

SUPPORTED DECISION-MAKING FROM THEORY TO PRACTICE: FURTHER REFLECTIONS ON AN INTENTIONAL PILOT PROJECT

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Supported decision-making (SDM) for persons with intellectual and developmental disabilities (I/DD)² has been part of legal scholarly discourse for more than a decade,³ but has, at least in the United States, entered the “real world” of practice only recently. Whether as a means to the lofty goal of a human right to legal capacity,⁴ as set forth in the United Nations Convention

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² SDM, and the right of legal capacity from which it derives, is applicable to three other groups: persons with psychosocial (mental health) disabilities; older persons with cognitive decline, dementia, Alzheimer’s, etc.; and persons with traumatic brain injuries (TBIs). The vast majority of work on SDM, both in the US and around the world, however, has focused on persons with I/DD, as does this article. For a provocative discussion of why there has been so little attention to older persons, and how SDM could be important to that population, see Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Guardianship to Supported Decision-Making*, 43 *FORDHAM URB. L. J.* 495, 498 (2016). For a discussion of legal capacity and persons with psychosocial disabilities, see generally PIERS GOODING, *A NEW ERA FOR MENTAL HEALTH LAW AND POLICY: SUPPORTED DECISION-MAKING AND THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES* (2017).

³ For example, Robert M. Gordon’s discussion of SDM’s emergence in Canadian legal frameworks helpfully traces its pre-CRPD origins. See, e.g., Robert M. Gordon, *The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making*, 23 *INT’L J. L. & PSYCH.* 61 (2000).

⁴ Legal capacity is defined as not only the right to make one’s own decisions, but to have legal agency, that is, “the power to engage in transactions and create, modify or end legal relationships.” Committee on the Rights of Persons

on the Rights of Persons with Disabilities (CRPD),⁵ or the more mundane “least restrictive alternative” to the imposition of guardianship,⁶ SDM has been theorized, analyzed, explicated, and interrogated. However, empirical evidence on how SDM might actually be practiced has been sorely missing. This article attempts to begin the conversation about what “doing” SDM looks like by reflecting on the experience of a large, grant-funded “intentional”⁷ SDM pilot project, Supported Decision-Making New York (SDMNY).⁸ This article describes the results to date: that, when done through a process that is thoughtfully designed, theoretically grounded, and well executed, *SDM really works!*

This SDM conversation is especially important now, with critical “real world” consequences. As the grant-funded project comes to its conclusion in the Spring of 2021, New York will need to decide whether to expand it statewide by building on the successes achieved and the lessons learned. The alternative would mean that, despite the substantial investment the State has already made in exploring, and now demonstrating how SDM can further the autonomy and self-determination of persons with I/DD, the SDMNY pilot results could be disregarded, and an extraordinary opportunity to lead the nation⁹ foregone.

with Disabilities, General Comment No. 1, Article 12: Equal Recognition Before the Law, ¶ 12, *U.N. Doc. CRPD/C/GC/1* (May 19, 2014) [hereinafter CRPD Committee].

⁵ G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006).

⁶ For an example of this use of SDM, see COMM’N ON DISABILITY RIGHTS, ABA, REPORT TO THE HOUSE OF DELEGATES: RES. NO. 113 (2017), https://www.americanbar.org/content/dam/aba/administrative/SDM%20Resolution_RevisedFinal%2013.authcheckdam.pdf.

⁷ I use the term “intentional,” which was employed by the author of a small, independent evaluation of the project, Elizabeth Pell, to distinguish what SDMNY is doing from the large number of projects that have websites, publish materials, or do group trainings, which are loosely categorized as “pilots.” See ELIZABETH PELL, SUPPORTED DECISION-MAKING NEW YORK: EVALUATION REPORT OF AN INTENTIONAL PILOT (Aug. 2019), <https://sdmny.org/wp-content/uploads/2019/12/Pell-SDMNY-Report-2019.pdf>.

⁸ For more information, visit www.sdmny.org. The reference to “further reflections” in the title of this article grows out of an earlier article that describes the first year of the project. See Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Pilot Project*, 39 CARDOZO L. REV. 495 (2017). Although the pilot has expanded to four additional sites since that time, my reflections are primarily confined to the experiences of the Hunter/CUNY site in New York City where I am located, and with which I have personal familiarity.

