wishes for his independence."

> "Kind of. Sort of. No one told me. I didn't really think about it. I was wanting to protect him. Nobody informed me about it. Nobody spoke to me about guardianship at all. I think the school may have mentioned it, suggested it as something to do when he was turning 18; he's 35 now. Nobody told me anything about anything."

> "I first learned about it when as I was a Medicaid service coordinator and sent to a training. They were presenting on SDMNY and I thought, "Wow this could really help [name]." …I learned how guardianship took [name]'s rights away and we didn't know that. [Name] is just like anyone else. He should have right to make decisions about his own life."

SDMNY information sessions were noted by guardians and potential guardians as an important source of clear information regarding the loss of rights that is a consequence of guardianship.

Evaluation Findings: Loss of Rights Accompanies Guardianship

- Most guardians and potential guardians (60%) reported awareness but not a real understanding of the specific loss of rights that accompanies a guardianship order for those with IDD in New York.
- Guardians believed guardianship was necessary to be involved and make decisions in an emergency or crisis.

- SDMNY information sessions were noted by guardians and potential guardians as an important source of clear information regarding the loss of rights that is a consequence of guardianship.

Limited Information Regarding Less Restrictive Voluntary Decision Aids

Prior to the SDMNY initiative, supported decision-making did not exist in New York State, though a number of alternatives to guardianship have been available, such as representative payees for SSI payments, joint or limited bank accounts, credit or bank cards with predetermined limits, powers of attorney for financial decisions—and for health care decisions, people with IDD may execute a healthcare proxy.

Guardians interviewed received almost no information about less restrictive, voluntary forms of decision assistance. Just one of the five guardians interviewed stated the option for representative payee was mentioned and no other alternatives.

Potential guardians interviewed were also more likely not to have heard about one or more less restrictive alternatives to guardianship. Those who were advised of less restrictive decision aids most frequently received information about a health care proxy (53%), followed by power of attorney (40%), and representative payee (33%) for SSI benefits.

Table 6 shows the extent to which guardians and potential guardians were advised, from any source, of less restrictive interventions to guardianship.

Table 6. Guardians and Potential Guardians Advised of Less Restrictive Alternatives

Available Legal Decision Supports	Guardians	Potential Guardians
Representative Payee	1*/5 (20%)	5/15 (33%)
Power of Attorney	0/5 (0%)	6/15 (40%)
Health Care Proxy	0/5 (0%)	8/15 (53%)

*Three guardians stated they are Representative Payees, though not because it was presented as a less restrictive intervention but as a consequence of assuming guardianship. One guardian was advised about payee.

The statements below from potential guardians convey the limited information they received to other forms of legally recognized assisted decision-making available in New York, and the pro forma nature of advice to secure guardianship.

> “No, at Board of Education, you have a parent coordinator. I retired from banking and stayed home. I was a parent coordinator at a preschool with special education. It was not my field and I didn’t know about autism and had a child that didn’t speak.

> So I went back school, in mental health. What I learned as a parent coordinator is that your job is not to inform parents but to invite outside agencies to come in and present to parents. So, unless they ask an attorney to come in and talk to parents—unless you are related to an attorney or you know one—unless they bring in speaker to specifically talk about alternatives, you as a parent aren't informed. Her pediatrician didn't talk to me about alternatives. Her school didn't talk to me about alternatives."

> "No, the Department of Education or medical providers are not promoting options. They're just making a blanket statement that people like her should not have any rights or make any decisions."

> "The Medicaid care coordinator told us about SSI and guardianship, but I didn't know you could be a Representative Payee and not be guardian. It wasn't presented that way. The idea at that office was that if he needed support with SSI, that a guardian would have to do that. Not true. But I didn't know. As for Power of Attorney, there was some fuzziness around that. Health care proxy, we do that ourselves. All those in our family have health care proxies. It's the most useful document if you know a person and this is what they would want. It's flexible. And it's not a lawyer document. We do it at home, just need witnesses to sign."

> "There should be more information about what guardianship is and clear up misinformation about what guardianship gets you, like you don't have to be guardian to be Rep Payee…lots of broad misinformation."

Evaluation Finding: Less Restrictive Alternatives

- Many family members (guardians and potential guardians) are not fully cognizant that alternatives to guardianship exist and were/are not able to make informed decisions about guardianship or alternatives.

Shared Values Underpin Interest in SDMNY

Guardians and potential guardians align on what led them to engage with SDMNY. It was their desire for people with IDD to have a voice, to speak for themselves, because they want to expand the network of those available to support their family member, and because they felt discomfort with guardianship. Below are statements from guardians and potential guardians regarding what attracted them to engage in SDMNY.

> "I want [name] to speak up for himself and advocate for himself and what he wants."
> –Guardian

> “I want [name] to have as much control over his life as he can, and I thought this was a good way of doing it.” –Guardian

> “Fit with our philosophy and [name] was excited about it. I’m not sure my wife still entirely understands it. Bit of skepticism. Let’s see what happens. It hasn’t really been tested over a longer period of time.” –Guardian

> “I got an invite to a workshop on SDM. I’m in the mental health field and on various mailing lists. I got an invite to an SDM workshop and I cancelled my appointments and went. Then I sat there and kind of had a little meltdown.” –Potential Guardian

> “Guardianship is a business, that’s what I felt at the end of day. There’s a cadre of lawyers that want you to get involved as it’s a payday. SDM doesn’t have the advocacy and legal backing. It’s a riskier path. My son is 18. He is relatively young and healthy; this is the time to do this.” –Potential Guardian

> “As parents we don’t know all the answers. To the extent that we can get some assistance for doing the best thing for [name], even though we have good intentions, if we could get some advice, that would be helpful. SDM is an alternative way that is more aligned with our philosophy of what [name] can do in the future.” –Potential Guardian

> “We are not going to consider guardianship, so we need to find something. And we are a lot older too. We are the adopted parents of [name]. He is our grandson. We are older to be in his life. We are always thinking when we are not here. In the moment we are having him as our main concern; always try to find some ways to make his life a little easier.” –Potential Guardian

> “I said we need to put some things in place should someone pass. That [name] will be taken care of and have rights to make her own decisions. She’s doing great things now. She needs support to keep making her own decisions and have a good life.” –Potential Guardian

> “I was turned off on guardianship and this seemed way to go.” –Potential Guardian

> “When they said SDM gives them all the say and they choose others who will be with them. He can listen but still want to do it his way. This is exactly what I have been

> waiting for. Each individual with disabilities will have their rights kept and they will make the final decision whether or not decision supporters say yes or no. Hopefully with this legal document (SDMA) no one can strip that away from him. His signature and others and contract – here we go!" –Potential Guardian

SDMNY Information Sessions Are Eye-opening!

SDMNY information sessions captured family members' hearts and minds because making decisions with voluntary supporters aligns with their values and how they want people with IDD to be treated in the world: to have a voice and be heard. Guardians and potential guardians mentioned that several messages relayed in SDMNY information sessions made deep impressions:

- Guardianship permanently removes rights including the right to vote and make decisions about one's own life.
- Risk-taking is a normal human experience that people with IDD also need to experience.
- Best practices change over time. Current best practice is to honor the human rights of people with disabilities, including use of customized, voluntary decision assistance such as SDM instead of guardianship.

The former judge's description of evolving best practice (from institutionalization to guardianship to SDM) provided perspective on changing practices and recognition of human rights for people with disabilities. For potential guardians, it was compelling to hear the former judge share her personal experience while on the bench, ordering guardianships until she realized people with IDD had preferences and capacity and should have their right to make decisions about their lives respected.

The quotes below convey the impact of SDMNY presentations on guardians and potential guardians.

> "The presentation at his school, well presented. They told story of how guardianship became the only way and how it is changing. Now there is an opportunity to make a different kind of decision which may be more aligned with how you want to treat your adult child. As described, it aligned with all the other things we wanted for him. It's okay to postpone guardianship and try SDMNY. Very informative. Answered all our questions. Highlighted what guardianship really is and clearly stated that guardianship takes rights away." –Potential Guardian

> "The SDMNY team came to his school and presented twice. I went both times and [name] came to the second presentation and at the most perfect time. I was so against guardianship that I was going to do nothing and hoped his brothers would have been there for him and that everything would be okay. My favorite story was

> from the judge. She told us she was writing up guardianships and working day to day in court with guardianships, and then she realized that so many people with disabilities could make decisions. She said it was "not nice" and "not the best way to treat people with disabilities." God bless her for keeping her eyes open and realizing that something she thought was good at one point now does not work. That story from a judge who was very involved with guardianships, I will carry that story with me. Made me feel I was correct in not doing guardianship." –Potential Guardian

> "I was so overwhelmed. The person who presented was a judge and she explained legal ramifications of removing your child's constitutional rights. That hit home. I have no other child than my daughter. When you apply for guardianship, if something happens to you, you can elect someone else to be guardian. I have a small family and so even doing guardianship, I didn't know who would have followed me. So I had opted for a non-profit agency to be her guardian after I passed. I realized she would be a ward of state and have no say in her life. She has the ability to make progress. This decision for guardianship is permanent. I don't know if she is going to be more independent at 28 years old, but this is a permanent decision, destined for the rest of her life. And even if she showed progress, then under guardianship she would have no right to make any decisions about her life. I didn't realize that I would be regressing her because all I wanted was for her to progress. This one decision would be undoing all the work I'd done for 18 years." –Potential Guardian

