

## PILOTING PERSONHOOD: REFLECTIONS FROM THE FIRST YEAR OF A SUPPORTED DECISION-MAKING PROJECT

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*The amazing Symposium on Personhood and Civic Engagement by People with Disabilities included a variety of perspectives: legal, cultural, historical, philosophical, and educational, including a panel on “Legal Barriers to Personhood” from which this article was derived. Despite legal analysis, theory, and even description, there was little “in the weeds” discussion of how personhood can actually be protected and preserved for persons with intellectual and developmental disabilities (I/DD).<sup>1</sup> Locating personhood within the human right of legal capacity, and positing guardianship in diametric opposition, this Article attempts to describe some of the lessons I have learned in the first year of an ongoing experiment in implementing legal capacity through supported decision-making (SDM). Demonstrating the success of this pilot project, the first in New York and the most extensive in the United States, is critical to influencing advocacy and legislative reform to promote and protect personhood. But first, some background.*

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<sup>1</sup> The almost complete lack of discussion in the scholarly literature of any actual or practical implementation of supported decision-making (SDM) makes this opportunity to describe an actual, existing SDM pilot especially appreciated. The editors of the *Cardozo Law Review* are to be commended for thinking “outside the box,” as well as for their enormous effort in putting together this important and inspiring Symposium and Symposium issue.

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### I. PERSONHOOD AND LEGAL CAPACITY

Many have written and theorized about the concept of personhood, but in many ways, at its simplest, our personhood is the consequence of all the decisions we have made over our lives. We “become” something or someone—a student, a spouse, a professional, a parent, a beekeeper, a marathon runner, etc.—by virtue of a series of choices we make: to work hard and get good grades; to date, to marry; to pursue a rigorous professional education and/or apprenticeship; to make a commitment to another to bring new life into the world, and to provide and care for it; to study bees, to buy and sell hives and to devote time to their care; to understand exercise physiology, to devote endless hours of training, to overcome injuries and discomfort, etc. Personhood depends on the ability to make choices or decisions and to have those choices or decisions recognized by others. That ability to make decisions and be recognized before the law is the human right of legal capacity.<sup>2</sup>

Human rights, including the right of legal capacity, derive from the Universal Declaration of Human Rights (UDHR),<sup>3</sup> adopted by the General Assembly of the United Nations in 1948, which proclaimed “[e]veryone has the right to recognition everywhere as a person before the law.”<sup>4</sup> The idea of human rights is an old one, but in its most recent iteration, it is the product of the world’s horror over World War II and genocide. The nations of the world adopted the UDHR and the human rights it contains to serve as “the foundation of freedom, justice and

<sup>2</sup> See generally Kristin Booth Glen, *Supported Decision-Making and the Human Right of Legal Capacity*, 3 INCLUSION 2 (2015).

<sup>3</sup> G.A. Res. 217 (III) A, Universal Declaration of Human Rights (Dec. 10, 1948).

<sup>4</sup> *Id.* art. 6.

peace in the world,”<sup>5</sup> and entered into a covenant recognizing and guaranteeing all of those inalienable, interrelated, and intra-dependent rights to their citizens.

Following adoption of the UDHR, the United Nations enacted a number of additional treaties or conventions setting out how human rights could be exercised on an equal basis with all others by members of several “vulnerable populations”<sup>6</sup> and the corresponding obligations of states parties.<sup>7</sup> The most recent of those conventions, directed to the needs of people with disabilities, is the United Nations Convention on the Rights of Persons with Disabilities (CRPD or the Convention)<sup>8</sup> which, in its General Principles, notes every person’s “inherent dignity, [and] individual autonomy including *the freedom to make one’s own choices . . .*”<sup>9</sup> Article 12 first reiterates the UDHR’s right of legal capacity: “States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.”<sup>10</sup> Article 12 continues: “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”<sup>11</sup> The meaning and extent of “legal capacity” was much debated during the course of negotiations around the CRPD,<sup>12</sup> but ultimately it was, and is, understood as “the ‘capacity to act’[] intended as the capacity and power to engage in a particular undertaking or transaction, to maintain a particular status . . . with another individual, and more in general to create, modify or extinguish legal relationships.”<sup>13</sup> That is, legal capacity is not only the right of persons with intellectual disabilities to make choices, but to have the law recognize their choices as valid and

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<sup>5</sup> *Id.* p.mbl.

<sup>6</sup> These include racial and ethnic minorities, children, women, persons with disabilities, and migrant workers. Other groups, such as older persons, do not (yet) have their own conventions.

<sup>7</sup> States parties are those countries that have ratified a Convention. See G.A. Res. 44/25, Convention on the Rights of the Child (Nov. 20, 1989); G.A. Res. 34/180, Convention on the Elimination of All Forms of Discrimination Against Women (Dec. 18, 1979); G.A. Res. 2106 (XX), International Convention on the Elimination of All Forms of Racial Discrimination (Dec. 21, 1965).

<sup>8</sup> G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006).

<sup>9</sup> *Id.* art. 3 (emphasis added).

<sup>10</sup> *Id.* art. 12, ¶ 1. This is important because it makes clear that the CRPD does not create any *new* rights.

<sup>11</sup> *Id.* art. 12, ¶ 2.

<sup>12</sup> See Ad Hoc Comm. on a Comprehensive & Integral Int’l Convention on the Protection & Promotion of the Rights & Dignity of Persons with Disabilities, Background Conference Document Prepared by the Office of the U.N. High Comm’r for Human Rights: Legal Capacity (Aug. 2015) [hereinafter OCHR Background Document], <http://www.un.org/esa/socdev/enable/rights/ahc6documents.htm>; Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future*, 34 SYRACUSE J. INT’L L. & COM. 429, 451–54 (2006).

<sup>13</sup> OCHR Background Document, *supra* note 12, ¶ 37.

enforceable contracts in the same way it would for all other persons. Making choices or decisions is not enough to constitute personhood; the power to act on them is also necessary.

Gerard Quinn, one of the gurus of legal capacity, puts it this way:

[L]egal capacity is the epiphenomenon. It provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe—a web of mutual rights and obligations voluntarily entered into with others. So it allows for an expression of the will and the lifeworld. That is the primary positive role of legal capacity. . . . Legal capacity opens up zones of personal freedom. It facilitates uncoerced interactions. It does so primarily through contract law. . . . [It] is entirely right to focus on issues like opening and maintaining a bank account, going to the doctor without hassle, buying and selling in the open market, renting accommodation, etc. This is how we positively express our freedom. This is how we can see legal capacity as a sword to forge our own way. . . . Viewed as a shield, [legal capacity] also helps persons fend off decisions made against them or otherwise ‘for’ them by third parties.<sup>14</sup>

If legal capacity is instrumental to personhood, then guardianship, which removes legal capacity in the name of “protection,” is its antithesis. Guardianship may be described as the legal means by which the State removes some or all of a person’s right to make decisions, and transfers that right to another, the guardian (also sometimes called a conservator).<sup>15</sup> The interplay between legal capacity and guardianship is clear, and the first official explication of Article 12 by the United Nations Committee on Persons with Disabilities (UN Committee)—the body responsible for interpreting the CRPD—made clear that guardianship is, in and of itself, a violation of Article 12.<sup>16</sup>

Returning to the idea that certain vulnerable populations may need assistance or accommodation in order to exercise their human rights, as

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<sup>14</sup> Gerard Quinn, Key Note Address at Harvard Law School Project on Disability Conference, Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD, <http://www.nuigalway.ie/cdlp/documents/publications/Harvard%20Legal%20Capacity%20gq%20draft%202.doc>.

<sup>15</sup> See Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93 (2012) [hereinafter *Changing Paradigms*].