⁹ No state has explicitly incorporated SDM and SDM facilitation into its provision of services for persons with I/DD nor, as discussed *infra*, passed

Additionally, and closely connected to the question of expansion, New York may soon begin consideration of a law that recognizes SDM and Supported Decision-Making Agreements (SDMAs). Rather than moving directly to legislation with no evidence base, and despite valid questions that have been raised about the actual “practice” of SDM¹⁰ as other states have done,¹¹ New York has wisely committed both time—five years—and resources—\$1.5 million—to test if and how SDM can be successfully and appropriately utilized as a less restrictive alternative to guardianship.¹²

This article is an effort to contribute an account of that “test” and why and how New York policy makers and legislators can benefit from what we have learned. First, though, a word about language: a core principle for SDMNY is that the persons with I/DD with whom we work are at the center of the SDM process, and that it is *their* process, not ours. As such, we refer to them not as “clients” or “persons with I/DD,” but, respectfully, as “Decision-Makers”; that term is used throughout this article when referring to them in relation to SDMNY.

Part I briefly explains SDM, guardianship for people with I/DD, especially in New York, reasons why parents and others may choose, or be pushed into guardianship for their loved ones, and describes the growing interest in utilizing SDM as a “less restrictive alternative” to that rights-depriving legal status. It

legislation that adopts a facilitation model as the basis of requiring third party recognition.

¹⁰ For example, an oft-cited article urging further research on SDM in practice, see Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN. ST. L. REV. 1111 (2013).

¹¹ To date, eight states and the District of Columbia have passed SDMA legislation. See TEX. EST. CODE ANN. § 1002.031 (West 2015); DEL. CODE ANN. tit. 16, § 94A (2016); ALASKA STAT. § 13.56 (2018); D.C. CODE § 7-2131 (2018); WIS. STAT. § 52 (2018); NEV. REV. STAT. ANN. § 162A (LexisNexis 2019); 42 R.I. GEN. LAWS § 42-66.13-1 (2019); IND. CODE ANN. § 34-30-2-126.8 (2019); N.D. CENT. CODE § 30.1-36.01 (2019). Several other states’ legislatures have recently considered similar legislation. See, e.g., H.R. 2034, 2019 Reg. Sess. (Kan. 2019), http://www.kslegislature.org/li/b2019_20/measures/hb2034/; S. 63, 2019 Gen. Assemb., Reg. Sess. (Conn. 2019), https://www.cga.ct.gov/asp/cgabillstatus/cgabilstatus.asp?selBillType=Bill&bill_num=SB00063&which_year=2019; H.R. 473, 2019 Gen. Assemb., Reg. Sess. (Ky. 2019), <https://apps.legislature.ky.gov/record/19RS/hb473.html>; S. 64, 191st Gen. Ct., Reg. Sess. (Mass. 2019), <https://malegislature.gov/Bills/191/S64>.

¹² 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).

notes, as well, New York's recognition of the changing environment for people with IDD, its commitment to the *Olmstead*¹³ "deinstitutionalization mandate," and the circumstances under which New York committed to funding the largest and most extensive SDM pilot project in the U.S.

Part II utilizes a framework developed by researchers in Australia, where there have been more, and more evaluated pilot projects than anywhere else, to reflect on how the SDMNY pilot is actually working. This framework permits an orderly consideration of how SDMNY is organized, how and why it developed its three-phase facilitation model, including the influence of earlier pilots around the world, its initial design and the challenges presented, theoretical contributions to the work to be done in facilitation with both Decision-Makers and supporters, development of an SDMA template, facilitator and mentor training, and post SDMA activity, including a mediation module.