> "I remember expressing a lot of concerns about decision-making and the risks involved, medical and financial. Joan [the project site coordinator] was good about responding to concerns but also thinking through rights, comparing with typical child, and the right to make mistakes. No one wants mistakes or bad decisions but it's a personal right she stressed. To make mistakes, that resonated with us. The more we heard about the program, the more we started to see [name]. And he was maturing, becoming clear about goals for himself. In the last year he was more independent. Yes, he needs help with everyday decisions, but big goals, big decisions, he is very good and clear about what he wants for himself. This project was about finding him support and allowing him to keep rights to make those big decisions for himself." –Potential Guardian

> "I want [name] to have as much control over his life as he can, and I thought this was a good way of doing it." –Guardian

> "The guardianship issue. I want [name] to speak up for himself and advocate for himself and what he wants." –Guardian

Evaluation Findings: SDMNY Appeals to Family Members

- Guardians and potential guardians are interested in SDMNY because SDM aligns with their values for how they want their family members with IDD to live: to have a voice, advocate for themselves, and have more control over their lives.
- SDMNY also appeals to family members because it is a mechanism to engage more people in the decision-maker's life and provide for future decision assistance after parents and other family members pass.
- SDMNY information sessions are very impactful. The information about limits of guardianship, removal of rights, evolution of best practices to SDM, and how deeply it matters allowing people to experience risk-taking and decision-making in their own lives is persuasive to family members.

Confidence in SDMNY

Imagining How Supported Decision-Making Will Work

Guardians expressed a range of expectations on how SDM would work in daily life. Two expressed reservations and have a 'wait and see' approach. Another expects her son to speak up for himself and restore his rights. One guardian views SDMNY exactly as the model for supported decision-making intends:

> "I thought he would have a group of people that would be supportive of him and they would help him to talk out goals he had. They would not make goals for him, but talk out whatever goals he wanted, and support him in those decisions."

Potential guardians view SDMNY as continuing what they are already doing, helping their family member to become more adept at decision-making and take steps toward adult life. The statements below are indicative of their expectations, hopes, and doubts for using the SDMNY process.

> "In the near term I don't know how things would change anyway. If under guardianship, he would have been stripped of his rights, but he'd still be living at home with us. SDM emphasizes his independence, which is good, and we approve of. We didn't see much downside to SDM. Not different. While SDM is not going to change his life in the near term, we're hoping it will help us on path for future, to set us up."

> "I thought it was a great idea, you didn't have one person, like guardian or rep payee, who is in control of every area of your life. You have one person per area of your life. And if they are not working you can change them. You don't have to stick

> with one person if they aren't working for you or with you. And they don't have to stay if they don't want to. Let's say there is one person with medical, she doesn't have to wait on that person, she can reach out to someone else. Different people to reach out to."

> "Well I still have my doubts. His sister and her fiancé, and my own fiancé, and his sister in FL, among us somebody is going to step in to care for my son. I don't know that [name] is really connected to these specific issues; he is not independent now. He lives with me. I think he can achieve independence—job, home, paying food, but his responsibility to take care of home, maintenance of a life. We have a signed SDMA now, but we are going to have to hover and keep track of him."

> "He has 2 brothers and many cousins he is extremely close with. Even without SDM he has a good crew and supporters. Just as they were talking, I was just thinking this is how it would be done even without a contract. I was already talking to them about when I am not here and what should continue for [name]."

> "They use a facilitator to teach your child to make their own decisions. Even if I am in the mental health field, sometimes I don't allow my daughter to make her own decisions. I wanted to take a couple of steps back so she could work with the facilitator and learn to make decisions."

Any Concerns With Decision-Makers Exercising SDM Chops?

The SDMNY agreement template includes a reminder to the decision-maker and supporters that the decision-maker is responsible for decisions made. This evaluation asked guardians and potential guardians if they had any concerns about decision-makers using SDM and making decisions per the arrangements outlined in the SDMAs. Guardians were more likely to express confidence than a concern; however, potential guardians were more likely to report concern than confidence.

Guardian Opinion: Concern for Decision-Maker Using SDM

Nearly all (4 of 5) guardians expressed faith in the SDMNY process and the decision-makers' use of SDM. Typical of those without concern is this parent-guardian's comment: "I have no concerns about [name] being able to do it. I have faith in his ability to talk about what he wants, to be realistic about it, and to express what he wants in his life. No doubts."

One guardian expressed apprehension should a decision-maker make a poor decision: "I have my concerns. If I feel he is making a poor decision I wonder what happens."

Potential Guardian Opinion: Concern for Decision-maker Using SDM

Three potential guardians (20%) reported having no concern with decision-makers' use of SDM and three (20%) have not thought about this and have not yet formed an opinion. Most potential guardians responded that they have concerns (n=9/15, 60%) regarding decision-makers' use of SDM though the nature of their concerns differ. They expressed the following concerns:

- Lack of experience using SDM
- Supporters treat decision-maker well
- What happens after a family member is no longer around
- Decisions respected by third parties
- Lack of legislation underpinning SDM

The following statements convey their varied concerns:

> "Definitely. One of his challenges—not that he wouldn't know to reach out—but doing it if someone is not there. He is going to have to learn to do that. He is not ready to take advantage of it on his own and learn to use the program. Once he learns, and he learns systems really well, he just has to practice and do it over and over. Time and him being more independent and not having us, it will force him to reach out to other people."

> "My worry, we will be his decision supporters now, but if we need people beside us as he gets older, as he matures. He is very careful about the people around him. He can spot a phony a mile away. He knows when someone will hurt him or not hurt him. He knows who not to make friends with. We worry about what happens when we aren't around."

> "It's not NY state law yet so that is a concern until it is. I'm waiting to hear."

> "So if something were to happen with police and [name] was put in jail due to autism. If I show up and am not guardian, is he on his own because he has no guardian? I'm not saying that I'll never use guardianship. I want to know what that situation would be and know what to do about it. I'm concerned about the 'what if' situations."

> "Only concern is if it doesn't go through legislation. More people would opt for this if there is more awareness. Information is just not out there. And it takes time to change people's thinking."

Third Party Respect for Decisions

Important for the adoption of SDM is respecting a decision made using an SDMA by third parties (such as a physician, landlord, banker, etc.). As several evaluation respondents noted, they are told that without guardianship they will lack legal standing to be involved in a medical emergency or other kind of crisis scenario. SDMNY staff wanted to know if the experience of using an SDMA, even if not legally binding on third parties at this time, was honored. But as so few decision-makers currently have signed SDMAs (n=8), this evaluation asked guardians and potential guardians if they had any concern or apprehension about other people respecting a decision made using SDM.

Guardian Opinion: Third Party Acceptance

Three guardians reported not being concerned as they have confidence in the supporters selected by the decision-maker. One guardian had not thought about this and had not formed an opinion. The other guardian has a concern, whether the decision-maker's mother, who is not a supporter, will honor his decisions once guardianship is relinquished.

Potential Guardian Opinion: Third Party Acceptance

Potential guardians are at different places with respect to other people honoring decisions made using the SDM process. A few expressed no opinion at this point (n=3/13, 23%) either because of recent participation in SDMNY or because the nature of such a challenge is unclear. Potential guardians with and without concern are equally divided (n=5/13, 38% each).

Those who expressed no apprehension mentioned several reasons:

- Other decision aids are in place such as a health care proxy or representative payee
- SDMNY is untested, so it is not clear how resistance would manifest
- Confidence in the supporters

Statements from potential guardians who are not concerned about third party acceptance at this point include:

> "Not that worried about it. He is still a push over, but I hope there are enough people involved that we can get together and talk about it and watch and wait with him."

> "Hard to anticipate what might come up. We have a lot of trust in the people in the program thus far. Trust it will not be them making the decisions, it's [name]. Not really seen it in play. He's grown so much in 4 years, it's hard to know how much more he'll grow."

Potential guardians who expressed concerns for recognition of decisions made using SDM explained: it's a crazy world, SDM is not in law yet, and it is a risk that others will treat the decision-maker with respect. Below are a few statements from these family members.

> "That is one of my fears. I hope that the people around him, the supporters understand, [name] will have the power to decide, he has the power to decide. Persons who do this will know this. You help him out with a decision and give him a reason why or why not in order so he can understand better. Treat him right. It makes a big difference. How people approach him and say something. We want nice people to be around him, people who care about him."

> "It worries me because it's not NY state law. I would feel much better if law and binding. But with his supporters I don't see why anyone would not accept his thought process. He's a smart individual. I don't see him having a problem. I've told him, if anyone says you are not capable, you are to fight tooth and nail, do whatever you have to do, to fight that."

> "I want someone to treat him fair."

> "I tell him he has to be careful with people. This is a world of craziness and things happen. I have to let him make decisions and live with them. If anything happens to him, then everything falls back to us, his finances, make sure his rent gets paid, if he goes into hospital and bills taken care of. We only help each other."