<sup>16</sup> Comm. on the Rights of Persons with Disabilities, General Comment on Article 12: Equal Recognition Before the Law, U.N. Doc. CRPD/C/11/4, at 3 (Nov. 25, 2014) [hereinafter Comm. on Rights of Persons] (“Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision-making regimes such as guardianship [and] conservatorship. . . . These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with [all] others.”).

to legal capacity, Article 12 continues: “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”<sup>17</sup>

The UN Committee describes “support” as a “broad term that encompasses both informal and formal support arrangements, of varying types and intensity.”<sup>18</sup> It goes on to explain: “For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication.”<sup>19</sup>

Article 12 is thus the basis of the current, worldwide movement for supported-decision making (SDM) as the means to advance and protect legal capacity and, ultimately, personhood, for individuals with intellectual or developmental disabilities (I/DD) as well as other cognitive disabilities.<sup>20</sup>

Since 2008, when the Convention came into effect, more than 170 countries in the world have ratified it,<sup>21</sup> and many have begun serious efforts to harmonize their domestic laws with the CRPD, including Article 12. Primarily, these efforts have been directed to reforming or

<sup>17</sup> G.A. Res. 61/106, *supra* note 8, art. 12, ¶ 3.

<sup>18</sup> Comm. on Rights of Persons, *supra* note 16, ¶ 17.

<sup>19</sup> *Id.* Support might also include:

measures relating to universal design and accessibility—for example, requiring private and public actors, such as banks and financial institutions to provide information in an understandable format . . . in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions.

*Id.*

<sup>20</sup> Article 12 applies equally to persons with psychosocial disabilities (formerly called mental illnesses), traumatic brain injuries (TBI), and older persons with progressive cognitive decline, dementia, Alzheimer’s Disease, etc. The vast majority of work on Article 12, both theoretical and practical, has, however, involved persons with I/DD, often defined as “significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. . . . [and which] originates before the age of 18.” *Frequently Asked Questions on Intellectual Disability*, AM. ASS’N ON INTELL. & DEVELOPMENTAL DISABILITIES, <http://aidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.WZ3mx9PyuT> (last visited Nov. 8, 2017); cf. Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the U.N. Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8, 10–11 (2012) (discussing how the CRPD has catalyzed international actors to focus time and energy on the right to legal capacity in ways that predecessors to the CRPD that mention SDM did not).

<sup>21</sup> As of July 1, 2017, 174 countries had ratified the CRPD. See *Convention on the Rights of Persons with Disabilities (CRPD)*, UNITED NATIONS, <https://www.un.org/development/desa/disabilities/convention-on%20-the-rights-of-persons-with-disabilities.html> (last visited Nov. 8, 2017).

repealing guardianship laws, with only modest success so far. In a number of countries, non-governmental organizations (NGOs) set about demonstrating that SDM could work in practice to permit persons with I/DD to make their own decisions, and so alleviate the need for guardianship. The pilot projects they created<sup>22</sup> have been enormously useful in changing public and official opinion and, in some instances, have resulted in significant legislative change. They have also provided both an inspiration and a roadmap for disability rights advocates in the United States.

## II. SUPPORTED DECISION-MAKING IN THE UNITED STATES

Unlike the vast majority of countries in the world, the United States has not ratified the CRPD, although the Obama administration signed it shortly after the beginning of President Obama's first term.<sup>23</sup> The idea of legal capacity and the right to make one's own choices is, however, consistent with the American notions of person-centered planning, self-determination, and inclusion that have been incorporated in service provisions for persons with intellectual disabilities<sup>24</sup> and, to a lesser extent, in legislation like the Americans with Disabilities Act<sup>25</sup> and Individuals with Disabilities Education Act.<sup>26</sup> As such, it has been embraced by officials at the U.S. Agency for Intellectual and Developmental Disability (AIDD) (later a part of the Administration for Community Living (ACL)),<sup>27</sup> and has also begun to appear in legal scholarship.<sup>28</sup>

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<sup>22</sup> See *infra* notes 36, 59, and accompanying text (discussing some of these pilots).

<sup>23</sup> See U.S. INT'L COUNCIL ON DISABILITIES, THE DISABILITY TREATY, <http://www.usicd.org/doc/CRPD%20One%20Pager%200731%202013.pdf> (last visited Nov. 8, 2017); see also *Depositary*, UNITED NATIONS TREATY COLLECTION, [https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg\\_no=IV-15&chapter=4&clang=\\_en](https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&clang=_en) (last visited Nov. 8, 2017).

<sup>24</sup> *Changing Paradigms*, *supra* note 15, at 128–31.

<sup>25</sup> Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101–12213 (2012).

<sup>26</sup> Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400–1482 (2012).

<sup>27</sup> See, e.g., Aaron Bishop & Edwin Walker, *Preserving the Right to Self-Determination: Supported Decision-Making*, ADMIN. FOR COMMUNITY LIVING (Jan. 28, 2015), <https://www.acl.gov/news-and-events/acl-blog/preserving-right-self-determination-supported-decision-making>.

<sup>28</sup> See, e.g., Nandini Devi, *Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities*, 41 J.L. MED. & ETHICS 792 (2013); *Changing Paradigms*, *supra* note 15; Dinerstein, *supra* note 20; see also Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010) (arguing for supported decision-making as an alternative to guardianship in order to satisfy the *Olmstead* inclusion mandate).

Perhaps the first major meeting in the United States specifically directed at legal capacity and SDM was an interdisciplinary roundtable held in New York City in 2012,<sup>29</sup> convened by the Commission on Disability Rights (CDR) and the Commission on Law and Aging (COLA) of the American Bar Association,<sup>30</sup> with support from the New York Community Trust and ACL. One major takeaway from that meeting was the need for some central entity to gather and disseminate information on SDM. ACL subsequently requested proposals for a National Resource Center on Supported Decision-Making (The Center).<sup>31</sup> In 2014, a five-year grant was awarded to a consortium of organizations including Quality Trust, a District of Columbia advocacy organization; the Burton Blatt Institute at Syracuse University; and the Beach Center on Disability and the Kansas University Center on Developmental Disabilities, both at the University of Kansas.<sup>32</sup>

The ACL grant also required the Center to make smaller community-based grants to organizations that were engaged in or were connected to SDM.<sup>33</sup> Over the past three years, it has awarded eleven such grants.<sup>34</sup> Individual protection and advocacy (P&A) agencies<sup>35</sup> in a number of states also began to talk seriously about SDM, and to experiment with and utilize it in litigation. Panels and presentations about SDM began to appear regularly at national conferences, and articles about legal capacity and SDM were published in legal and other professional journals.

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<sup>29</sup> For the roundtable agenda, briefing paper, summary, and participant list, see *Supported Decision-Making*, A.B.A. <https://www.americanbar.org/groups/disabilityrights/resources/article12.html> (last visited Nov. 8, 2017).

<sup>30</sup> These two Commissions had previously sponsored a series of meetings that led to the first round of reform of adult guardianship statutes in the late 1980s. See *Changing Paradigms*, *supra* note 15, at 108–10.

<sup>31</sup> See *Supported Decision-Making*, *supra* note 29.

<sup>32</sup> *About*, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, <http://www.supporteddecisionmaking.com/about> (last visited Nov. 8, 2017).

<sup>33</sup> See *id.* Although the grants were small, only ranging up to \$5000, they enabled some of the recipients to expand on already existing SDM projects. See, e.g., NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, STATE GRANT REPORT, <http://supporteddecisionmaking.org/sites/default/files/sdm-cop-2016-maine.pdf> (last visited Nov. 8, 2017).

<sup>34</sup> Email from Morgan Whitlatch, Lead Project Dir., Nat'l Res. Ctr. for Supported Decision-Making, to Kristin Booth Glen, Univ. Professor & Dean Emerita, CUNY Sch. of Law (July 10, 2017); see also NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, ANNUAL PERFORMANCE REPORT (Sept. 30, 2016) [hereinafter ANNUAL PERFORMANCE REPORT] (on file with author); NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, SEMI-ANNUAL PERFORMANCE REPORT (Mar. 30, 2017) [hereinafter SEMI-ANNUAL PERFORMANCE REPORT] (on file with author).