Part III considers the many lessons that a pilot project is uniquely positioned to learn by its charge to experiment with issues like how, and from where, to recruit Decision-Makers and facilitators; how to utilize, and whether to compensate mentors; the continuous evolution of facilitator training; the need for post-SDMA support for both Decision-Makers and supporters, and a deepening understanding of what support for decision-making actually requires. One lesson that is particularly salient here is the discovery of a strong consensus from persons considering petitioning for guardianship of the critical importance of SDMA legislation. Throughout, Part III highlights the potential relevance of our "learnings" for policy makers and legislators, while Part IV considers what an expansion of the pilot, and legislation based on the necessity of a real "process" for authentic SDM, might look like, and what it will take to get there.

I. BACKGROUND

A. *SDM and Guardianship*

SDM derives both from our general understanding of how *everyone* makes decisions,¹⁴ and from Article 12 of the CRPD,

¹³ See *Olmstead v. L.C. by Zimring*, 527 U.S. 581, 595 (1999).

¹⁴ Consider, for example, any major decisions you have made in your life: choosing an educational path; buying a house or signing a lease; agreeing to a

which provides that all persons have a right to legal capacity, regardless of disability, and that States Parties have an obligation to provide the support necessary to exercise that right. An oft-cited definition, SDM is “a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”¹⁵

This definition suggests that SDM can take many forms, from entirely informal (and mostly invisible), to a practice involving a formal contract recognized by legislation. It is likely that the vast majority of persons with I/DD in New York are not subject to guardianship, and live successfully in the community, getting assistance from others in their lives as needed and/or desired.¹⁶

There is, however, significant pressure on parents of transition-age youth with I/DD to pursue guardianship.¹⁷ One of the common arguments poses an apocryphal situation in which the person with I/DD is in an emergency room, in apparently desperate need of treatment, and deemed unable to give consent. The parent is confronted with the imaginary (and blatantly false¹⁸) “choice”: if you have guardianship, and the ability to

particular medical treatment; getting married—or not. Almost certainly you consulted with others, friends and family, or engaged experts, like lawyers or accountants, collected information, asked for opinions, etc. Decision-making does not occur in a vacuum for anyone. It is both useful and important to see SDM in this larger, more universal framework, or what Professor Wolf Wolfensberger famously denominated “normalization.” G. Allan Roeher, *Forward to WOLF P. WOLFENBERGER ET AL., THE PRINCIPLE OF NORMALIZATION IN HUMAN SERVICES* (1972).

¹⁵ Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8, 10 (2012).

¹⁶ There are no good statistics about guardianships of persons with I/DD in New York, or even nationally, but statistics about the number of persons with I/DD in the country suggest that those under guardianship are only a small percentage of the larger whole. See discussion in Kristin Booth Glen, *Introducing a “New” Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. J. 1, 8 n.28 (2018).

¹⁷ See, e.g., Carrie E. Rood et al., *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process*, 39 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 319 (2015).

¹⁸ In fact, regulations of the Office of Persons with Developmental Disabilities (OPWDD) deal with this very situation, authorizing persons in a ranked list of relationship to a person with I/DD who receives services from OPWDD to give consent for “professional medical treatment.” N.Y. COMP. CODES R. & REGS. tit. 14, § 633.11(a)(1)(iii)(b) (2020).

direct the treatment, your child will live, if you don't, s/he will die.¹⁹ Schools, health care providers, and other parents of transition-age youth with I/DD make guardianship the unquestioned default position when young adults reach the age of majority.²⁰

Parents or other family members may also seek guardianship for their loved ones with I/DD later in life because, for example, there is an inheritance, no matter how modest, or a third party who believes the person lacks capacity based on her/his disability refuses to engage in a transaction directly with her/him, and insists on guardianship as protection against potential liability. Service providers may find it far easier to deal with a legal guardian than doing the work of understanding the wishes of a client with I/DD. As parents grow older, and less able to care for adult children with I/DD, they may seek guardianship in order to place their loved one in a "safe" residential facility, or siblings may become guardians to clearly establish their legal authority over their intellectually disabled brother or sister.²¹

B. Guardianship for Persons with I/DD in New York

In New York,²² the consequence, in all of these situations, is the total removal of all the person's legal and civil rights, including the ability to make decisions about health care, education, finances, where s/he may live, with whom, whether s/he can work, marry, and, arguably, the right to vote.²³ The New

¹⁹ I have personally heard this story, or some variation on it, literally dozens of times while doing information sessions or in one-on-one conversations with parents of young adults with I/DD. Ironically, at an information session for families in Westchester, a woman stood up after another mother had related her fears about the story, and said "I am my son's guardian, and when we were in the ER, I told that to the doctor, who said, 'I don't care who you are; this is the treatment we are giving him!'"