Formal Recognition Important to Increase Confidence in SDM

The New York State Developmental Disabilities Planning Council, the SDMNY grant funder, anticipated this pilot would provide narratives and data to inform a New York State law reform initiative to advance the use of SDM, reserving guardianship as a last resort. SDMNY staff believe strongly that a change in law is necessary to ensure that third parties accept and honor decisions made with SDM, and to offer family members confidence in SDM's practical utility.

> "Potential guardian petitioners have asked why they should go through all the SDMA process if health care providers or financial agency representatives will still be able to insist on a guardian for legally binding and enforceable decisions." –SDMNY staff

Staff envision New York's law as building upon other states and incorporating the facilitation process piloted for achieving an SDMA:

> "We need to demonstrate that, with appropriate and chosen supports, people with IDD can make decisions that are as good—or no worse—than neurotypical people.

> We need to dispel the myth that guardianship protects. We need to find a way to reallocate existing resources, and the services they pay for, to ensure that there is a robust system of SDM facilitation to enable people with IDD to enter into SDMAs but not limit the recognition of the capability of people with IDD to having an SDMA."

This evaluation explored whether formal recognition of SDM in law or policy would affect guardian and potential guardian confidence in decision-makers' use of SDM, including after the guardian or potential guardian's death. All 5 guardians and all 15 potential guardians responded affirmatively. "Absolutely!" and "Definitely" were frequent responses to this question, although one guardian added, "It really depends on the individual. Case by case."

> "If the legislature adopts this, it would give us a lot more confidence of what could happen in the future. [Name] is young and we'll figure it out. We'll go to guardianship if we have to. But we'd feel better if we had a system that aligns with our philosophy and have it part of law, legalized. I did have a conversation with an attorney and asked if he'd be a notary for Power of Attorney. He expressed concern about it; he was being a professional. I respect his opinion. If SDM is in the law, it would strengthen everyone's role." –Potential Guardian

> "Definitely. It's great to have something like this. I have worked with physical disability, mental illness, aged people, people who can't move their body, but have a mind. You should have some authority to make decisions for yourself: health, finances, home, whatever. Disability shouldn't take your rights away. I'm glad they came up with an option to guardianship or payee." –Potential Guardian

> "Sure of course, I would be fearful of him perhaps losing some of his rights [mom's statement]. I don't know how it would change things [dad's statement]. If years from now, somewhere down the line, if SDM isn't on the books, people and agencies take advantage of people. Having it as law that would … I would feel more secure knowing that his rights and desires are protected by a law [mom's statement]."
> –Potential Guardian Parents

> "Yes! It should be all over! That's why I'm participating in this evaluation, for it to be all over, not just in NY." –Potential Guardian

> "Yes, if I wasn't here, it would give me confidence for him to have other decision supporters; then his voice would be heard." –Potential Guardian

Guardian and potential guardian respondents even offered recommendations for provisions in the law that would increase their confidence, noting:

- Include a process for reporting and investigating concerns
- Ensure the SDMA is a legally enforceable contract, but also a contract that can be modified and terminated

A non-statutory suggestion to increase confidence was suggested by a potential guardian, who recommended that SDMNY provide regular updates, particularly legal updates, to those involved with SDMNY:

> "No one has offered to provide regular updates. It's a pilot and there is a presumption that it gets done and then disappears. How am I going to know if law changes or progress made? No one said, "Would you like to sign up for our newsletter?"

This guardian reflects on the importance of formal recognition for decisions made by people with disabilities:

> "It has to be funded. It has to be supported financially. If the program is not funded or all voluntary, parents are not going to learn about it when kids are 15. It's still a program on social services model; we all have to take time off during the day. I am also supportive of a much broader change of social services, including mental health. I see in much larger terms. This is just one part of broader needs of people. We are very privileged to be able to do this (SDMNY). I have two younger brothers who are blind, so I've gotten to see how this works over a very long period of time, seen creativity and intelligence of those with disabilities, whether visible or not. It's a loss to society to not allow people to be themselves and make decisions."

Evaluation Findings: Confidence in SDM

- Most guardians involved with SDMNY have confidence in decision-makers' use of SDM.
- Most potential guardians expressed concerns regarding decision-makers' use of SDM. The nature of their concerns varies:
  - Lack of experience using SDM
  - Supporters treat decision-maker well
  - What happens after a family member is no longer around
  - Decisions respected by third parties
  - Lack of legislation underpinning SDMNY and SDM
- Legal recognition of SDM would increase guardian and potential guardian confidence in SDM viability—for example, that decision-makers' rights would be protected in the future, that third parties would accept decisions made using SDM, and that SDM will continue to support their family members with IDD even after parents and other family members pass away.

SDMNY Impact

Impact on Decision-Makers

Another significant area explored by this evaluation was whether the experience of learning about SDM, rights, and responsibilities, and whether moving through the SDMNY facilitation process, has had discernable impact on decision-makers. Other SDM evaluations in the U.S. and abroad have found positive impacts on individuals who adopt SDM as well as positive impacts on their relationships with supporters. Table 7, below, compares impact findings from four SDM pilot evaluations including this one.

Table 7. SDM Impact on Individuals Using SDM and Decision Supporters

SDM Pilots with Evaluation Information	Positive Impact on Individuals Using SDM	Positive Impact on Decision Supporters
Supported Decision-Making New York	Impacts reported by guardians and potential guardian family members of persons with IDD including autism engaged in SDMNY: • Increased happiness and happy to be making own decisions • Increased self-esteem and self-advocacy • Trying new things, experiences • Gaining skills • Increased confidence • Less anxious • Excited • Feels more mature, grown up	Some potential guardians reported no change; some noted it's too early in SDMNY process to determine. Potential guardians who reported change noted: • They stepped back and allowed decision-maker to make more decisions • Decision-maker increased voice and communication • Increased opportunities for important conversations • Reduced family member fears
CPR-Nonotuck Supported Decision-Making Pilot, Evaluation Report 2016	9 adults with IDD adopted and expressed satisfaction with SDM: • More engagement in decision-making • Ways supporters provided decision assistance • Preferences and decisions were respected across all decision areas (e.g., health, finances…) • 1 guardianship vacated; rights restored • Increased self-esteem and self-advocacy • Increased happiness	• Parents who had reluctantly adopted guardianship relinquished that role for a rights-affirming option. • For families that did not have guardianships, SDM offered reassurance for their decision not to petition for guardianship and increased feelings of security knowing decision supporters are committed in SDM agreements.

SDM Pilots with Evaluation Information	Positive Impact on Individuals Using SDM	Positive Impact on Decision Supporters
South Australia Office of the Public Advocate, Supported Decision-Making Project, Evaluation Report 2012	26 adopted SDM. Specific benefits to most of the participants including: • Increased confidence in themselves and in their decision-making skills • Growth in their support networks • Many reported that they felt more in control of their lives. • Evidence of increased engagement with the community, either through expanding their options or through making decisions that changed their circumstances	Supporters reported changes including: • Changes to the way they considered decision-making with the participants • Positive improvements in the nature and quality of their interpersonal relationships
Bulgarian Center for Not-for-Profit Law, Cost Benefit Analysis of SDM, Research 2014	36 persons adopted SDM for six months (16 with IDD, 20 with mental health). Measured changes in quality of life (QOL): • SDM contributes to increased QOL • SDM contributes to independent living • SDM contributes to inclusion and participation in community life • Increased social network and relations of mutual trust	Not reported. However, cost savings were evaluated. SDM reduced usage intensity of health care services, reduced intensity of psychiatric consultation and hospitalizations. Greater inclusion improved employment opportunities.

The level and amount of SDMNY impact or change is likely underreported in this evaluation because:

- the evaluation did not explore impact or change with decision-makers themselves; and
- at the time that guardians and potential guardians were interviewed, decision-makers were at various stages of the facilitation process, most without completed SDMAs, and thus not yet using SDM out in the world.

Guardian Opinion: Impact on the Decision-Maker

Even though most decision-makers are not yet at the stage where they have an executed SDMA and are using SDM out in the world, four of five guardians reported noticing positive changes. The other guardian stated they are too new to SDMNY to respond to this question. Changes were noticed even when, in one guardian's opinion, the decision-maker may not fully understand what supported decision-making is all about. Positive impacts include:

- Happier
- Greater self-esteem and pride
- Less anxious / learning to calm down
- Doing new things, gaining skills
- Happy to be making own decisions

Guardian reflections on the positive changes in decision-makers are presented below:

> "He may not understand what it is. Since his graduation, he keeps a copy of SDMA. Excited. Gave him structure and attention and bringing people into his life. He may be parroting back, but he is making choices. He's learning to calm himself down. He goes to self-advocacy meetings. He is getting support to make good decisions."

> "I think it's made him happier and less anxious. Sometimes he is tormented by my mother, as any decision could be overturned. And they listen to him and he feels he is being heard. Yeah, definitely seeing him do things I've never seen him do before. I've seen him grow."

> "He is happy about being able to make his own decisions. It has helped his self-esteem. He feels better about himself."