<sup>35</sup> The federal government funds P&As in every state to provide legal services to persons with disabilities, particularly aimed at deinstitutionalization following *Olmstead v. L.C.*, 527 U.S. 581 (1999), and generally promoting inclusion and self-determination. See 42 U.S.C. §§ 15041–15045 (2000).

Meanwhile in 2014, in Northampton, Massachusetts, a public interest law office with a long history of expertise in disability rights, the Center for Public Representation (CPR), partnered with a progressive provider organization, Nonotuck Resource Associates, to create one of the first pilot projects<sup>36</sup> utilizing SDM in the United States. Although small in numbers and limited in scope, that project, along with its thoughtful and detailed independent evaluation,<sup>37</sup> helped lay a foundation for pilots in other states.

In 2015, Texas passed the first SDM statute in the United States.<sup>38</sup> It defines SDM as:

a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.<sup>39</sup>

In 2016, Delaware also passed an SDM statute,<sup>40</sup> and, as of this date, five other states and the District of Columbia are studying or considering passage of similar statutes.<sup>41</sup>

The federal government, through ACL, funds Developmental Disability Planning Councils (DDPCs) in every state<sup>42</sup> and provides monies for re-granting.<sup>43</sup> In 2015, the New York State DDPC issued a request for proposals for the creation of an educational campaign and two pilot projects, one to use SDM to divert persons with I/DD at risk of guardianship, and a second to restore rights to persons already subject

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<sup>36</sup> Technically, the first pilot was in San Angelo, Texas, but the CPR/Nonotuck Project was the first designed to systematically utilize SDM and Supported Decision-Making Agreements (SDMAs). See *Pilot Project*, CTR. FOR PUB. REPRESENTATION & NONOTUCK RES. ASSOCS. INC., <http://supporteddecisions.org/pilot-project> (last visited Sept. 19, 2017) [hereinafter *Pilot Project*].

<sup>37</sup> The website entails information about the pilot, including the evaluation by the Human Services Research Institute (HSRI). See *Pilot Project*, *supra* note 36.

<sup>38</sup> TEX. EST. CODE ANN. §§ 1357.001–.003 (West 2017).

<sup>39</sup> § 1357.002(3).

<sup>40</sup> DEL. CODE ANN. tit. 16, §§ 9401A–9410A (West 2013).

<sup>41</sup> D.C. Council 154, 22d Period (D.C. 2017); S. Res. 44, 120th Gen. Assemb., Reg. Sess. (Ind. 2017); H.B. 900, 127th Leg., 2d Reg. Sess. (Me. 2016); H.B. 713, 2017 Gen. Assemb., Reg. Sess. (N.C. 2017); S.B. 264, 110th Gen. Assemb., Reg. Sess. (Tenn. 2017); H.B. 941, 110th Gen. Assemb., Reg. Sess. (Tenn. 2017); H.J. 190, 2014 Gen. Assemb., Reg. Sess. (Va. 2014).

<sup>42</sup> Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106–402, 114 Stat. 1677 (codified as amended at 42 U.S.C. 15001–15115 (2012)). State developmental disability councils are part of the Developmental Disabilities Network, created by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000.

<sup>43</sup> See, e.g., *Developmental Disabilities Planning Council: Grant-Funded Projects*, N.Y. STATE, <https://ddpc.ny.gov/grant-funded-projects> (last visited Nov. 10, 2017) (describing the process for project funding).

to guardianship.<sup>44</sup> The grantee was required to expand the pilots geographically and to include all of “the diversity of the citizens of New York.” It was also tasked with exploring and making recommendations about long term sustainability.

In 2016, the DDPC grant was awarded to a consortium consisting of faculty from Hunter College of the City University of New York (CUNY); the New York State Association of Community and Residential Agencies (NYSACRA), a statewide association of providers; and, the Arc of Westchester, a large local provider of services to persons with intellectual disabilities and their families. Disability Rights New York (DRNY), the P&A agency for New York State,<sup>45</sup> is also a partner and provides legal services in connection with the restoration pilot. The consortium project is now known as Supported Decision-Making New York (SDMNY).

### III. THE SDMNY PILOTS

Despite New York State DDPC’s ambitious goals and requirements for the project, the actual funds available were modest, even with the required match from the consortium members.<sup>46</sup> This was both a curse and a blessing: the former for obvious reasons and the latter because it required continued thoughtful consideration of budgetary limitations that would be important in any analysis of sustainability.

SDMNY’s core staff<sup>47</sup> 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,<sup>48</sup> Hunter College generously added to the team

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<sup>44</sup> Funding Announcement, Developmental Disabilities Planning Council (DDPC), Notice of Availability of Federal Funds and Requests for Proposals by the New York State Developmental Disabilities Planning Council (2015) (on file with author).

<sup>45</sup> In addition to the DDPCs, ACL funds P&A agencies in every state to provide legal services to persons with disabilities, especially in relation to deinstitutionalization and the inclusion mandate of *Olmstead v. L.C.*, 527 U.S. 581 (1999). See 42 U.S.C. §§ 15041–15045; see also DISABILITY RTS. N.Y., <http://www.drny.org> (last visited Nov. 10, 2017).

<sup>46</sup> ANNUAL PERFORMANCE REPORT, *supra* note 34 (providing details of grant for AIDD/ACL SDM project); SEMI-ANNUAL PERFORMANCE REPORT, *supra* note 34 (same).

<sup>47</sup> Because of the state-wide nature of the grant, project funds are also allocated to NYSACRA and, to a lesser extent, the Arc of Westchester, recognizing the increasing input and responsibilities they will have across the project’s five-year timeline.

<sup>48</sup> In addition to the pilots, SDMNY was to create an educational campaign on SDM for a variety of stakeholders, including persons with intellectual disabilities, their families, providers, educators, lawyers, judges and the court system, as well as the general public. This campaign

by providing two years of funding for a full-time coordinator of facilitation and education, a position essential to the project's success.

The project was designed to begin in New York City, utilizing SDMNY staff and the CUNY/Hunter faculty associates to develop and test a facilitation model over approximately eighteen months. Next, the model was scheduled to expand to Westchester County with the assistance of consortium partner, the Arc of Westchester. In years three to five we would utilize the (by then) tested and refined model to roll out pilots in three to five geographically diverse sites across New York State.<sup>49</sup> In addition to helping design and implement these pilot programs, NYSACRA would develop and create "learning communities" comprised of representatives from provider and stakeholder organizations in the targeted geographic areas to help plan implementation of the pilots there, and, optimally, to carry "learnings" from the process back to their organizations to create a multiplier effect.

The first task, however, was to create a model to facilitate the use of SDM by persons with intellectual disabilities.<sup>50</sup> Our model reflects several basic precepts:

- The person with an intellectual disability would always be at the center of the process, even if she was currently under guardianship. To signal and reinforce the centrality of the person, she was denominated "the decision-maker" (DM).<sup>51</sup>
- The model would use a facilitator to work with the DM to explore the ways in which she made decisions and what trusted persons she wanted as supporters.<sup>52</sup>
- The facilitator would then work with the DM and her chosen supporters to create a written agreement,<sup>53</sup> the supported

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was to use a variety of formats including print materials, social media, an extensive website to be designed (built and maintained by the project), community presentations and presentations at professional conferences, journal articles, etc. In addition, the project was to create modules on SDM for use in graduate courses in social work, nursing, education and special education, and law, and to recruit and utilize an extensive and diverse advisory council of stakeholders and others critical to the long-term success of SDM. Finally, but far from insignificant, because the grant came from a semi-autonomous state agency through the New York State Comptroller's office, using federal government (i.e., ACL) funds, the three-layered reporting requirements were, and still are, a time-consuming bureaucratic nightmare.

<sup>49</sup> NYSACRA is anticipated to take a primary role in identifying agencies among its membership who are committed to the principles of SDM and willing to provide sites for the expanded project.

<sup>50</sup> *Our Process*, SDMNY, <http://sdmny.org/our-process> (last visited Nov. 10, 2017).