²⁰ See PELL, *supra* note 7, at 48.

²¹ See Karen Andreasian et al., *Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities*, 18 CUNY L. REV. 287, 293 n.31 (2015).

²² Most states have a single guardianship statute for all categories of persons with cognitive and intellectual disabilities, including older persons with progressive cognitive decline, dementia, Alzheimer's, etc. New York is one of a few states that has a separate statute for persons with I/DD. See NAT'L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION 69 (Mar. 22, 2018), <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>.

²³ Although it is fairly clear that the legislature intended to deprive people

York guardianship statute for persons with I/DD²⁴ provides only for plenary guardianship; unlike the adult guardianship statute²⁵ that was revised as part of a national reform movement in the late 1980's and early 1990's, there is no provision for "tailoring" the guardianship, or limiting the guardian's powers to only those circumstances in which the person has been proven to lack functional capacity.²⁶

17-A is entirely diagnosis driven, completely ignoring the enormous continuum of abilities and/or impairments possessed by persons with, e.g., Down Syndrome, Cerebral Palsy, Autism Spectrum Disorder, etc. Essentially unchanged since its enactment in 1966, it was intended to provide a simple procedure for parents to continue their legal authority over "retardates," then thought to be eternal children because "the need for guidance and assistance are determinable at an early age and remain so for life."²⁷ The statute is now widely recognized as both outdated and as violating basic constitutional rights to due process.²⁸

C. *The Emergence of SDM*

As early as 1990, while considering sweeping reform of existing conservator and committee laws for adults who lacked or had lost "capacity,"²⁹ the legislature directed a study to re-think 17-A based on changes in "the care, treatment and understanding of [persons with I/DD]" and "new legal theories regarding the rights of such individuals."³⁰ Although the legislature also provided for

subject to guardianship of the right to vote, a change of language in successive statutes has made the prohibition more problematic, and in the absence of judicial explication, unsettled. *See generally* Kristin Booth Glen, *Not Just Guardianship: Exploring the Invisible Taxonomy of Laws, Regulations and Decisions that Deny Legal Capacity to Persons with Intellectual Disabilities*, 13 ALB. GOV'T. L. REV. (forthcoming 2020).

²⁴ N.Y. Surr. Ct. Proc. Act Law § 101 (McKinney 2020).

²⁵ N.Y. Mental Hyg. Law § 81.01–44 (McKinney 2020).

²⁶ Andreasian et al., *supra* note 21, at 310–11.

²⁷ Rose Mary Bailly & Charis B. Nick-Torok, *Should We Be Talking?: Beginning a Dialogue on Guardianship for the Developmentally Disabled in New York*, 75 ALB. L. REV. 807, 818, 819 (2012). *See id.* at 818 (discussion of the legislative intent).

²⁸ Andreasian et al., *supra* note 21, at 289, 301 n.65.

²⁹ This reform resulted in the enactment of Article 81 in 1992. *See* N.Y. Mental Hyg. Law § 81.01 (McKinney 2019) (further discussion of reforms under Practice Commentaries by Rose Mary Bailly).

³⁰ Andreasian et al., *supra* note 21, at 289. *See also* N.Y. Surr. Ct. Proc. Act Law § 1750 (McKinney 2016) (Historical and Statutory Notes).

delivery of proposed amendments based on such reconsideration by the end of 1991, no study was released,³¹ no changes were proposed, and 17-A remained virtually unaltered for the next two decades. In 2017, two bills substantially revising 17-A³² were introduced in the legislature, presumably in response to a federal lawsuit filed by Disability Rights New York (DRNY) challenging the constitutionality of the existing law,³³ but never emerged from committee. Since the federal case was dismissed on abstention grounds,³⁴ whatever momentum had developed has come to a grinding halt.

