



Center for Public
Representation

**Statement for the Written Record from
Center for Public Representation**

**Submitted to
The Special Committee on Aging
United States Senate**

**Hearing on
Guardianships, Conservatorships, Protective Arrangements,
and Alternatives**

March 30, 2023

The Center for Public Representation (CPR) thanks the Senate Special Committee on Aging for planning this hearing and for seeking public input, stories, and suggestions for reform related to the guardianship, conservatorship, interdiction, and other protective arrangements (collectively referred to here as “guardianship”).

CPR is a nationally recognized legal advocacy center committed to protecting and advancing the rights of people with disabilities and all others who are devalued in today’s society. CPR uses legal strategies, systemic reform initiatives, and policy advocacy to enforce civil rights, expand opportunities for inclusion and full community participation, and empower people with disabilities to exercise choice in all aspects of their lives. CPR utilizes systemic reform initiatives to promote the integration and full community participation of people with disabilities. Working on state, national, and international levels, CPR is committed to equality, diversity, and social justice in all its activities.

CPR has long worked to promote guardianship reform and, since 2014, has primarily focused its efforts to promote meaningful alternatives to guardianship. We have come to understand that retaining the right to exercise choice is perhaps the most fundamental right we have as human beings and among the most precious human rights. As such, CPR has been a national leader in promoting Supported Decision-Making (SDM) as a meaningful and superior alternative to guardianship. In addition to launching the nation’s first formally evaluated SDM pilot in 2014,¹ CPR provides technical assistance on SDM throughout the national Protection and Advocacy (P&A) network. CPR also is a lead partner in the Center on Youth Voice, Youth Choice,² a national resource center founded in the Fall of 2020 that supports state teams in promoting alternatives to guardianship for youth with intellectual or developmental disabilities. In addition, CPR’s legal experts authored two seminal law review articles on SDM, which informed the deliberations of delegates at the Fourth National Guardianship Summit in May 2021³ and

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resulted in key recommendations to promote SDM and other less restrictive alternatives to guardianship.⁴

The Problems with Guardianship

The U.S. legal system is overly reliant on restrictive guardianships as the way in which to address the needs of people with disabilities and older adults whose abilities to independently make decisions are being questioned. Guardianship takes away fundamental rights people have to direct their own lives – rights that many in the United States never imagined could be restricted. While the specifics of the law varies from state to state, guardianship orders routinely authorize third parties to make decisions about the most personal and important decisions in an individual’s life – choices that can impact the person’s own body and reproductive health; how and where they receive medical, psychiatric, and psychological treatment; how their money and financial resources are spent; and even with whom they associate. In some states, guardianships also can prohibit someone from voting or getting married.⁵ Once imposed, guardianships can be extraordinarily difficult to terminate, even when an individual’s personal or medical circumstances change significantly or there is a viable alternative available.⁶ Despite media exposés,⁷ state and federal inquiries,⁸ and major revisions to guardianship laws over the last three decades, the guardianship system in the United States continues to strip autonomy and dignity from the very people it is designed to protect and places them at risk of abuse, neglect, and exploitation.

In CPR’s work, we have identified many pipelines to guardianship that must be critically examined and systematically dismantled. For example, in the disability community, turning 18 years old is often the trigger for initiating guardianship proceedings. Indeed, school systems frequently not only fail to advise families of other options, but they remain one of the major sources of referrals for guardianship.⁹ Among aging people with disabilities, the guardianship trigger can be a hospitalization, a sudden illness, or a diagnosis of dementia. As their abilities are compromised or questioned, aging adults can find themselves up against the threat of guardianship – an all-too-commonplace construct in the disability world. Medical personnel, legal professionals, and service providers often presume incapacity based on diagnosis alone, without performing further analysis or engaging in a process to support the person to make decisions, with or without support.¹⁰

In November 2018, this Committee issued a report that called for comprehensive data collection to inform and improve the nation’s guardianship system, which serves at least 1.3 million seniors and people with disabilities nationwide.¹¹ Over four years later, there is still no cohesive system of data collection. That same committee report urged judges to rely more on alternatives to guardianship,¹² such as SDM, healthcare proxies, advanced directives, and durable powers of attorney. But despite these important policy recommendations, we frequently find that guardianship continues to be the default for people with disabilities and older adults nationwide.