<sup>51</sup> *Id.*

<sup>52</sup> *Id.*

<sup>53</sup> As with all the previous pilot projects, a written agreement was important for many reasons including the potential ability to utilize it with third parties who might otherwise be unwilling to accept decisions made by the DM and/or to insist on a guardian. *Id.*

decision-making agreement (SDMA), reflecting their understanding of the process going forward.<sup>54</sup>

- Sessions would be scheduled so as not to exceed an hour in length.<sup>55</sup>
- The DM would always have the right to remove or add supporters or to change or cancel the agreement.<sup>56</sup>
- There would have to be a replicable model for training facilitators from a variety of backgrounds.<sup>57</sup>
- The facilitation process itself would have to be paid for through existing or repurposed sources, or have minimal or no cost.<sup>58</sup>

In creating our model, the history of several pilot projects around the world was useful, although far from dispositive. Each had distinctive characteristics that did not easily translate into the expansive model SDMNY was attempting to create. Each had its own answers to critical questions about the model's ultimate purpose, the identity and status of facilitators, recruitment of participants, whether the pilot should be freestanding or agency based, and, of course, finances.

#### IV. LEARNING FROM OTHERS AND ITS LIMITATIONS

One of the best and longest-running pilots<sup>59</sup> is a partnership between the Bulgarian Center for Not-for-Profit Law (BCNL) and the Bulgarian Association of People with Intellectual Disabilities (BAPID).<sup>60</sup>

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<sup>54</sup> *Id.* This is one of the many ways in which SDM differs from person-centered planning (PCP), a question we are often asked. PCP is an agency-centered process that is directed at choosing services for the person with I/DD and occurs within the agency setting. SDM is an ongoing process that the DM can use (with alterations as necessary) for a lifetime, whenever and wherever presented with decisions in areas in which he has chosen to receive support.

<sup>55</sup> *Id.* This time limitation was drawn from general learning theory as well as the perceived attention spans of the DMs.

<sup>56</sup> *Id.* This is the single provision that must be included in every SDMA.

<sup>57</sup> *Id.* Here, we had to anticipate the multiple diversities—race, class, age, geographic, etc.—that would be involved in scaling up the model for use across New York State and the possibility that there might not be agencies available to provide facilitators, or a sufficient number of facilitators.

<sup>58</sup> *Id.* This, of course, was a huge challenge, and one posed by the grant itself. No model, however elegant in its design or effective in practice, would actually make SDM a meaningful alternative to guardianship across the state unless there was some realistic way to pay for it.

<sup>59</sup> The Bulgarian pilot began in 2012 and has now served more than 150 clients. See Video Interview with Marietta Dimitrova, N.Y. (June 14, 2017), <http://sdmny.org/kristin-booth-glen-video-interview>; BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, SUPPORTED DECISION MAKING OR HOW PEOPLE WITH INTELLECTUAL DISABILITIES OR MENTAL HEALTH PROBLEMS CAN LIVE INDEPENDENT LIVES (2014), <http://inclusion-international.org/wp-content/uploads/2014/01/Podkrepen.pdf>.

<sup>60</sup> The BCNL pilot actually had two components. Beside the I/DD participants, who initially

The pilot relies on BAPID, a private family-based provider organization, for recruiting its clients, and pays professional facilitators to work with those clients and their chosen supporters over a long period of time.<sup>61</sup> The Bulgarian pilot is funded by a number of grants, including the Open Society Foundations (OSF), and has been extensively evaluated.<sup>62</sup>

The pilot in the Czech Republic runs out of the office of an NGO that includes both lawyers and social workers who serve as the facilitators for clients with I/DD and, to a lesser extent, psychosocial disabilities. As in the Bulgarian pilot and all others except the pilot in Israel, the supporters are chosen by the person with I/DD. The Czech pilot, which also receives funding from OSF, has been limited in the number of clients it can serve by the size of its staff, raising issues about sustainability as well as the cost of paid social workers.<sup>63</sup> A similar project is now underway in Latvia.<sup>64</sup>

The CPR/Nonotuck project, which also facilitates people with I/DD and their chosen supporters, has, at least until now, recruited participants entirely from persons receiving services from Nonotuck and has utilized only paid Nonotuck employees as their facilitators.<sup>65</sup> The pilot was essentially self-funded, but the evaluation was supported by a grant from OSF.

The Israeli pilot, which also received funds from OSF, differed from others in several ways. First, it was deliberately planned to last for only one year<sup>66</sup> and was limited to supporting participants with financial

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numbered twenty, BCNL also partnered with the Global Initiative on Psychiatry to facilitate SDM with persons with psychosocial disabilities, an enormously interesting and important experiment beyond the scope of this article. BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, SUPPORTED DECISION MAKING: GUIDEBOOK TO RIGHTS ENFORCEMENT (2014), [http://bcnl.org/uploadfiles/documents/analyses/guidlines\\_revisedfinaleng.pdf](http://bcnl.org/uploadfiles/documents/analyses/guidlines_revisedfinaleng.pdf).

<sup>61</sup> Many of the clients with I/DD had recently been returned to the community from special institutions in which they had no social contacts and no opportunity to make even the simplest decisions. For those clients, the initial “facilitation” was environmental, orienting them to, and engaging them in a community from which they could eventually choose supporters. This environmental facilitation often took a year or longer, after which supporters were chosen and the parties were facilitated in making an SDMA. *Id.*

<sup>62</sup> *Id.*; see also BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, COST BENEFIT ANALYSIS OF SUPPORTED DECISION-MAKING (2014), [https://www.bapid.com/bapid/wp-content/uploads/2014/08/SDM\\_report\\_engED.pdf](https://www.bapid.com/bapid/wp-content/uploads/2014/08/SDM_report_engED.pdf).

<sup>63</sup> See *Study Visit to Czech Republic Was Carried out, to Explore Supported Decision Making Model in the Czech Republic*, ZELDA (Sept. 2, 2015), [www.zelda.org.lv/en/activities/study-visit-to-czech-republic-was-carried-out-to-explore-supported-decision-making-model-in-the-czech-republic-2150](http://www.zelda.org.lv/en/activities/study-visit-to-czech-republic-was-carried-out-to-explore-supported-decision-making-model-in-the-czech-republic-2150).

<sup>64</sup> Unfortunately, little material on the Latvian pilot is currently available in English.

<sup>65</sup> See *Pilot Project*, *supra* note 36.

<sup>66</sup> It began with supporter training in July and August 2014, followed by “support meetings” held between September 2014 and October 2015. An average of thirty meetings were held with each participant. Several separate “family members meetings” were held for families of the participants. BIZCHUT, SUPPORTED DECISION-MAKING SERVICE FOR PERSONS WITH DISABILITIES: SERVICE MODEL 43 (2015), <https://www.bizchut.org.il/he/wp-content/uploads/>

decisions. Unlike the other pilots in which facilitators worked with DMs and their chosen supporters, the Israeli pilot recruited and trained supporters,<sup>67</sup> a majority of whom were volunteers,<sup>68</sup> and matched those supporters, one to one, with persons with I/DD.<sup>69</sup>

By now, Australia has had the most experience with pilots, beginning with an early pilot run by the Public Guardian in South Australia,<sup>70</sup> and now extended to four additional states.<sup>71</sup> Interest in and support for SDM has resulted in a now well-developed facilitation model and training regime<sup>72</sup> which, however, is far too extensive to meet the sustainability criteria of the DDPC grant. That model also depends almost entirely on the use of paid agency personnel as facilitators, and continues as long as the client receives services from the agency—and perhaps even beyond.

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2017/06/Support-system-Model-Bizchut.pdf (providing an extensive discussion and evaluation of the Israeli pilot).

<sup>67</sup> Training was extensive, consisting of eight sessions of “supporter training,” each of which involved four forty-five minute units and twenty sessions of “practicum,” which were comprised of three forty-five minute units. The Bizchut director and a professional from another agency conducted the trainings. *Id.* at 35.

<sup>68</sup> Of the eleven supporters who completed the project, two were paid staff and nine were volunteers, some of whom had no prior experience working with persons with intellectual disabilities. *Id.* at 34, 37.