D. SDM in New York

Despite the failure of legislative reform, the executive branch, the courts, and civil society have increasingly demonstrated appreciation of the problems related to 17-A guardianship.³⁵ At the same time, SDM, and the human right of legal capacity from which it derives, began to receive national and local attention.³⁶ In 2014 the Administration for Community Living (ACL), a division of the U.S. Department of Health and Human Services (HHS), funded a National Resource Center on Supported Decision-Making, and in 2015 Texas passed the first statute recognizing SDM.³⁷ In that same year, DRNY, the State's new

³¹ A study was written, but never released. See Andreasian et al., *supra* note 21, at 289.

³² See Assemb. 8171-A, 2017 Leg., Reg. Sess. (N.Y. 2017); Assemb. 5840, 2017 Leg., Reg. Sess. (N.Y. 2017); S. 5842, 2017 Leg., Reg. Sess. (N.Y. 2017).

³³ Disability Rights N.Y. v. New York, 2017 WL 6388949 (S.D.N.Y. Aug. 16, 2017), *aff'd*, 916 F.3d 129 (2d Cir. 2019).

³⁴ *Id.*

³⁵ See, e.g., OLMSTEAD CMTY. INTEGRATION FOR EVERY NEW YORKER, REPORT AND RECOMMENDATIONS OF THE OLMSTEAD CABINET: A COMPREHENSIVE PLAN FOR SERVING NEW YORKERS WITH DISABILITIES IN THE MOST INTEGRATED SETTING (2018), <https://www.criminaljustice.ny.gov/opca/pdfs/9-Olmstead-Cabinet-Report-101013.pdf> (calling for reform of 17-A and including recognition of SDM); *In re* Mark C.H., 28 Misc. 3d 765 (N.Y. Surr. Ct. 2010) (reading a requirement of periodic reporting and review into 17-A to avoid unconstitutionality); Andreasian et al., *supra* note 21, at 293 n.31.

³⁶ The first national meeting about SDM was an interdisciplinary roundtable convened by the American Bar Association's Commissions on Disability Rights, and Law and Aging, with assistance from the federal Administration on Community Living, and funding from the New York Community Trust, held in New York City on October 21, 2012. Glen, *supra* note 8, at 500–01.

³⁷ TEX. EST. CODE ANN. § 1002.031 (West 2015). Since that time, seven additional states and the District of Columbia have also passed SDMA statutes. See sources cited *supra* note 11.

Protection and Advocacy agency (P&A),³⁸ convened a working group on SDM. After several meetings, a consensus arose that a pilot project demonstrating how persons with I/DD could use SDM to make their own decisions would be an important step in moving both the concept and practice of SDM forward.

Jennifer Monthie, who was then the PADD Director of DRNY, approached the New York State Developmental Disability Planning Council (DDPC) about the possibility of a significant grant to test the use of SDM as an alternative to guardianship. The suggestion resonated with DDPC's commitment to "promoting self-determination and independence,"³⁹ and in 2015 DDPC issued an RFP for a five-year project. Its objective was to create an educational campaign on SDM for a wide variety of stakeholders,⁴⁰ and to develop and administer two pilots: one to utilize SDM to divert persons at risk of guardianship, and the second to use SDM to restore rights to persons currently subject to guardianship.⁴¹

In January 2016, the \$1.5 million, five-year grant was awarded the SDMNY consortium led by Hunter College/CUNY, joined by the New York State Association of Community and Residential Agencies (now the New York Alliance for Inclusion and Innovation, ["New York Alliance"]), a statewide association of

³⁸ 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. by Zimring*. See 42 U.S.C. §§ 15041–15045 (2012); Glen, *supra* note 8, at 503 n.45.

³⁹ DEVELOPMENTAL DISABILITIES PLANNING COUNCIL, <https://ddpc.ny.gov> (last visited Mar. 2, 2020).