Potential Guardian Opinion: Impact on the Decision-Maker

Family members who are not guardians were split on whether they've noticed changes in the decision-maker since enrolling in the SDMNY Diversion pilot: 8 of the 15 potential guardians interviewed noticed a change (53%), 2 did not (13%), and 5 consider the experience too short-lived to ascertain change (33%). Where change was noted, the SDMNY experience is associated only with positive impacts on decision-makers, specifically:

- More mature / feels like an adult
- Greater confidence
- Excited
- Speaking up more / increased advocacy for self and others
- Sees a future and takes more ownership of goals
- Proud of self
- Reaching for more independence, for challenges, willing to take things on

Potential guardians who were unsure if they could discern any SDM-related change noted that it is either too soon in the process to tell, or the decision-maker is at a personal growth stage and developmental changes may or may not be influenced by the SDMNY process.

The following is a selection of statements from potential guardians who note SDMNY-associated positive changes:

> "Yeah, I think so. It's really good for him. Helping him see his future and take more ownership of his goals and his future."

> “I feel he has been more of an advocate for himself. There was a conversation with him, I can’t remember the specifics, and I said, ‘No, you can’t do that’ and he said, ‘No, I can. It’s my decision.’ He has thrown that out a few times. Kudos to you! He is more confident and has a say and is utilizing his say.”

> “Yes, I’ll give you an example. Two months ago, she got sick from a restaurant. Before, another time when she was sick, she went to an urgent care with her mom and because she’s in a wheelchair they turned her away! They didn’t let her in the door. This time when they went to hospital, when she got there she asked, ‘Are you trained in disability care?’ ‘Are your trained to help me?’ She had never done this before. Before, this young lady through her teens, she did not speak beyond ‘hi.’ We had to encourage her to find and use her voice. That’s why it’s so important she gives speeches about her story. She’s giving a speech to the Girl Scouts with disabilities on Long Island. She’s opened up tremendously. Even with her mom, she is telling her mom, ‘This is not what I want for my future. I want something different.’

Facilitator Opinion: SDMNY Impact on Decision-Makers

Facilitators surveyed for this evaluation reported that the SDMNY process positively impacted decision-makers. Facilitators either observed positive changes themselves or positive impacts were shared with them. Three of the four facilitators noted an increase in decision-maker self-empowerment as they gained experience and realized more control over their lives.

> “This has been and continues to be a rewarding experience for me as I see the decision-maker learning and gaining more and more confidence as he progresses through the phases of the process.” –Facilitator

Impact of SDMNY Experience on Facilitators

The SDMNY facilitation experience impacted facilitators as well as decision-makers. Surveyed facilitators have been in this role from 6 to 19 months. The average experience across the four respondents was just under one year (11.75 months). Regardless of the time they have been engaged in SDMNY, each facilitator reported that they also have been impacted by the SDMNY experience:

- SDM has changed the way they speak about people with IDD.
- They have stopped making assumptions about what people with IDD want and what their goals are.
- They are incorporating SDM into their professional work (occupational therapy and recreational programs).

Impact on Guardian and Potential Guardian Relationships with Decision-Makers

Guardian Opinion: Impact on Relationship with Family Member

Guardians held a range of opinions on whether their relationships with decision-makers had been impacted since engaging in SDMNY. Two guardians reported they did not yet have enough experience to note any changes. Another guardian said the relationship is unchanged; she and the decision-maker had a very close relationship before SDMNY and that continues. One guardian noted a change in the relationship with the decision-maker and stated it has brought them closer, strengthening the relationship. One guardian relayed that the relationship has not yet changed, but he anticipates change as he learns to step back. This guardian stated:

> "I look forward to relinquishing authority. Big transition here as I am the primary emotional support person and I'm ready for it to stop. I've a strong sense of responsibility but I'm ready to take a step back. He doesn't like it when I go away. But I don't want to get calls every morning and evening. Patterns are deep. Not due to SDMNY. If he successfully relies on others in SDM, if they took over to figure out activities to do, then I'll know that it has made a contribution."

Potential Guardian Opinion: Impact on Relationship with Family Member

Potential guardians also hold a range of opinions on whether their relationships with decision-makers had been impacted since engaging in SDMNY.

One-third (n=5/15) report no change in their relationships. Four potential guardians said it is too soon in the process to determine, that they are still figuring things out. And one family member mentioned their relationship already aligns with honoring the decision-maker's preferences and choices:

> "We already always consider his opinion. We ask him, 'What should we do right now?' We let him make a mistake every once in a while, to see for himself. He respects that."

Most potential guardians (n=10/15) have noticed changes in their relationship with the decision-maker, and all changes are welcome and exciting. Potential guardians are taking conscious steps back, allowing decision-makers to become agents of their lives. A few of these family member responses follow.

> "He is standing up for his choices with me. We are very attached to each other, but I am trying to take a step back so he can be the independent person he needs to be.

> I'm letting him be comfortable in that role and so when I'm not here and not able to help him, he will be fine."

> "Progress in that I'm taking steps back. I'm transitioning."

> "Definitely…it opened things up a bit for all of us, thinking about the future together. Why don't you ask someone else in addition to us? More moving forward which is good for him and for us."

> "Expands my knowledge. Reminder to me of his personhood and separateness, as that can get lost in the nitty gritty of coordinating, making sure he has what he needs. Doing it as his guardian would have been a different feeling. I wouldn't have been checking with him and he would not have been active in it. I would have been doing it to get it done."

> "She and I talk every day. It's been a huge difference. She never liked to talk, she used the computer, and now she has to talk, not text. "You have to talk," I tell her. It's amazing to hear her communicate the way she talks now. For her mom it's a bit of a shock, because she never talked like that before."

SDMNY staff who serve as mentors have noticed positive changes in the relationships between decision-makers and supporters and expressed delight in watching the decision-maker take more of an active role in decision-making and how supporters can step back to allow the decision-maker to find her/his voice.

Evaluation Findings: SDMNY Impacts

Impact on Decision-Makers

The SDMNY experience has positively impacted decision-makers, including those with and without guardianship orders. Positive impacts include:

- Increased happiness including happy to be making own decisions
- Increased self-esteem
- Increased self-advocacy
- Trying new things, experiences
- Gaining skills
- Increased confidence
- Less anxious
- Excited
- Feels more mature, grown up

Impact on Facilitators

- Facilitators who participated in this evaluation reported that the SDMNY training and experience changed their perspective and removed some stereotypes about people with IDD. These facilitators are incorporating SDM into their professional work activity.

Impact on Relationship with Family Member Guardian or Potential Guardian

- Where guardians and potential guardians noted changes in their relationship with the decision-maker due to SDMNY involvement, the changes have been positive. Family members are taking steps back and allowing decision-makers to have their own opinions and express them. Family members are engaging decision-makers in important conversations about their future.

Guardian and Potential Guardian Concerns for the Future

This evaluation asked potential guardians and guardians what they are most concerned or worried about for decision-makers' futures. The range of concerns was wide, and what mattered most to each group did not align in priority. However, concerns expressed by guardians and potential guardians are, for the most part, typical of concerns that parents have for their adult children in the general population.

Potential guardians are most concerned about decision-makers being employed, able to support themselves, being independent, having a voice, and able to manage once parents pass away. Guardians are most concerned that decision-makers are not taken advantage of, that decision-making skills are honed for making good decisions, and that affordable housing is available. Table 8 shows the concerns for the decision-maker's futures reported by guardians and potential guardians.

Table 8. Concerns for Decision-Maker's Future

Areas of Concern	Potential Guardians	Guardians
Work/ support self/ meaningful activity	7/15	--
When I am not here	4/15	1/5
Independence / strengthens voice	4/15	--
Have relationships / family	3/15	--
Manage money / be taken advantage of	3/15	3/5
Making decisions/ use supporters	2/15	3/5
Health / healthcare	2/15	--
Everything	2/15	--
Be happy	2/15	--
SDMNY function after pilot ends / monitoring	1/15	--
Housing, affordable	1/15	3/5
Staff to support	--	1/5

Has SDMNY Addressed Concerns That Led, or Could Have Led, to Guardianship?

This evaluation explored whether the SDMNY process reduces or alleviates concerns that lead family members to consider or to become a guardian. On this matter guardians and potential guardians reported different experiences. Potential guardians note their concerns or worries have been reduced due to SDMNY involvement, whereas guardians report that concerns or worries that led them to become a guardian remain.

Potential Guardians: Has SDMNY Reduced Concerns That May Have Led to Guardianship?

Nearly all potential guardians (n=12/15, 80%) interviewed reported that their concerns for the future were lessened due to engaging in SDMNY, though one potential guardian noted, *"Guardianship wasn't going to solve it either."* Another potential guardian, new to SDMNY, stated it was too early to tell. Below are comments from potential guardians who expressed a reduction in fears or concerns due to SDMNY involvement.

> "Yes, it's helpful in life. There are not many options, but with the right training he can go through life. I feel everybody needs guidance and help, a boost, a little coaching in life."

> "Yes, she is going to know who her supports are, and it will be laid out. Could prevent some other problems."