The Answer within Supported Decision-Making

Under the SDM model, individuals can turn to a network of supporters – trusted family members, friends, colleagues – to help them make decisions regarding healthcare, finances, jobs,

and personal matters. The principles and inherent values of SDM can be embraced by anyone who needs assistance making decisions over the course of their lifespan. SDM, sometimes in conjunction with healthcare proxies and durable powers of attorney, is a viable alternative that offers people customized decision-making assistance, so they can retain their right to exercise self-determination throughout their lives.

Decades of research studies have correlated self-determination with people being healthier, more independent, and better able to recognize and resist abuse.¹³ On the flip side, the National Core Indicators (NCI) project consistently has found the people under guardianship surveyed are less likely to live in the community, less likely to work in integrated settings, and less likely to have friends or other social networks.¹⁴ From our seven SDM pilots in Massachusetts and Georgia, CPR knows that the SDM model works, strengthens support networks, and can transform lives. To see evidence of this, you have only to read the powerful stories from seven Massachusetts SDM pilot participants who have shared statements that are being submitted to you along with CPR's testimony. For more stories about SDM, please visit our website: www.supporteddecisions.org.

SDM has also been recommended and endorsed by a number of respected national organizations and federal agencies, including the American Bar Association, the National Guardianship Association, the National Council on Disability, delegates of the Fourth National Guardianship Summit, the Uniform Law Commission, the U.S. Department of Education, and the U.S. Department of Health and Human Services, among others.¹⁵ However, more work is needed to cement recognition and implementation of SDM across the United States, so that people with disabilities and older adults can be diverted away from court systems and towards options that allow them to retain their legal rights.

Recommendations for Federal Advancement of Supported Decision-Making

The United States must recognize its important role to advance SDM as part of a broad international human rights movement impacting people with disabilities world-wide.¹⁶ CPR supports the recommendations made by members of the Consortium for Constituents with Disabilities (CCD) Rights Task Force in the statement they submitted to you. In addition, we consider the following Congressional actions essential:

1. Direct the Secretary of Education to issue guidance that: (a) prohibits school systems from presenting guardianship as the singular or primary option for students with disabilities who are approaching adulthood; (b) promotes the use of alternatives to guardianship in transition planning, and (c) reinforces that the Individuals with Disabilities Education Act, as amended, requires provision of transition planning services that maximize student's opportunities for self-determination in adulthood.¹⁷
2. Focus federal policy on advancing the systematic adoption, implementation, and sustainability of evidence-based alternatives to guardianship that are voluntary in nature – *i.e.*, decision-making arrangements that are chosen and able to be cancelled or changed by the people with disabilities themselves.

3. Clarify that SDM is an accommodation under the ADA that allows people to retain the right to make informed decisions about their own lives, per the recommendation of the Fourth National Guardianship Summit.¹⁸
4. Establish federal grant programs and other financial incentives for states and territories to reduce the number of guardianships and increase access to other options, including Supported Decision-Making. The federal government should work with states and guardianship network organizations to educate stakeholders – courts, lawyers, guardians, school personnel, families – about SDM.¹⁹
5. Establish federal incentives for states to enact laws that establish robust due process protections in guardianship proceedings,²⁰ with the goals of preventing unnecessary guardianship from the outset, promoting access to less-restrictive alternatives, and overcoming barriers to rights restoration. These due process protections should guarantee the person who is facing or under guardianship has the right to zealous legal representation of their stated interests by an attorney of their choosing and at the state’s expense, if they cannot otherwise afford one.
6. Establish requirements for states and territories to collect detailed data on guardianship and report them to a national data collection entity.²¹
7. Establish long-term investment in a new nationwide technical assistance center to advance the practice of SDM and address gaps in SDM implementation.

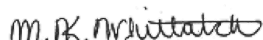
In summary, federally funded programs must prioritize alternatives to guardianship, ensure that investments are made to help states improve access to them; and ensure additional research and technical assistance on best practices for SDM is consistently funded over time.

We appreciate the opportunity to provide the Committee with our perspective on the importance of federal action to promote access to Supported Decision-Making and less-restrictive alternatives to guardianship. We look forward to working with Congress and the Administration to ensure that people with disabilities do not have their rights removed unnecessarily.