⁴⁰ There is neither time nor space here to describe SDMNY's achievements in this related mission, but the numbers tell a convincing story. In less than four years, SDMNY has conducted over 100 information sessions for parents, people with I/DD, educators, transition coordinators service providers, lawyers and judges, etc. attended by over 2,000 people; has created and maintained an informational website that has received over 3,000 visits; has participated in webinars, panels and conferences at venues from stakeholder organizations like ARC NY, INCLUDEnyc, the Self-Advocacy Association of New York State (SANYS), Parent to Parent of New York State, to professional organizations like the American Bar Association, the New York State Bar Association, the New York City Bar Association, and Mental Hygiene Legal Services (MHLS); and has published articles in law reviews, I/DD publications and provider journals. See *Articles*, SDMNY, <https://sdmny.org/downloads/articles> (last visited Mar. 2, 2020).

⁴¹ In virtually all respects, these two pilots were and are identical, except that, in the restoration pilot, at the conclusion of facilitation and signing the SDMA, the Decision-Maker may be referred to DRNY to commence proceedings to terminate the guardianship. Accordingly, throughout this article I will refer to "the pilot" unless there is an actual difference between the two.

provider agencies, and the Arc Westchester, a large service provider located in Westchester County. DRNY was to serve as the “legal arm” for the purpose of bringing restoration proceedings. The grant began on April 1, 2016, and ends on March 31, 2021.⁴² Simultaneously a five-year, \$375,000 grant for an independent evaluation of the project was awarded to the Council on Quality and Leadership (CQL).⁴³

II. A RESEARCH-BASED FRAMEWORK FOR UNDERSTANDING AND REFLECTION ON THE SDMNY PILOT

At the outset, there were three immediate tasks: developing a facilitation model, recruiting persons with I/DD to participate in the pilot, and developing a plan to recruit and train volunteer facilitators. While we began with certain assumptions,⁴⁴ our understanding of the challenges we faced changed significantly over the first year or two—and continues to evolve to this day.

There is, clearly, a huge gap between thinking and writing about legal capacity and SDM, and figuring out how to make it actually work for a wide variety of persons with I/DD. We benefitted enormously from the work on SDM done by pilot projects around the world,⁴⁵ and were inspired by the CRPD,⁴⁶

⁴² Unfortunately, the State Comptroller did not sign off on the contract until August 2016, so although the start and conclusion dates remained unchanged, any hiring or other expenditures were delayed until September.

⁴³ CQL is an organization that “provides accreditation, training, certification, research and customized consultation services to organizations and systems that share [its] vision of dignity, opportunity and community for all people.” THE COUNCIL ON QUALITY AND LEADERSHIP, <https://c-q-l.org> (last visited Mar. 2, 2020).

⁴⁴ See Glen, *supra* note 8, at 509–16.

⁴⁵ There was also a small pilot in Massachusetts that was a collaboration between the Center for Public Representation, a well-established disability rights public interest law firm and legal advocacy center, and Nonotuck Associates, a progressive provider agency. See *Initial SDM Pilot: CPR and Nonotuck*, CPR SUPPORTED DECISION-MAKING, <https://supporteddecisions.org/supported-decision-making-pilots/initial-supported-decision-making-pilot-cpr-and-nonotuck> (last visited Mar. 2, 2020).

⁴⁶ Article 12 of the CRPD guarantees the right of legal capacity, understood as both the right to make decisions, and the legal agency to have them recognized, to all persons, regardless of disability, and further requires that signatories to the Convention (“States Parties”) provide the supports necessary to exercise that right. United Nations, *supra* note 5, at art. 12(2), (3). There is, however, no mention of “supported decision-making” in the Convention itself. When the CRPD came into effect, in several countries that had ratified, or were preparing to ratify, efforts were begun to demonstrate how SDM might work in

but our unique circumstances and the ambitious goals of the grant called for a critical inquiry and willingness to innovate beyond what had already been attempted and/or accomplished.

The DDPC grant required that our methodology be appropriate for, and available to, a group as diverse as the population of the State. Rather than the relatively homogeneous populations involved in prior pilots, SDMNY needed to be designed for people of diverse racial, ethnic, and linguistic backgrounds, for people of all economic classes, urban, suburban and rural, young and old, citizens, immigrants, and un-documented persons.