> "I think it's a great program, but it's a process. It took almost two years to complete the program. You want to make sure you have the right people. You have to have frequent meetings and it's hard to get everyone together at the same time. Help people understand that. But it's a program that is necessary especially if parents are over 50, well, 50 is probably too late. If you don't put this into place your child may be placed under guardianship or payee and you won't have choice. And now you have choice. It's horrible for someone to make decisions for you because you're disabled; it's a horrible feeling. Everybody has rights and wants to be involved in decisions about their life. Best thing you can do for a person."

> "Yes it has. I'm less fearful. If we were not in the pilot program, she would not have had opportunities to have conversations with people other than me, to explore her feelings with someone who is not a family member. These conversations aren't held with anyone else, no one in school, not with her pediatrician, but only with parents. So bringing in facilitators, it's a good experience. She has had to explore with 3 facilitators. One day when I'm not around she will feel more comfortable talking about her feelings. I would not have ever thought she needed these kinds of conversations, but it's about how she needs to advocate for herself if I'm not around."

> "It has reduced stress that he has a legal document that says I can and will make my own decisions versus if SDM wasn't there, I was just going to say God be with him."

Guardians: Has SDMNY Reduced Concerns That Led to Guardianship?

All five guardians stated their concerns remain and had not been diminished, as yet, by SDMNY involvement. One guardian is hopeful that with more experience, concerns will reduce: "Too early to tell. I hope so, I really don't know if it will or not. I hope it will have some effect." Comments from other guardians follow.

> "I still worry about his decision-making."

> "The two things that were core were access to health care and financial decision-making, and this doesn't really address them. I still manage his staff. I manage his finances. He has gotten more assertive with medical care because he likes doctors. He will take himself to the doctor now. But SDM has not contributed to day-to-day structure of his life."

Evaluation Finding: Has SDMNY Reduced Concerns Leading to, or That Led to, Guardianship

- Most potential guardians report that SDMNY engagement has reduced concerns that may have led to guardianship petitions. For guardians, SDMNY involvement has not yet reduced concerns that led them to petition for guardianship.

For Consideration - It may be useful to ask guardians again, after decision-makers have signed SDMAs in place and have been making decisions with supporter assistance for a period of time, whether SDM has reduced concerns that led to guardianship.

Restoration of Rights

One of the goals for SDMNY is to restore the decision-making rights of 45 individuals through adoption of SDMNY and discharge of guardianships. Given that guardians report they have no concerns about decision-makers' use of SDM, nor concerns about third-parties honoring decisions made using SDMNY, it would seem that guardians would have indicated greater interest in restoring decision-making rights to their adult family members. However, this does not yet seem to be the trajectory. It may be that the lack of statutory grounding for SDM means holding onto a firm legal standing for involvement in medical and financial matters.

One of the five guardians participating in the evaluation is not planning to relinquish guardianship or request to limit the guardianship to cover fewer decision domains. As this guardian stated:

> "We are not going back on his guardianship. It was suggested indirectly that we do so. It has been implied that guardianship was not a good thing to do. I'm concerned that attitude comes from people who don't have children with disabilities. When we got the diagnosis, I started thinking about the life span, because I've seen it. I've seen resiliency, and the stress, and the social isolation. It's why I'm an advocate for people to be as full a human being as they possibly can."

Two guardians are undecided at this stage and need additional time, experience, and information.

> "My main concern is protecting [name]. I don't know the benefits of one over the other. I need to talk to someone familiar with both procedures. My concern is that [name] have as much control over his life as possible while protecting him and making sure he's safe. How to balance that out. Which would lend itself to balancing his control and making sure he's safe."

This guardian also shared some of the difficulty of a decision to relinquish guardianship given her son's non-verbal communication and history of being mistreated:

> "Unsure at this point. It's a very tough role to be in as a parent. I have to balance his independence and his own wishes against protecting him. Especially because of the language. Because he can't tell someone and know he will be understood, and his feelings respected. Very often he's mistreated because of communication, because if he's frustrated and has no way to express it and if a person doesn't take time to figure out why he may act in way to express frustration. But his actions get judged by themselves, often out of context, or as behavior that is inappropriate or unacceptable. It is not seen as communication but as a defect in ability to control himself. The management of him gets addressed, not what he wants. That makes him feel that he's a bad person. Decisions made that are not always in his best interests. Staff are interested in making their work easier, and people aren't machines, they can't be looked at as behavior. You have to be willing to put yourself in his shoes, to wake up and not be able to communicate. Be sensitive to the frustration. This is an everyday experience for [name]. I think he handles it heroically. I can't imagine what that must be like, the frustration that would entail. If people looked it at it that way instead of how difficult the person is making the situation, it would be a huge change. When children are young, we are tolerant, but

> as they age, we are less tolerant, we put medication on them, put them in hospital. It’s a huge problem.”

The other two guardians participating in the evaluation plan to petition the court to end guardianship. One of these guardians wants others to know how important it is for people to make decisions about their lives and for their decisions to stand and not be overturned by a guardian:

> “I think the world should know what a great person my brother is. Every person who meets him loves him and says what a great person he is. Everybody who is like him should have their own rights. He should be able to speak for himself and his mother should not negate what he wants; it’s really unfair. We talk every day. Everyone who meets him says what an amazing person he is.”

Evaluation Findings: Restoration of Legal Rights

- Two of five guardians stated an intention to petition the court to terminate the guardianship and restore legal rights to the decision-maker.
- One guardian does not plan to terminate guardianship, but by participating in SDMNY, has noted positive impacts on the decision-maker’s self-esteem, mood, and personal growth.
- Two guardians are open to considering termination and need additional time, SDM experience, and information.

Recommendations for Sustaining SDM into the Future

SDMNY provides a model and process for empowering people with IDD to have a voice and make decisions about their lives with trusted supporters of their choosing. SDM can be utilized with or without additional legally recognized decision-making instruments such as Durable Powers of Attorney, Health Care Proxies, and Representative Payees for Social Security and SSI benefits.

This evaluation provides stories and opinion on how SDM can be utilized as an alternative to guardianship for people with IDD in New York State. Below are additional recommendations for sustaining SDM. These recommendations are based on evaluation conversations with family member guardians and potential guardians and surveys of facilitators and staff.

Recommendation 1: Include people with IDD throughout all stages of pilot and evaluation, not as touch points, but as full partners

When asked what they would change if they knew at the outset of the pilot what they know now, pilot staff mentioned engaging people with IDD throughout as full partners—from the establishment of the pilot to research, training, recruitment, and on through planning expansion and system change strategies.

> "Through this project I have become more acutely aware of the ethical dimensions of a project with clear objectives of systemic change built into the project's 5-year work plan and grant agreement with the donor that at best is inclusive of persons with IDD but not necessarily tasked with developing a policy or systems-change agenda that is directed primarily by them." –SDMNY staff

Opportunities to more broadly include people with IDD in SDMNY include roles such as:

- Paid staff involved in planning, implementation and research
- Peer facilitators (Initial exploration could pair a self-advocate with an experienced facilitator)
- Paid presenters in facilitator trainings
- Paid presenters for all information sessions

Recommendation 2: Develop and maintain SDMA-engaged user groups

When initially designed, SDMNY staff planned for facilitators to check in once a month by phone with SDMA users they had assisted; however, given the commitment period for volunteer facilitators (through the signing of an SDMA) and the fact that these check-ins would not have provided decision-makers or supporters with an opportunity to share their experience with others and learn from one another, this expectation was not operationalized. Instead, SDMNY staff began hosting monthly SDMA user group meetings. Thus far, user group sessions have been offered only to decision-makers. In these meetings, staff have reviewed the contents of the SDMA, and discussed how decision-makers have, or could, use their SDMAs in conversations with their supporters.

> “At the project’s outset, it was anticipated that facilitators will check in once a month by phone with SDMA users whom they have assisted; however, I believe that a more robust, ongoing forum for communication, troubleshooting, and experience-sharing will be necessary for SDMA users to engage meaningfully with these tools in the future.” –SDMNY staff

Providing an ongoing, regular opportunity to communicate, problem solve and offer mutual support, as well as to gain information about SDMNY experience, is valuable. Access to user groups should be offered to decision-makers as well as supporters.

Recommendation 3: Reform New York guardianship law

This evaluation provides evidence on the lack of accurate information provided to family members about guardianship and a lack of knowledge about less restrictive alternatives to guardianship that guide people to guardianship.

The school-to-guardian pipeline is operating in New York. Schools, attorneys, health care professionals, and other parents with children with IDD exert persuasive influence toward guardianship.

It is a profound finding that 60% of guardians (at the time they filed for guardianship) and 62% of potential guardians did not realize that guardianship removes a person’s rights. These guardians and potential guardians want their family members with IDD to gain independent living skills and live meaningful lives connected to their communities.

With the advent of model law developed by the UGCOPAA, New York has a thoughtful template for revisions that reflects current standards of practice and human rights progress. Reform to New York guardianship law should require examination of the individual’s life experience in decision-making, available and potentially available assistance and support for decision assistance, and an assessment of informal or other formal supports available in the person's community. Guardianships, in order to meet the last resort expectation, should not be imposed unless SDM and other less restrictive protective arrangements have been tried and found unsuitable.