<sup>69</sup> *Id.* at 35.

<sup>70</sup> See *Resources: Supported Decision Making*, OFF. PUB. ADVOCATE, [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making) (last visited Nov. 10, 2017) (providing relevant documents about the project in Australia, including an initial and final independent evaluation).

<sup>71</sup> Pilots in four Australian states (South Australia, Australian Capital Territory, New South Wales, and Victoria) are described in a useful summary publication by the Queensland Office of the Public Guardian. OFF. PUB. ADVOCATE: SYSTEMS ADVOCACY, A JOURNEY TOWARDS AUTONOMY? SUPPORTED DECISION-MAKING IN THEORY AND PRACTICE: A REVIEW OF LITERATURE 21–26 (Feb. 2014), [http://www.justice.qld.gov.au/\\_\\_data/assets/pdf\\_file/0005/249404/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-review-of-literature-March-2014.pdf](http://www.justice.qld.gov.au/__data/assets/pdf_file/0005/249404/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-review-of-literature-March-2014.pdf); see also *New Trial of Supported Decision-Making in Australia—a Sneak Peak*, RIGHT TO ACT CAMPAIGN (June 17, 2015), <http://www.righttoactcampaign.com/breaking-news-new-trial-of-supported-decision-making-in-australia-a-sneak-peak> (describing the pilot in New South Wales and also discussing an evaluation of the pilot by the Center for Disability Law at the National University of Ireland). Like the United States, Australia is a federal system leading to a greater degree of experimentation, and, at least initially, there is variation among the several models as against the federal government. For a current model, see Piers Gooding, *South Australia Supported Decision-Making Training: Adelaide*, NAT’L RES. CTR. FOR SUPPORTED DECISION-MAKING (Mar. 5, 2016), <http://www.supporteddecisionmaking.org/node/433>.

<sup>72</sup> For instance, the facilitation training offered by Cher Nicholson, who has been involved with all of the Australian projects, consists of a two-week intensive, followed by six months in which the trainers are in contact with the facilitators and do a number of site visits. See *About Cher Nicholson & ASSET (SA)*, WORDPRESS.COM, <https://www.assetsa.wordpress.com> (last visited Nov. 10, 2017); see also *Breathing to Heal*, WORDPRESS.COM, <https://assetsa.wordpress.com/training-workshops/breathing-to-heal> (last visited Nov. 10, 2017).

## V. ADAPTING THE MODELS

A first, and critical, question for us was whether to base the project and facilitation model within existing provider agencies, as most pilots have done, or whether to create a freestanding model that could be adapted to multiple settings. Self-advocates especially have voiced concerns that relying too greatly on an agency model could end up with SDM as simply another service provided, rather than the more liberatory, personhood-affirming process anticipated by the CRPD.

As we analyzed existing models and visited or spoke with their creators,<sup>73</sup> we also observed that, with the exception of Israel, in addition to the use of paid (whether by a partner agency or by the project itself) facilitators, those facilitators often remained continuously involved with the clients and their supporters long past the signing of a SDMA. It seemed that the purpose of the SDM process had moved from creating an ongoing structure in which supporters could assist the client in making her own decisions—and producing an SDMA formalizing that structure—to assistance in actually achieving the client's goals. Much as we would have loved to follow suit, it was unlikely that such a robust commitment was feasible to roll out across the state, given the parameters of the DDPC grant.

At the same time, however, a very different kind of experiment was—and is—taking place in Texas. The State passed the first SDM law in 2015,<sup>74</sup> albeit with little empirical evidence of how SDM might actually work in practice.<sup>75</sup> Once the statute went into effect, various

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<sup>73</sup> The project director was previously involved with the Bulgarian project which she first visited in 2013; she revisited the Bulgarian project and the Czech Republic project in the summer of 2016. She was also involved with the Nonotuck project from its inception and other project staff spent time there in the fall of 2016. She and the project coordinator had meetings with persons connected to Australian, Israeli, Latvian, and Kenyan pilots through several “convenings” sponsored by the Open Societies Foundations. See *Supported Decision Making*, INCLUSION INT’L (May 20, 2016), <http://inclusion-international.org/support-decision-making> (describing a workshop organized by the Open Society Foundations and American University, Washington College of Law, which convened representatives from, but not limited to, Argentina, Bulgaria, China, Columbia, India, Ireland, Israel, Lithuania, and Peru, in order to discuss the challenges and successes regarding implementation of supported decision-making throughout the world). With financial assistance from DRNY, the project was able to bring Australian pioneer trainer Cher Nicholson and an associate to New York for a four-day demonstration training in November of 2016.

<sup>74</sup> See TEX. EST. CODE ANN. §§ 1357.001–.003 (West 2017).

<sup>75</sup> In 2009, the Texas Legislature authorized and funded a small pilot in San Angelo, Texas, but that experiment had mixed results, arguably raising more questions than it was able to answer. Although it was able to educate and train a number of volunteers on the principles of SDM, it only established one SDMA. Project staff and volunteers were, however, able to avoid several guardianships through other means and to restore rights to at least one person subject to guardianship. See Interview with Lucille Wood & Helen Gaebler (Dec. 19, 2016) (discussing the absence of data collection on how parties to Texan agreements are using them). See

efforts to educate persons with I/DD and their families about SDM arose<sup>76</sup> but without dedicated funding, they were somewhat bare-boned. What training exists is more about how to fill in the statutory form SDMA and less about how to facilitate the creation of a meaningful and individualized SDM process for persons with I/DD and their families.

Most of the international models and CPR/Nonotuck did *more* facilitation over a longer period of time than the DDPC grant anticipated. Meanwhile, Texas, with a statute already in place, no legislature to persuade, and a clear and legally binding alternative to guardianship now available, was doing an abbreviated version of SDM training that seemed considerably *less* than DDPC's charge to SDMNY.

So what was the SDMNY model going to look like, what was its ultimate purpose, and who was going to deliver it?

## VI. THE FACILITATION MODEL

### A. *Basic Elements*

Following our review of other pilots, a site visit to the CPR/Nonotuck project, and a four-day demonstration training on the Australian model, after many iterations, the SDMNY partners and staff developed a two-day training program, defining the ultimate purpose of SDMNY's facilitation as follows: creating a process for educating the client with I/DD (via the DM) and her chosen supporters about SDM, and modeling a process of how to use SDM, resulting in a negotiated and individualized SDMA.<sup>77</sup>

With the SDMA, directed by the DM, as the end goal of the facilitation, the process focused on the elements necessary to negotiate and create it. We ultimately came to call these elements "the big four." They are:

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*generally* TEX. DEP'T OF AGING & DISABILITY SERVS., VOLUNTEER-SUPPORTED DECISION-MAKING FOR PEOPLE WITH COGNITIVE IMPAIRMENTS: A REPORT OF THE SAN ANGELO ALTERNATIVES TO GUARDIANSHIP PROJECT (Dec. 2012) (on file with author).

<sup>76</sup> For instance, one of the first institutions to create formal, though limited, training on SDM and SDMA was a clinic at the University of Texas, Austin School of Law, which partnered with local school districts to target transition-aged youths and their families. The clinic conducted three-hour information and training sessions and explained the SDMA accompanied by an offer to have participants return for signing. See *Supported Decision-Making Project—Arc of the Capital Area with Texas Law INCLUDE Project—FULL*, TEX. LAW, <https://www.law.utexas.edu/probono/opportunities/supported-decision-making-project-eanes-with-texas-law-include-project-2-2-2> (last visited Nov. 10, 2017).

<sup>77</sup> If and when New York adopts an SDM statute, it may choose to employ a statutory SDMA form, as is the case in Texas, though such form might—and should—simply provide a "safe harbor" while more individualized forms would also be legally valid.

- (1) *Which*<sup>78</sup> areas the DM wants support in;
- (2) *Who*<sup>79</sup> she wants to support her;
- (3) *What* kind(s) of support<sup>80</sup> she wants; and,
- (4) *How*<sup>81</sup> that support is to be given.