Respectfully submitted,



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- ¹ See CTR. FOR PUB. REPRESENTATION, *Initial SDM Pilot: CPR and Nonotuck*, <https://supporteddecisions.org/supported-decision-making-pilots/initial-supported-decision-making-pilot-cpr-and-nonotuck/> (last visited March 21, 2023) (includes information about SDM pilots, including formal evaluations).
- ² See CTR. ON YOUTH VOICE, YOUTH CHOICE, <https://youth-voice.org> (last visited March 21, 2023)
- ³ See Cathy E. Costanzo, Kristin Booth Glen, and Anna M. Krieger *Supported Decision-Making: Lessons from Pilot Projects*, 72 SYRACUSE L. REV. 99 (2022), <https://lawreview.syr.edu/wp-content/uploads/2022/09/99-163-Costanzo-2.pdf>; Morgan K. Whitlatch, Rebekah Diller, *Supported Decision-Making: Potential and Challenges for Older Persons*, 72 SYRACUSE L. REV. 165 (2022), <https://lawreview.syr.edu/wp-content/uploads/2022/10/5.-Whitlatch-Diller.pdf>.
- ⁴ Summit Delegates, *Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability - Recommendations Adopted by Summit Delegates*, 72 SYRACUSE L. REV. 29 (2022), <https://lawreview.syr.edu/wp-content/uploads/2022/09/29-40-Preface-2.pdf> (see Recommendations 2.1, 2.2, 2.3, 2.4, 3.3, 3.4, and 5.2).
- ⁵ See NAT'L COUNCIL ON DISABILITY, *Beyond Guardianship: Towards Alternatives That Promote Greater Self-Determination*, 92-94 (March 2018) (hereafter, "NCD 2018 Report"), <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>; NAT'L COUNCIL ON DISABILITY, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities*, 29-36 (June 2019), <https://ncd.gov/publications/2019/turning-rights-into-reality> (hereafter, "NCD 2019 Report");
- ⁶ See ABA COMM'N OF LAW & AGING AND THE VIRGINIA TECH CTR. FOR GERONTOLOGY, *Restoration of Rights in Adult Guardianship: Research & Recommendations* (2017), https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf.
- ⁷ See, e.g., BLOOMBERG LAW, *In the Name of Protection* Series. Parts 1 to 5 (March 2023), <https://news.bloomberglaw.com/interactive/guardians-dark-side-lax-rules-open-the-vulnerable-to-abuse>.
- ⁸ See, e.g., U.S. GOV'T ACCOUNTABILITY OFFICE, *Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors* (September 2010), <https://www.gao.gov/assets/320/310741.pdf> (report finding hundreds of allegations of physical abuse, neglect, and financial exploitation by guardians in 45 states and D.C. between 1990 and 2010); U.S. GOV'T ACCOUNTABILITY OFFICE, *Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults* (Nov. 2016), <https://www.gao.gov/assets/690/681088.pdf>.
- ⁹ See NCD 2018 Report, *supra* note 5, at 92-94; NCD 2018 Report, *supra* note 5, at 29-36.
- ¹⁰ See Whitlatch & Diller, *supra* note 3, at 178-181.
- ¹¹ U.S. SENATE SPECIAL COMMITTEE ON AGING, *Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Americans*, at 6-7 (Nov. 2018), https://www.aging.senate.gov/imo/media/doc/Guardianship_Report_2018_gloss_compress.pdf.
- ¹² See *id.* at 7 and 22.
- ¹³ See Whitlatch & Diller, *supra* note 5, at 172, fn. 22 (citing myriad of studies linking better life outcomes to promotion of self-determination).
- ¹⁴ Valerie Bradley, Dorothy Hiersteiner, Jane St. John, and Mary Lou Bourne, *What Do NCI Data Reveal About the Guardianship Status of People with IDD?* National Core Indicators Data Brief, at 6 (2019), https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf
- ¹⁵ See CTR. FOR PUB. REPRESENTATION, *U.S. Agencies and National Organizations Promoting Supported Decision-Making*, <https://supporteddecisions.org/about-supported-decision-making/organizations-advocating-for-supported-decision-making/> (last accessed Mar. 21 2023).
- ¹⁶ CTR. FOR PUB. REPRESENTATION, *SDM as an International Movement*, <https://supporteddecisions.org/about-supported-decision-making/sdm-as-an-international-movement/> (last accessed March 21, 2023).
- ¹⁷ See NCD Report 2019, at 80; Summit Delegates, *supra* note 4, at 34 (Recommendation 3.3).
- ¹⁸ See Summit Delegates, *supra* note 4, at 34 (Recommendation 2.4).
- ¹⁹ See *id.* at 32-34 (Recommendations 2.1, 2.2, and 2.3).
- ²⁰ See *id.* at 31-32 (Recommendations 1.2 and 1.3).
- ²¹ See *id.* at 36 (Recommendation 4.1).