Recommendation 4: Pass legislation recognizing SDMAs created through a planned and evaluated facilitation process, such as SDMNY

The SDMNY initiative aims to deliver evidence to support legislation, regulations, and policies to ensure supported decision-making is a readily available alternative to guardianship in the future. This evaluation contributes the opinion and experience of pilot staff, facilitators, guardians and potential guardians toward that goal. Legislation is necessary to ensure that people with IDD have the right to make their own decisions with support of their choosing, to have those decisions recognized and honored by third parties, and to relieve third parties of liability for good faith reliance on the SDMA decision process.

Guardians and potential guardians interviewed for this evaluation clearly conveyed that legislation would increase their confidence that decisions would be honored and decision-makers would retain rights. Statutory recognition for SDMNY and SDM agreements would legitimize SDM as a viable alternative to guardianship and significantly increase interest and participation in SDMNY.

For SDM sustainability, identify a responsible entity to check on how SDMAs are functioning for decision-makers and supporters, and a responsible entity to assist decision-makers with SDMA changes after grant funding ends.

Another independent evaluation of SDMNY is underway. For SDMNY Years 4 and 5, the New York State Developmental Disabilities Planning Council (DDPC) contracted with the Burton Blatt Institute to conduct an evaluation examining SDMNY operations and outcomes in greater depth; that evaluation will likely add to the evidence base for SDM legal standing in New York.

Recommendation 5: Share the News – SDMNY Works!

As demonstrated in similar pilot programs of SDM, SDMNY participation has positive impacts on a person with IDD and the person's relationships with family members. Positive impacts reported for people with IDD participating at this early stage of SDMNY engagement included increased self-advocacy, greater self-confidence, a wider array of experiences and trying new things, reduced anxiety, and greater happiness. Family members report taking steps back and allowing decision-makers to have their own opinions and express them and are also engaging decision-makers in important conversations about their future.

The SDMNY training and experience also impacts the thinking and actions of facilitators. Facilitators have gained greater awareness of the capabilities of people with IDD and have stopped making assumptions or imposing goals.

The work of SDMNY has impacted SDMNY staff as well. The following are staff reflections on how the SDMNY experience thus far has impacted their thinking and belief in SDM as vehicle for desired social change:

> “I think the most impactful change will be societal, consistent with an expressive theory of behavioral change. If SDM can provide decision-makers, supporters, and their allies the vocabulary for voicing their demand for greater respect for their decision-making processes, even if these differ in appearance or substance from those of the general population, then society at large will more readily perceive and be willing to remove the barriers to persons’ with IDD decision-making that arise too frequently in the interactions in informal, everyday settings. If SDM can thematize and visibilize these barriers, then the people in their lives will become more sensitized to whether their conduct either abets or obstructs persons’ with IDD autonomous decision-making. Because SDM assigns a positive value to promoting decision-making autonomy, it can make it easier to make society at large aware of decision-making barriers and to galvanize support for norm changes that eradicate these barriers in service of maximizing autonomy.”

> “It really works! It takes time, and is a thoughtful, well-tested process with integrity, not just having someone sign a piece of paper.”

> “This is not just signing a piece of paper. It's about a real transformation, that we have now seen over and over, in which people with IDD become real agents of their own lives.”

Previous evaluations of other pilots have been shared with project funders, advisory councils, evaluation participants, state policy makers, posted to SDM pilot websites, and made widely available through the National Resource Center on Supported Decision-Making.

Attachments

A. Evaluation Background, Methods & Approach

Institutional Review Board (IRB) review is a safeguard process to ensure research that involves human subjects does not subject people to harmful research practices. IRB review critiques the researcher's protocols and procedures for ensuring that research participants understand the nature of the research, that risks and benefits are transparent, and that consent is informed.

An IRB package was prepared and submitted to the Hunter/CUNY IRB in September 2018. The IRB package contained background information on SDM internationally and nationally, information about the grant award and the funder's requirement for an independent evaluation, evaluation research questions, evaluation protocols, consent procedures, interview instruments, and data security. For this evaluation research, involving only "non-vulnerable" adults, risks of harm for participating in this evaluation were anticipated to be minimal, if any. Benefits were adding to the knowledge base of SDM in practice. Participation was voluntary with evaluation respondents free to withdraw at any time and to skip any questions they did not want to answer.

IRB authorization to proceed with the evaluation was secured in late December 2018. Due to the shortened timeframe and the requirement that evaluation funds be expended by March 31, 2019, a modification to the evaluation plan was requested to combine the proposed two phone interviews into one. Consolidated interview instruments and revised consent forms and protocols were submitted to the IRB with a request for expedited review. IRB authorization for a combined interview protocol arrived in late January 2019. Data collection began February 1st. (See Attachment B for the combined set of Potential Guardian interview questions. See Attachment C for Guardian and Former Guardian combined interview questions.)

SDMNY Recommendation: Institutional Review Board (IRB)

SDMNY staff recommend that when an independent evaluation is a part of a project, plan for the IRB process from the project start. Include time for preparation of the IRB package and several months for IRB review and approval.

Guardian and Potential Guardian Interview Data Collection

Participating in this evaluation was voluntary and open to all family members with an SDMNY-enrolled decision-maker between December 2018 and May 2019.

After the evaluation plan was reviewed and approved by the Hunter/CUNY IRB, the next step was for SDMNY staff to reach out to involved guardians and potential guardians and offer the opportunity to participate in this research. Staff explained the purpose for an evaluation, that participation was voluntary, and there would be no advantage or disadvantage to participating in the evaluation. For family members interested in learning more about the evaluation, including any risks and benefits, the Senior Project Coordinator shared their preferred contact information with the evaluator. The evaluator contacted guardians and potential guardians and discussed the purpose of the evaluation, time commitment, and risks and benefits. For those who consented to participate, a phone interview was scheduled for a time and date convenient for that guardian or potential guardian.

Staff projected 30 SDMNY-involved potential guardians and guardians would participate in this evaluation. Although the evaluation was extended several times to include as many respondents as possible, 24 guardians and potential guardians gave permission to the Senior Project Coordinator to be contacted by the evaluator to discuss participation in the evaluation. Of the 24 potential evaluation respondents:

- 20 consented to and participated in telephone interviews
- 1 declined to participate
- 3 did not respond to evaluator outreach

Telephone interviews were scheduled for the convenience of respondents. For three interviews, a husband and wife jointly spoke with the evaluator. These interviews were counted as one interview with an exception. When collecting personal characteristic information (such as age, race, etc.), the demographic information was requested for both the husband and wife and is reported in this evaluation. For all other evaluation information, responses of a husband and wife are combined and reported as a single respondent as per their request.

Staff and Facilitator Data Collection

Online surveys were conducted to collect key SDMNY staff reflections (from the Project Director, Senior Project Coordinator, NYC Site Coordinator, and Faculty Associate) and reflections from facilitators. Questions for staff covered the development of the SDMNY model, outreach and recruitment, challenges and strategies, and thoughts for sustaining SDMNY initiatives after grant funding ends. (See Attachment D for the SDMNY Key Staff Online Survey.) Given that the role of facilitator is a volunteer position, the facilitator survey was very short and focused on facilitator impressions regarding training and perceived impacts of SDMNY. (See Attachment E for the Facilitator Online Survey.)

B. Potential Guardian (Diversion Pilot) Evaluation Interview Questions

What is your relationship to [individual's name], the "Decision-maker"? ___________________

(If not parent or sibling) Length of time you have known [individual's name]: _______________

An important question this research seeks to answer is what concerns or advice influence people to consider guardianship of adults with intellectual and/or developmental disabilities (I/DD). The following questions ask if you have considered guardianship, and why.

1. Did you ever consider guardianship for [individual's name]?
   a. [If no] Why didn't you consider guardianship? (Skip to question 2)
   b. [If yes] What concerns or advice led you to consider guardianship, or to become a guardian?
   c. [If yes] How did you think guardianship would have addressed those concerns?
2. At the time you learned about guardianship (or were advised to become a guardian), were you also advised of other decision-making assistance options?
   a. Representative (or "rep") payee? Yes/No (If yes, please explain)
   b. Power of attorney? Yes/No (If yes, please explain)
   c. Health care proxy? Yes/No (If yes, please explain)
   d. Person-centered planning? Yes/No (If yes, please explain)
   e. Supported decision-making? Yes/No (If yes, please explain)

3. What were or have been your primary source(s) of information about guardianship?
4. Did you know that guardianship removes an individual's legal rights?
5. Have you had any experiences with health care providers that led you to believe guardianship would have been necessary to provide health care services to [individual's name]? If yes, please describe.
6. Have you had any experiences with schools or teachers that led you to believe guardianship would have been necessary for the school or teachers to provide educational services to [individual's name]? If yes, please describe.
7. Have you had any experiences with disability service providers that led you to believe disability service (such as Medicaid-funded services) delivery required a guardian? If yes, please describe.
8. Have you had any experiences with banks or financial institutions that led you to believe guardianship was necessary to provide financial services to [individual's name]? If yes, please describe.
9. Have you had any experiences with other parents or family members that led you to believe guardianship was necessary for [individual's name]? If yes, please describe.