There have been more pilot projects, and more research about evaluation of those projects in Australia than anywhere else. Between 2010 and 2015, there were six small pilot projects⁴⁷ in various states across Australia.⁴⁸ The intent of, and goals for, those projects were “to ensure support reflected a rights-based approach, assure greater accountability of supporters, provide training and backup to supporters and expand the availability of decision-making support to people without strong or resourceful informal networks.”⁴⁹

Researchers at Latrobe University in Melbourne examined the projects using five basic categories that also provide a useful framework for reflecting on the SDMNY project: “program

practice to meet their obligations under Art. 12. These efforts, in the form of pilot projects were primarily spurred by non-governmental organizations (NGOs) with the exception of Australia, where governmental agencies took the lead. See, e.g., Glen, *supra* note 16, at 52 n.252. Although the United States signed the Convention at the beginning of the Obama administration in 2009, it failed ratification by the Senate in 2012 and 2014; it has not made it to another vote since. Arlene S. Kanter, *Let's Try Again: Why the United States Should Ratify the United Nations Convention on the Rights of People with Disabilities*, 35 *TOURO L. REV.* 301, 332, 333 (2019). As such, the US is one of a handful of non-ratifiers in the world. See *Status of Treaties*, UNITED NATIONS TREATY COLLECTION,

https://treaties.un.org/pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4 (showing 181 ratifying states to date) (last visited Mar. 2, 2020).

⁴⁷ Those pilots ranged from six to thirty-six Decision-Makers. Jacinta Douglas & Christine Bigby, *Development of an Evidence-Based Practice Framework to Guide Decision-Making Support for People with Cognitive Impairment Due to Acquired Brain Injury or Intellectual Disability*, 42 *DISABILITY & REHABILITATION* 434, 435 (2018), <https://www.tandfonline.com/doi/pdf/10.1080/09638288.2018.1498546?needAccess=true>.

⁴⁸ Two were located in South Australia, and one in Victoria, New South Wales, Australian Capital Territory, and Western Australia. Christine Bigby et al., *Delivering Decision-Making Support to People with Cognitive Disability-What Has Been Learned from Pilot Programs in Australia from 2010 to 2015*, 52 *AUSTL. J. OF SOC. ISSUES* 222, 224 (2017).

⁴⁹ *Id.*

rationale, program design, methods and characteristics, organizational arrangements, and participants.”⁵⁰ These categories, which I use here, are helpful in sorting through how SDMNY was organized, how and why we developed the three-phase SDMNY facilitation model, and the various characters who populate our work.

A. *Rationale*

As noted, the DDPC grant was focused on consideration and use of SDM as an alternative to guardianship, specifically for persons at risk of guardianship, and for those already subject to it. As such, the focus was on a legal framework related to traditional guardianship law rather than a specifically human rights-based approach. Article 12’s guarantee of the right of legal capacity has, however, also informed our practice from the outset.

A legal framework pointed towards the creation of a document that could be used to divert putative petitioners for guardianship by avoiding situations in which a person with I/DD’s decisions might be questioned or dishonored based on an alleged “lack of capacity.” Similarly, the document would be important in the case of persons already subject to guardianship, demonstrating the existence of a formalized process for decision-making with support “less restrictive” than the existing guardianship.

Although this legal focus meant that an SDMA would be the apparent end product of our process, commitment to a rights-based approach required that the document would only be the *end*, but not the *means* for SDM. Here we immediately distinguished our objective from existing SDMA legislation which simply describes SDM, provides a form agreement or sets forth what such an agreement should contain, and requires third-party acceptance with immunity for good faith reliance.⁵¹

Rationale for the SDMNY project thus included a significant commitment to the process of SDM, understood not only as

⁵⁰ *Id.* at 225.

⁵¹ To date, eight states, and the District of Columbia have passed SDMA legislation, all of which basically reflect these primary provisions, with variations relating to, e.g. who may make such agreements, qualifications for supporters, formalities for making the agreement, etc. See sources cited *supra* note 11. For a list of SDMA statutes with links to each, see *Supported Decision-Making Laws*, SDMNY, <https://sdmny.org/sdm-laws> (last visited Mar. 2, 2020).

facilitating support for decisions, but also empowering the decision-maker in utilizing decision-making to exercise self-determination and autonomy. And, because the SDMNY facilitation process (and the resulting SDMA) would be used, at least in the restoration pilot, in litigation, it had to be carefully structured in a way that demonstrated the integrity of the decision-making process to judges—as well as to stakeholders more broadly.