So how does this translate into facilitation? We settled on a three-phase model. Facilitators should do the following:

- (1) focus on the big four as they initially work with the DM;
- (2) explain the big four to the DM's chosen supporters even as they educate the supporters about SDM<sup>82</sup>; and,
- (3) achieve agreement, always directed by the DM herself, among the DM and supporters on each aspect of the big four to be incorporated in the written SDMA.

We saw that facilitators would need materials to utilize in each of the three phases, so we developed the following documents: (a) a worksheet in simple and pictorial language for use in the first phase with the DM; (b) a "cheat sheet" to prompt the DM in exploring the big four; (c) a big four chart to summarize the results of the first phase, written information on SDM, the project, and the big four for the second phase; (d) another cheat sheet to prompt participants' discussion and negotiation in the third phase; (e) a second summary big four chart; and (f) a template for draft SDMA.<sup>83</sup>

We also recognized that facilitators may need ongoing guidance, as well as assistance and counsel when particularly difficult issues arise, so the model includes "mentors" who are already experienced in SDM. Mentors will meet with facilitators before they begin the process, help them understand forms used for reporting progress, and briefly check in

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<sup>78</sup> Areas might include, for example, any or all finances, health, living situations, education or employment, relationships and intimacy, etc. See *Our Process*, SDMNY, <http://sdmny.org/our-process> (last visited Nov. 10, 2017).

<sup>79</sup> With younger DMs, these would generally be expected to include family members but could also include friends, teachers, or neighbors, etc. Older DMs might choose peer supporters, friends from work, faith-based institutions, or similar service providers, etc. See *id.*

<sup>80</sup> Kinds of support may include: gathering information and/or presenting it in easy-to-understand formats; helping to weigh alternatives, including considering the likely consequences of making, or not making, a decision; communicating the decision to third parties; and, assisting with the implementation of the decision. See *id.*

<sup>81</sup> For example, a DM may want a single supporter for each area of decision-making and to meet in-person with that supporter. A DM may want to have several supporters who would meet together or with whom she would communicate by phone, email, video-chat, etc., or to have a "circle" of all supporters who would come together for particularly important decisions. See *id.*

<sup>82</sup> We also see phase two as an opportunity to reposition supporters from their prior roles, often as decision-makers who best know how to genuine supporters who can appreciate and accept the "dignity of risk." See *id.*

<sup>83</sup> Because the process may potentially lead to many variables, facilitators are expected to rely more on the big four chart by incorporating its contents into the final SDMA drafted by project staff.

with facilitators after each session. They will also convene groups of facilitators to exchange experiences and best practices. The initial mentors are project staff and faculty associates, but over time, facilitators who show special ability and interest may also be asked to serve as mentors to others.<sup>84</sup>

Although signing the SDMA signals the end of the facilitation, it is not intended to conclude the project's relationship to the DM and her supporters. The plan calls for monthly check-ins by the facilitator (if still available) or mentor for the first year after the formal facilitation process is completed. The independent project evaluator<sup>85</sup> will also continue to monitor how SDM is working for all participants, particularly whether concerns that might otherwise have led to guardianship (in the diversion project) or that brought about a guardianship (in the restoration project), have been alleviated by the use of SDM.

With at least a draft model<sup>86</sup> in place, we had to plan how to recruit and train facilitators, another process that took many iterations and considerable time. We also had to decide who those facilitators might be, given that the paid and/or agency model utilized by most other pilots was not necessarily sustainable in the long term.

### B. *The Facilitators*

To date, SDMNY has explored three potential sources of facilitators. One of the project faculty associates, having taught at the Hunter School of Social Work, sought out Master of Social Work (MSW) students who could initially facilitate in a volunteer capacity until we were able to create a fieldwork placement that could give them academic credit for their work.<sup>87</sup>

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<sup>84</sup> We also recognize that it is important for mentors to continue doing their own facilitations with DMs and their supporters, not only because each facilitation is its own learning experience, but also because of the enormous satisfaction facilitators report from that hands-on experience.

<sup>85</sup> See *Developmental Disabilities Planning Council: Supported Decision-Making*, N.Y. STATE, <https://ddpc.ny.gov/supported-decision-making-0> (last visited Nov. 10, 2017) (making a separate award of \$75,000 per annum for the purpose of conducting an independent evaluation).

<sup>86</sup> We anticipate that as we actually use the model, we will necessarily make changes based on our experience.

<sup>87</sup> This assumption subsequently proved overly simplistic since in order to receive credit, MSW fieldwork requires a set number of hours per week, which is difficult to control given the schedules of DMs and their supporters. More recently, we began exploring the possibility of recruiting occupational therapy associate (OTA) students as volunteers with the hope of creating for-credit fieldwork through the OTA program at LaGuardia Community College. Like social work programs, the ubiquity of occupational therapy and OTA programs around the state make this a particularly rich target cohort.

We were also encouraged by NYSACRA to reach out to agencies sympathetic to our mission, since the overall project plan anticipated rolling out the pilots to three to five additional geographically diverse locations in years three to five. The likelihood was that some or all of those additional sites would be agency-based, so including agency personnel now would give us an opportunity to experiment with using them as facilitators. However, the agencies we spoke with, though willing to participate on a trial basis, immediately raised the cost of diverting staff from other paid services. Exploring the ability to use Medicaid waiver funds to pay for facilitation thus became another related aspect of the project.<sup>88</sup>

Each of the two previous target groups either have direct professional experience with persons with I/DD or are students in programs where coursework can provide familiarity. We are also beginning to recruit facilitators from among “pure volunteers.” The ability to train and utilize “ordinary” people as facilitators could provide a major benefit in expanding the project and, ultimately, the use of SDM in New York, especially when one considers issues of sustainability, the enormous diversity of environments—urban, suburban, exurban, and rural—that make up New York State, transportation issues, agency capabilities and proclivities, etc.

In order to test what modifications or additions to the model might be necessary for training non-professional volunteers, we are partnering with ReServe,<sup>89</sup> a well-regarded organization that recruits retirees and matches them with not-for-profit organizations.<sup>90</sup> By working with a single agency that does the initial recruiting, deals with insurance issues, and otherwise relieves our limited staff of additional obligations, this experiment is made more viable, although the ultimate intent is to look to a variety of recruiting sites such as faith-based institutions, union retirees, community associations, etc.

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<sup>88</sup> The present uncertainty about federal Medicaid funding after the passage of Trump’s administration budget and while debate continues on the repeal of the Affordable Care Act makes this challenge even more difficult, and its solution even more problematic.

<sup>89</sup> For information about the organization, see generally REERVE, <http://www.reserveinc.org> (last visited Nov. 10, 2017).

<sup>90</sup> As part of its commitment to treating the volunteer activities as real jobs, ReServe pays its “ReServists” a modest hourly stipend, and the not-for-profit employer, in turn, pays ReServe for the stipend and its administrative expenses. While the expense of partnering with ReServe may not be a sustainable model over time, the advantages we receive from their services more than justify the modest cost at this point in the project. *Who We Are*, REERVE, <http://www.reserveinc.org/who-we-are> (last visited Nov. 10, 2017).

*C. Training the Facilitators*

The initial SDMNY facilitation training was presented entirely live, and included simulations utilizing project personnel and volunteers as actors. Project members including the project director, coordinator of education and training, and two faculty associates were the instructors. While this worked well, in anticipating the coming geographical roll-out, we realized the need to create materials to standardize the facilitation training. The first aspect of this effort has been creating videos of the simulations for each phase, attempting to capture both the kinds of challenges that might arise and skills and strategies useful for dealing with them. We are also creating an extensive manual, including descriptions of the process, copies of forms and other written materials, and interactive exercises and background material on the techniques utilized. Despite the necessary emphasis on standardization, we continue to believe that it is critically important to include people with I/DD in all our trainings.<sup>91</sup>

There are also issues regarding the length of the facilitation training. The first training was squeezed into a single day because of our concern that potential facilitators might find an additional day or days impossible to fit into their schedules. Evaluations from that training, while uniformly positive, persuasively argued that there was simply too much material to cover in a single day, and that more time for practicing skills and simulations would significantly increase the value of the trainings. We have taken those recommendations to heart, and subsequent trainings are scheduled for six-hour periods over two successive days.