10. Guardianship is a legal process that has some financial costs; for example, many petitioners choose to hire an attorney. Did costs influence your decision not to pursue guardianship?

This research also wants to learn why people decided to try out Supported Decision-Making New York (SDMNY). The next few questions ask how you learned about SDMNY and what influenced you to get involved.

11. How did you first learn about SDMNY and what information did you receive?
12. What led you to become involved in SDMNY, if at all?
13. When you first learned about SDMNY, how did you think it would work for [individual's name]?
14. What are your biggest concerns for [individual's name] future? What are you most worried about?

This research is interested in whether Supported Decision-Making New York (SDMNY) appears to have made a difference on Decision-makers.

15. From your perspective, how has participating in SDMNY affected or changed [individual's name], the "Decision-Maker"?
16. Some people have reported that using supported decision-making fosters changes, such as in their self-esteem and self-confidence. What changes, if any, have you noticed or been made aware of in [individual's name] since participating in the SDMNY process?
17. What change, if any, have you noticed in your relationship to [individual's name] since participating in SDMNY?
18. What change, if any, have you observed or been made aware of in how *others* engage with [individual's name] since participating in SDMNY?

This research wants to learn whether the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced concerns that could have led to guardianship.

19. In your opinion, has the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced any concerns or fears that led you to become a guardian? If yes, please explain.
20. Do you have any concerns about [individual's name] using supported decision-making now or in the future?

21. Do you have concerns about other people honoring the Supported Decision-Making Agreement (SDMA) that [individual's name] developed through the SDMNY process?

22. Would you be in favor of formal recognition of supported decision-making (such as in a law or government policy) if formal recognition required others (doctors, schools, lawyers, service providers, etc.) to honor Decision-Makers' SDMAs?

23. Would formal recognition of supported decision-making (such as in a law or government policy) affect your confidence in [individual's name]'s use of supported decision-making in the future, including after when you pass away? If either yes or no, please explain.

Did we miss asking you about something important to you?

24. Is there anything else that I should have asked you, or that you want to tell me about your experience in the SDMNY project?

Thank you! The next few questions are personal such as your age and race. Just as the other questions I've asked you today, these additional questions are voluntary. It is up to you whether to answer or not. You can decline to answer any single question, or all of them. If you do answer it will help us determine if any shared demographic influences may be relevant. Shall I start these questions?

25. What is your age?
26. Please identify one or more race: White, Black or African American, Asian, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, Other_____
27. What is your ethnicity? Hispanic or Latino, Not Hispanic or Latino
28. What is your primary language?
29. What is your legal status in relation to Decision-maker? parent, sibling, other relative, guardian, trustee, etc.
30. Who lives in your home with you?

- Decision-maker [individual's name]?
- Spouse or Partner?
- Children other than the Decision-maker [individual's name]?

31. Do you work outside the home?

Thank you for sharing your opinion and experience for this research! Your answers will help people in New York and other states learn about supported decision making and how best to use it.

C. Guardian and Former Guardian (Restoration Pilot) Evaluation Interview Questions

Length of time as guardian for [individual’s name], the “Decision-maker”:_________________

Personal connection, if any, to [individual’s name]: ____________________________________

(If not parent or sibling) Length of time known [individual’s name]: _______________________

Were you the original guardianship Petitioner for [individual’s name]? ___________________

An important question this research seeks to answer is what concerns or advice influenced people to become guardians of adults with intellectual and/or developmental disabilities (I/DD). The following questions ask about your experience.

1. What concerns or advice led you to become a guardian for [individual’s name]?
2. At the time, were you aware that guardianship removed all of [individual’s name]’s legal rights?
3. At the time you learned about guardianship (or were advised to become a guardian), were you also advised of other decision-making assistance options?
    a. Representative (or “rep”) payee? Yes/No (If yes, please explain)
    b. Power of attorney? Yes/No (If yes, please explain)
    c. Health care proxy? Yes/No (If yes, please explain)
    d. Person-centered planning? Yes/No (If yes, please explain)
    e. Supported decision-making? Yes/No (If yes, please explain)

This research also wants to learn why people decided to try out Supported Decision-Making New York (SDMNY). The next few questions ask how you learned about SDMNY and what influenced you to try it out.

4. How did you first learn about SDMNY and what information did you receive?
5. What led you to become involved in SDMNY, if at all?
6. When you first learned about SDMNY, how did you think it would work for [individual’s name]?
7. What are your biggest concerns for [individual’s name] future? What are you most worried about?

This research is interested in whether Supported Decision-Making New York (SDMNY) appears to have made a difference, an impact, on Decision-makers.

8. From your perspective, how has participating in SDMNY affected or changed [individual's name], the "Decision-Maker"?
9. Some people have reported that using supported decision-making fosters changes, such as in their self-esteem and self-confidence. What changes, if any, have you noticed or been made aware of in [individual's name] since participating in the SDMNY process?
10. What change, if any, have you noticed in your relationship to the Decision-Maker [individual's name] since participating in SDMNY?
11. What change, if any, have you observed or been made aware of in how *others* engage with [individual's name] since participating in SDMNY?

This research wants to learn whether the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced concerns that had previously led to guardianship.

12. In your opinion, has the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced any concerns or fears that led you to become a guardian? If yes, please explain.
13. Do you have any concerns about [individual's name] using supported decision-making now or in the future?
14. Do you have concerns about other people honoring the Supported Decision-Making Agreement (SDMA) that [individual's name] developed through the SDMNY process?
15. Would you be in favor of formal recognition of supported decision-making (such as in a law or government policy) if formal recognition required others (doctors, schools, lawyers, service providers, etc.) to honor Decision-Makers' SDMAs?
16. Would formal recognition of supported decision-making (such as in a law or government policy) affect your confidence in [individual's name]'s use of supported decision-making in the future, including after when you pass away? If either yes or no, please explain.
17. What are your thoughts about ending guardianship now that [individual's name] is involved in SDMNY?
18. Are you more likely to consent to end the guardianship or limit the guardianship so that it affects fewer types of decisions?

Did we miss asking you about something important to you?

19. Is there anything else I should have asked you, or that you want to tell me, about your experience in the SDMNY project?

Thank you! The next few questions are personal and, as with earlier questions, completely voluntary to answer – up to you whether to answer or not. You can decline to answer any or all of them. If you choose to answer, it will help us determine if any shared demographic influences are relevant. Shall I start these questions?

20. What is your age?
21. Please identify one or more race: White, Black or African American, Asian, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, Other_____
22. What is your ethnicity: Hispanic or Latino, Not Hispanic or Latino
23. What is your primary language?
24. What is your legal status in relation to Decision-maker: parent, sibling, other relative, guardian, trustee, etc.
25. Who lives in your home with you?
    a. Decision-maker [individual's name]
    b. Spouse or Partner
    c. Children other than the Decision-maker [individual's name]?
26. Do you work outside the home?

Thank you for sharing your opinions and experience for this research! Your answers will help people in New York and other states learn about supported decision making and how best to use it.

D. SDMNY Key Pilot Staff Online Survey

SDMNY Model Development and Advisory Council

1. What is your role in SDMNY? What are you responsible for in this role?
2. How was the SDMNY pilot program model developed? Include influences and modifications from other SDM models.
3. Describe what is unique about the New York SDM model. Describe how this model extends the development of SDM in new ways in the U.S.
4. What SDMNY design elements do you view as most essential to the future success of supported decision-making use by Decision-Makers in NY?
5. How was the Advisory Council constituted and what is its role?
6. What significant contributions, if any, has the Advisory Council or its members made to date?
7. What changes, if any, might enhance the Advisory Council's impact?
8. How might you make better use of Advisory Council expertise?

Facilitators and Mentors

9. Describe the role and function of facilitators.
10. What qualifications (such as degree, language fluency, experience with individuals with I/DD, knowledge of developmental disabilities system, etc.) are required to be a facilitator?
11. What characteristics or traits do you note in the most effective facilitators?
12. What were the original strategies for recruiting facilitators? If there have been any changes to recruitment strategies, describe the change and what led to making a change.
13. How was the training of facilitators developed?
14. Over the course of this pilot, have there been any changes to the facilitator training? If so, describe significant changes and what led to making a change.
15. What issues, if any, have arisen with facilitators, and how have issues been addressed?
16. What is the role of mentors?
17. What are the required qualifications for mentors, if any?
18. What are the most important characteristics of a good mentor?
19. How has the role of mentors changed over the duration of the pilot, if at all?

20. How are mentors recruited and trained?
21. Considering the long-term sustainability of Decision Makers' use of supported decision-making in NY, what do you think is important for recruitment and training of facilitators and mentors?

SDMNY Outreach and Recruitment of Individuals with I/DD

22. What were the original strategies for outreach and recruitment to individuals with I/DD, parents and guardians? If strategies changed over the course of the pilot, please describe the change and what led to the change.
23. What have been the most successful outreach and recruitment activities?
24. What have been the main barrier(s) to outreach and recruitment activity and how have any barriers been addressed?
25. What do you think are the most important lessons learned related to recruitment of individuals with I/DD?

Supported Decision Making Agreements (SDMA)

26. What is the SDMA, and how is it created? Please include in your description the various considerations and stakeholders involved.
27. How long does it generally take for a Decision-Maker to complete an SDMA? Please include number of meetings, frequency of meetings, and over what period of time.
28. Have there been any changes to the SDMA since the pilot was launched? If yes, please describe those changes and what prompted them.
29. How do Decision Makers make changes to SDMAs (to their decision supporter OR to areas for decision assistance)?
30. What is the role of SDMNY after an SDMA is signed? What do you expect for those with executed SDMAs using supported decision-making into the future?

Safeguards

31. How do you address the concerns of parents and others about protection, including protection from abuse, neglect or exploitation?
32. What safeguards for Decision Makers and Supporters are built into the SDMNY pilot process and the SDMA, if any?
33. What mechanisms, if any, are there for concerns or complaints that an SDMA is being misused, or for disputes among or between Supporters and/or the Decision-Maker?

Lessons Learned and Next Steps

34. What would you do differently if you knew at the pilot onset what you know now?
35. What is your estimated percentage of time in FTEs per month allocated to:
    a. Project management including project coordination with project partners and reporting to funder
    b. Education and outreach activities
    c. Recruitment and support to facilitators
36. What, in your opinion, have been the biggest surprises over the course of this pilot?
37. How do you imagine the pilot expanding and continuing after the grant is over?
38. What changes (legal, societal, regulatory, etc.) do you see as necessary to advance supported decision-making as a viable alternative to guardianship?
39. What are key lessons learned from this SDM demonstration pilot important to share with interested stakeholders and the public?

Please use this space for anything else you would like to note for the evaluation.

E. SDMNY Facilitator Online Survey

1. Please note your name and organization.
2. What drew you to SDMNY and to become a facilitator?
3. How long have you been a facilitator?
4. How did the Facilitator training affect your understanding of supported decision-making, and/or your commitment to the SDMNY process?
5. Now that you have experience as a facilitator, what changes if any would enhance the training?
6. What differences, if any, have you observed or heard, about the impact of using facilitated supported decision-making with individuals with I/DD?
7. In what way are you employing or adapting supported decision-making to your own work environment, and what is that environment?
8. Is there anything else you would like to share about your experience as an SDMNY facilitator?

F. Endnotes and References

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[13] Bifocal, Vol. 38, Issue 6. *ABA Urges Supported Decision Making as Less-Restrictive Alternative to Guardianship.* October 2017. Located online: https://www.americanbar.org/groups/law_aging/publications/bifocal/vol_38/issue-6--august-2017-/aba-urges-supported-decision-making-as-less-restrictive-alternat/

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People with Disability in the ACT, ACT Disability, Aged and Carer Advocacy Service, September 2013, p. 7. Located online: http://www.adacas.org.au/media/1083/spectrums-of-support-final-20130911.pdf

[22] SDMNY Planning Group members: Project Director (Kristin Glen), Hunter College faculty (Michelle Ballan, John Brown, Gina Riley and Michael Siller); NYSACRA, now the New York Alliance for Inclusion and Innovation (Ann Hardiman and then Desiree Loucks Baer); and the Arc Westchester (Larry Faulkner).

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[24] Cher Nicholson, Founder and Lead Trainer, The Practical Facilitation S.D.M. Training. Train the trainer model. Contact information: +61-409-302-687, cher.nicholson@bigpond.com, ASSET SA, Adelaide, South Australia

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[26] Pell, E., and Mulkern, V., Supported Decision Making Pilot: Pilot Program Evaluation Year 2 Report, p. 19. Located online: https://www.hsri.org/files/uploads/publications/SDM_Pilot_Evaluation_Year_2_Report_HSRI_2016_FINAL.pdf

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Errata

Page	Original Text	Corrected Text	Explanation
iv	During the third year of the grant, Hunter/CUNY subcontracted with an independent consultant to conduct the one-year focused process evaluation reported here, related to SDMNY Restoration and Diversion pilot activity.	During the third year of the grant, Hunter/CUNY subcontracted with an independent consultant to conduct the one-year focused process evaluation reported here, related to SDMNY Restoration and Diversion pilot activity **at SDMNY's New York City pilot program site**.	The scope of this evaluation was limited to SDMNY's New York City pilot program site and did not include SDMNY's four additional pilot program sites.
1	The United States, North Korea, and Sudan are among those countries that have yet to do so.	The United States, **Botswana**, **Eritrea**, and **South** Sudan are among those countries that have yet to do so.	Sudan ratified on April 24, 2009, and the Democratic People's Republic of Korea ratified on December 6, 2016. By contrast, neither Botswana, Eritrea, nor South Sudan has done so.
1	The UNCRPD has made it to the Senate floor, but the majority vote has yet to be achieved.	The UNCRPD **ratification package** has made it to the Senate floor, but the **super**majority vote has yet to be achieved.	The U.S. Senate votes on the ratification instrument, not the treaty itself, and requires a supermajority for passage.
10	SDMA Facilitators and Mentors	SDM**NY** Facilitators and Mentors	The heading refers to facilitators and mentors participating in the SDMNY pilot programs.
23	Completing an SDMA using the SDMNY facilitation process typically takes twice as long or longer than expected, from a year up to 18 months.	Completing an SDMA using the SDMNY facilitation process typically takes twice as long ~~or longer~~ than **originally** expected, from a year up to 18 months.	Since expectations at project outset were for a 6-to-9-month process, 12 to 18 months represents exactly double that duration.
28	Adding video simulations, one for each of the three facilitation phases, in collaboration with Outside Voices, a theater group of people with IDD	Adding video simulations, one for each of the three facilitation phases, in collaboration with Outside Voices **Theater Company**, a theater group of people with IDD	Group's name corrected.
29	When facilitators have not been able to continue the	When facilitators have not been able to continue the	The Site Coordinator, not the mentor, is responsible

	SDMNY process to its completion (e.g., through the signing ceremony), either the assigned mentor or Site Coordinator has stepped in, or the mentor secured another facilitator.	SDMNY process to its completion (e.g., through the signing ceremony), either the assigned mentor or Site Coordinator has stepped in, or the ~~mentor~~ **Site Coordinator** secured another facilitator.	for facilitator assignments and reassignments.
30	SDMNY staff initiated SDMA user focus groups facilitated by mentors.	~~SDMNY staff initiated SDMA user focus groups facilitated by mentors.~~	The focus groups are not facilitated by mentors.
30	Mentor qualifications are twofold: first, completion of the SDMNY facilitator training, and second, successful facilitation experience with at least one decision-maker through the creation of an SDMA.	Mentor qualifications are twofold: first, completion of the SDMNY facilitator training, and second, successful facilitation experience with at least one decision-maker ~~through the creation of an SDMA~~.	SDMNY requires that the mentor be further along in the facilitation process than the mentee.
31	Developing a training and resource manual for mentors is planned for Year 4.	Developing a ~~training and~~ resource manual for mentors is planned for Year 4.	SDMNY does not have plans to develop a training for mentors.
53	In New York State having a guardian means a person with IDD loses all legal capacity to make decisions about their life, including decisions about their health and health care, their finances, what kind of education, who to associate with, where to live, who to live with, and where to work.	In New York State having a **17A** guardian means a person with IDD ~~loses all~~ **may lose** legal capacity to make decisions about their life, including decisions about their health and health care, their finances, what kind of education, who to associate with, where to live, who to live with, and where to work.	The original statement neglects to account for the difference between 17A guardianships of only the property or only the person, each of which affects a narrower scope of decision-making areas.
56	Prior to the SDMNY initiative, supported decision-making did not exist in New York State, though a number of alternatives to guardianship have been available, such as representative payees for SSI payments, joint or limited bank accounts, credit or bank cards with	Prior to the SDMNY initiative, supported decision-making **agreements were not used** ~~did not exist~~ in New York State, though a number of alternatives to guardianship have been available, such as representative payees for SSI payments, joint or limited bank accounts,	Supported decision-making, at least informally, has always existed, even if it has not been known by that name. SDMNY introduced SDMAs to New York State, as well as a specific process for developing them.

	predetermined limits, powers of attorney for financial decisions—and for health care decisions, people with IDD may execute a healthcare proxy.	credit or bank cards with predetermined limits, powers of attorney for financial decisions—and for health care decisions, people with IDD may execute a health care proxy.	
76	One of the goals for SDMNY is to restore the decision-making rights of 45 individuals through adoption of SDMNY and discharge of guardianships.	One of the goals for SDMNY is to **assist** ~~restore the decision-making rights of~~ 45 individuals **subject to guardianship orders to create SDMAs** ~~through adoption of SDMNY and discharge of guardianships~~.	SDMNY's objectives do not include rights restoration of 45 persons, only the facilitation of agreements through the Restoration pilot program. SDMNY, through its legal arm DRNY, however, remains committed to ensuring that Restoration decision-makers receive legal aid to pursue rights restoration if they so choose.
80	The school-to-guardian pipeline is operating in New York.	~~The school-to-guardian pipeline is operating in New York.~~	The school-to-guardianship pipeline generally refers to a causal relationship whereby school personnel recommend that parents of students with IDD seek guardianship as part of their transition planning. However, this conclusion is likely beyond the scope of this evaluation.