*D. The DMs*

For the diversion pilot, our initial plan was to work with transition-age youths in special education programs at several schools in New York City. Anecdotally, the most likely point at which parents tend to seek guardianship of their young adult children with I/DD is around the time the children turn eighteen years old, becoming adults with full legal capacity, and thus no longer—at least in law and theory—subject to the power of their parents. We believed, and repeatedly have been told, that most parents were encouraged to do so by school personnel who warned them (incorrectly) that without guardianship they would lose the ability

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<sup>91</sup> We believe that they should not only be expected to volunteer but should also be compensated to the extent possible.

to participate in their child's educational planning,<sup>92</sup> or by New York State Office for People With Developmental Disabilities (OPWDD)<sup>93</sup> employees who (incorrectly) refused to deal with them in securing benefits unless they were guardians. We were, however, somewhat surprised to learn how little those parents knew or understood about the total loss of their children's rights that guardianship entails.

An early partnership with Cooke Center Academy—an outstanding “private”<sup>94</sup> school for students with special needs—allowed us to work out the kinks of recruiting DMs in a school setting. The first task was to educate a willing and committed staff on SDM, and achieve their buy-in to SDM as a viable alternative to guardianship for many of their students. This was followed by information sessions for parents, students, and parents and students together, which generated interest and, in some cases, subsequent participation in the project<sup>95</sup> from DMs whose parents had been considering guardianship (including parents who had already begun the process but placed it on hold to explore SDM) as well as one DM already under guardianship.

SDMNY also reached out to several self-advocacy organizations, including a theater group whose members we use in our trainings. Although it may come as a surprise, a number of self-advocates are themselves under guardianship, and several have joined the project as DMs. We have also done information sessions for two different self-advocacy groups and have recruited additional DMs from them.

Through the advocacy and encouragement of NYSACRA, we have met with the staff of several provider agencies in New York City and are planning information sessions with their clients and clients' families in the early fall. An information session on family day at the Arc of Westchester also resulted in interest and eventual participation by

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<sup>92</sup> See also Arlene S. Kanter, *Guardianship for Young Adults with Disabilities as a Violation of the Purpose of the Individuals with Disabilities Education Improvement Act*, 8 J. INT'L AGING L. & POL'Y 1, 36 (2015) (confirming the role of schools in promoting guardianship to parents).

<sup>93</sup> OPWDD is the state agency responsible for administering Medicaid waiver benefits and other state funded benefits for people with I/DD. See *Office for People with Developmental Disabilities: Agency Overview*, N.Y. STATE, [https://www.opwdd.ny.gov/opwdd\\_about/overview\\_of\\_agency](https://www.opwdd.ny.gov/opwdd_about/overview_of_agency) (last visited Nov. 10, 2017).

<sup>94</sup> The tuition of many Cooke students is reimbursed by the New York City Board of Education, resulting in a truly diverse student body, though some tuition is privately paid and the school has a substantial and devoted donor base.

<sup>95</sup> After receiving an expression of interest, we held individual meetings with potential participants to further explain the process. If they decided to go forward, we had DMs eighteen years of age and older, not presently under guardianship, sign consent forms which were accompanied by plain language information sheets that would also be read aloud and explained. Their parents signed similar “assent” forms. If the potential DM was under eighteen years of age, or currently subject to guardianship, consent forms were signed by the parents or guardian in accordance with their legal status, and the potential DMs signed “assent” forms—notwithstanding that doing so is without legal consequence—to help affirm their personhood.

several DMs. A presentation at the NYSACRA annual conference led to a number of inquiries from agencies outside New York City and to at least one request to join the project by a person under disability and his guardian.

One encouraging source of potential DMs for the project has been referrals from attorneys who have learned about the project through presentations and publications, and who have come to believe that persons for whom their clients seek guardianship might be better served by SDM. Finally, outreach to the court system appears to be paying off as we have received referrals from at least one surrogate's court, and from a law school clinical program that often serves as guardian ad litem for another surrogate's court.

### E. Outreach Efforts

A major form of outreach has been general information sessions on SDM conducted at a variety of organizations including schools, self-advocacy organizations, parents' groups, agency information days, etc. We have also begun outreach to the larger legal community through presentations at law review symposia,<sup>96</sup> bar association events,<sup>97</sup> a National Guardianship Association conference,<sup>98</sup> and at events held by our state P&A<sup>99</sup> and National Disability Rights Network, the national organization of P&As.<sup>100</sup> In cooperation with colleagues from Brooklyn Law School's Disability Rights Clinic, we designed and held trainings on guardianship and SDM at the annual Judicial Seminars run by the New York State Office of Court Administration. While many of these

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<sup>96</sup> Symposium, *Personhood and Civic Engagement by People with Disabilities*, 39 CARDOZO L. REV. 413 (2017); Symposium, *Localizing Human Rights in the New Era: Strategies for State and Local Implementation of Human Rights in the United States*, 49 COLUM. HUM. RTS. L. REV. (forthcoming 2017); *Disability & Civil Rights Clinic Breakfast Roundtable*, BROOK. L. SCH. (Nov. 18, 2016), <https://www.brooklaw.edu/newsandevents/events/2016/11-18-2016>.

<sup>97</sup> DISABILITY LAW COMM. OF THE N.Y.C. BAR ASS'N, REVISITING S.C.P.A. 17-A: GUARDIANSHIP FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (2015), <http://www2.nycbar.org/pdf/report/uploads/20072850-ReportreviewingSurrogatesCourtProcedureActMENHEA1.15.16.pdf> (discussing N.Y. SURR. CT. PROC. ACT LAW §§ 1750–1761 (McKinney 2011) to draw the New York Legislature's attention to the need to improve procedures in Surrogates Court Procedure Act, Article 17-A).

<sup>98</sup> Colloquium, *Guardianship: Enhancing the Lives of People with Disabilities*, ALB. L. SCH. (Apr. 7, 2017), <https://www.albanylaw.edu/centers/government-law-center/publications/SiteAssets/Pages/Publications/Final%20Materials%20Colloquium%20on%20Guardianship.pdf>.

<sup>99</sup> For example, on April 12, 2017, the DRNY held a fourth anniversary celebration event in Albany, New York.

<sup>100</sup> *Annual Conference*, NAT'L DISABILITY RIGHTS NETWORK, <http://www.ndrn.org/annual-conference.html> (last visited Nov. 10, 2017) (detailing information regarding annual conference held in Baltimore, Maryland from June 12 to June 15, 2017).

presentations are couched in the language of alternatives to guardianship, we always also emphasize the *human right* of legal capacity, and its importance for promoting and protecting personhood.

A prime source of outreach for SDMNY is the Project Advisory Council, which the grant requires to be broadly representative of all stakeholders. The group includes self-advocates, parents, siblings, surrogates and other representatives of the court system, state legislators, lawyers,<sup>101</sup> legal academics, educators,<sup>102</sup> social workers, occupational therapists, mediators, an OPWDD Commissioner, and the New York City Commissioner of the Mayor's Office on People with Disabilities.<sup>103</sup>

The kickoff Advisory Council was held in March of 2017, and began with a moving segment on the infamous Willowbrook School<sup>104</sup> and remarks by a survivor of that terrible institution, noted self-advocate Bernard Carabello. Participants were moved by depiction of the devastating impact on personhood that virtual imprisonment and the denial of all choice can have on people with I/DD. The importance of personhood and its connection to legal capacity and SDM was, as well, emphasized by the keynote speaker, noted Canadian and international human rights activist and author, Michael Bach.<sup>105</sup> Breakout sessions focused on strategies for disseminating information on SDM and the pilots into the communities represented by Advisory Council members. We have already begun to see results from these relationships, including the invitation to present at the New York State summer judicial institute and referrals of DMs to the project.

A final and hopefully especially effective means of outreach is the recently launched SDMNY website.<sup>106</sup> The continuously increasing number of requests for information we receive suggests that it will be widely utilized and will prove an important source for educating a

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<sup>101</sup> The lawyers represent a number of different constituencies, from the New York Civil Liberties Union and New York State Bar Association leaders on disability rights, to private practitioners with substantial guardianship practices. See *Advisors*, SDMNY, <http://sdmny.org/about-sdmny/advisors> (last visited Nov. 10, 2017).

<sup>102</sup> These include the Dean of the Hunter College School of Education, a high-ranking official of the New York City Department of Education, and a national leader in inclusive education from the University of Rochester's Warner School of Education. *Id.*

<sup>103</sup> See *id.* (providing a complete list of Advisory Council members).

<sup>104</sup> We showed clips from videos of the exposé by Geraldo Rivera. *Willowbrook: The Last Great Disgrace 1972*, GERALDO, <http://geraldocom/page/willowbrook> (last visited Nov. 10, 2017); see also DAVID J. ROTHMAN & SHEILA M. ROTHMAN, *THE WILLOWBROOK WARS: BRINGING THE MENTALLY DISABLED INTO THE COMMUNITY* (2d ed. 2005). Sheila Rothman is also an Advisory Council member.

<sup>105</sup> The SDMNY Advisory Council kickoff meeting was held at the Roosevelt House of Hunter College on March 31, 2017.

<sup>106</sup> See SDMNY, <http://sdmny.org> (last visited Nov. 10, 2017).

variety of stakeholders and the general public on SDM, legal capacity, and personhood.

#### F. Evaluation

However successful the pilot projects may be, their use in advancing policy and legislation, and the likelihood they will be replicated elsewhere, depends in large part on a thorough, professional, and independent evaluation.<sup>107</sup> DDPC anticipated this need by making a separate five-year grant to the Council for Quality Living (CQL), a well-regarded organization best known for its work in accrediting agencies through its *Personal Outcome Measures* instrument (POM).<sup>108</sup> We are looking to the process evaluation done by HSRI of the CPR/Nonotuck Project as a good example,<sup>109</sup> with evaluations of other projects,<sup>110</sup> asking important questions as well as providing useful information. Our experience thus far has been that, although more time-consuming than expected, collaboration with CQL assisted by DDPC, has served to sharpen our thinking, clarify our goals, and improve the project in multiple ways.

### VI. LESSONS FROM THE FIRST YEAR

It has been a privilege to participate with SDMNY colleagues who have laid the foundation for a viable SDM facilitation model. Each step of the process has yielded new opportunities to learn from our knowledgeable and committed partners. While creating a process for enabling SDM is undoubtedly critical to advancing the right of legal capacity and personhood, experiences in the pilots' first year highlighted two other crucial areas: special education and third-party acceptance.

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<sup>107</sup> This was the case in Israel where a carefully evaluated pilot led to legislative change. *Legal Capacity*, MINISTRY OF JUSTICE, <http://www.justice.gov.il/En/Units/CommissionEqualRightsPersonsDisabilities/Equality-and-Inclusion/Pages/Legal-Capacity.aspx> (last visited Nov. 10, 2017).

<sup>108</sup> For more information about the CQL and the POM, see *CQL Accreditation*, COUNCIL ON QUALITY & LEADERSHIP, <https://c-q-l.org/accreditation> (last visited Nov. 10, 2017) and *Personal Outcome Measures*, COUNCIL ON QUALITY & LEADERSHIP, <https://c-q-l.org/the-cql-difference/personal-outcome-measures> (last visited Nov. 10, 2017).

<sup>109</sup> See *Pilot Project*, *supra* note 36.

<sup>110</sup> See, e.g., WESTWOOD SPICE, MY LIFE, MY DECISION: AN INDEPENDENT EVALUATION OF THE SUPPORTED DECISION MAKING PILOT (Apr. 2015), [https://www.adhc.nsw.gov.au/\\_\\_data/assets/file/0009/346194/sdm\\_pilot\\_project\\_evaluation\\_report.pdf](https://www.adhc.nsw.gov.au/__data/assets/file/0009/346194/sdm_pilot_project_evaluation_report.pdf); CMTY. MATTERS PTY LTD, HCSCC SUPPORTED DECISION MAKING PROGRAM 2014-15: EVALUATION REPORT (Sept. 1, 2015), <http://www.hcsc.sa.gov.au/wp-content/uploads/2015/11/HCSCC-SDM-Project-2015-Evaluation-Report1.pdf>.

Through our work with transition-age youth, we see that although decision-making may appear to evolve “naturally” for neuro-typical children, it is a skill that must be explicitly and systematically taught to those with intellectual and developmental disabilities, beginning not at transition, but at the start of the educational journey, as early as pre-kindergarten. While there are some best practices relevant to such an endeavor, the “deficit model” still permeates much of special education, which often focuses more on teaching compliance than what is necessary for self-determination. The pilots have already illuminated an essential project for promoting and protecting personhood: changing special education to embrace systematic enhancement of decision-making capacity, including identification and effective use of supports.

Using SDM in order to *make* choices is no guarantor of personhood unless those choices are respected and honored by others. Getting third parties like healthcare providers, financial institutions, etc. to accept SDMA requires legislation.<sup>111</sup> Successes from the pilots will hopefully provide powerful evidence in support of such legislation in New York and perhaps elsewhere. In the meanwhile, however, we have come to understand the importance of obtaining acceptance from public actors, most significantly OPWDD and the Department of Education and Health.

The need for such acceptance has become clear in information sessions, especially with parents, who want to see direct benefits (and/or protections) from participating in the pilots. Because their main reasons for considering guardianship often relate to barriers encountered in their children’s schools, in obtaining benefits, or the fear that they will be helpless in a medical emergency, we need to be able to assure them that an SDMA, even if not legally binding on private third parties, will be honored by our partners in the public sphere. There is precedent for recognizing SDMA in the educational context<sup>112</sup> and aspects of already existing policy that may prove persuasive to OPWDD.<sup>113</sup> In the working groups at the Advisory Council kickoff meeting, several members raised

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<sup>111</sup> For example, the Texas SDM statute requires third parties to “rely” on SDMA and relieves them of civil and criminal liability if such reliance is done in good faith. TEX. EST. CODE ANN. § 1357.101 (West 2017).

<sup>112</sup> For example, the District of Columbia Public Schools have passed a regulation requiring its schools to recognize and give effect to SDMA. *Supported Decision-Making*, D.C. PUB. SCHOOLS, <https://dcps.dc.gov/page/supported-decision-making> (last visited Nov. 10, 2017).

<sup>113</sup> In 2014, Governor Cuomo’s *Olmstead* Cabinet issued a report that criticized the existing guardianship statute for people with intellectual and developmental disabilities, N.Y. SURR. CT. PROC. ACT LAW §§ 1750–1761 (McKinney 2011), as potentially violating the *Olmstead* inclusion mandate; the Cabinet instead encouraged “the ability of people with disabilities to make their own choices to the maximum extent possible.” REPORT AND RECOMMENDATIONS OF THE OLMSTEAD CABINET 27 (Oct. 2013), <http://www.governor.ny.gov/sites/governor.ny.gov/files/archive/assets/documents/olmstead-cabinet-report101013.pdf>.

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the necessity of reaching out to the State Department of Health, and that is now high on the agenda.

The lessons of the first year about the concrete ways in which SDM can be operationalized to advance the right of legal capacity and personhood, many of which have come through trial and error, will only proliferate as the project advances. Our facilitation model is still a work in progress, as is the way in which facilitators are recruited and trained, and how most effectively to engage persons with I/DD and their families. We have come to see partnership with the educational system as critical to the long-term goals of the project, and have become more focused in the advocacy necessary to engage public institutions in accepting SDMAs. But while all of this will inform our ongoing work over the next four years, the greatest lesson has been the ways in which facilitating SDM has increased the confidence, capacity, and self-determination of the wonderful and inspiring people with I/DD with whom we are privileged to work.