B. Organizational Arrangements

At the outset, the project was centered in the SDMNY New York City site, housed at the Silberman School of Social Work of Hunter College, in the East Harlem neighborhood of Manhattan. Staffing included a Project Director, a Project Coordinator, a Hunter College Faculty Associate and a part-time Project/Office Assistant.⁵² Hunter/CUNY was to spend the first year developing an SDM facilitation model, and to begin recruitment of Decision-Makers and facilitators, with input from the New York Alliance and the Arc Westchester.

Piloting the model, including training facilitators, was scheduled to begin in the New York City site in year two, with expansion to the Westchester site six months later. The plan was for Arc Westchester to utilize the model with some of its own service clients, as well as others who might be recruited from surrounding areas. Although it would only receive funding from the DDPC grant for two years, it was hoped that Arc Westchester would incorporate SDM facilitation as part of its ongoing work, thus demonstrating the sustainability of the model through provider agency adoption and buy-in.

The original organizational design anticipated that the New York City site would begin to wind down in year three, when New York Alliance was to take primary responsibility for piloting the model through a roll out to three to five new, geographically diverse sites around the state. Those expansion sites,⁵³ together

⁵² Salaries and fringe benefits for the Project Coordinator and Office Assistant, and for a portion of the Faculty Associate's time, were directly funded by the DDPC grant. As part of the required "match" for the grant, CUNY contributed sixty percent of the Project Director's time.

⁵³ The three expansion sites allowed us to experiment with a variety of entities as site coordinators, responsible for recruiting Decision-Makers, recruiting and training facilitators, matching Decision-Makers and facilitators, and providing mentoring to facilitators. They are: Rochester/Western New

with Arc Westchester, would continue to recruit Decision-Makers, recruit and train facilitators, and oversee the facilitation process through conclusion of the grant period. When it became apparent that this configuration would not be able to meet the grant's "deliverable" of the minimum of 135 participants provided for in the contract, the organizational design was adjusted. Piloting would continue at the New York City site through the end of year five, with diminution in the number of participants the other sites were required to enroll and facilitate.⁵⁴

The organizational design also called for creation of an Advisory Council ("the AC") made up of a wide and diverse group of stakeholders, prominently including self-advocates.⁵⁵ The AC initially met at a day-long conference in year one,⁵⁶ with quarterly meetings by teleconference to be held thereafter, and a "summing up" and "next steps" conference planned for the end of year five.

One other aspect of organizational arrangements requires mention, that of finances. While the initial sum of \$1.5 million seemed like a large amount, on a yearly basis, reduced by the customary ten percent overhead charged by the CUNY Research Foundation (RF), which technically received and administered the grant funds, it was only \$270,000. That amount, to be

York, with a provider agency, Heritage Christian Services, as site coordinator; Long Island, with SANYS as site coordinator; and Albany/Capital Region, with the New York Alliance for Inclusion and Innovation, as site coordinator.

⁵⁴ This had budgetary implications, as the Project Coordinator, who was designated to spend fifty percent of his time on administering the project more broadly (including managing project finances, overseeing the work of expansion sites, coordinating with DDPC and having primary responsibility for the website) and fifty percent on the pilot work at the New York City site, was originally scheduled to go half time in years three to five, when NYC would no longer be engaged in piloting. When the project design changed, allocation to the NY Alliance was reduced in order to continue him full time.

⁵⁵ See *Advisors*, SDMNY, <https://sdmny.org/about-sdmny/advisors> (last visited Mar. 5, 2020), for a list of AC Members.

⁵⁶ The conference was held on March 31, 2017 at Roosevelt House in New York City, serendipitously simultaneous to an exhibit there highlighting Eleanor Roosevelt's leadership in the creation of the Universal Declaration of Human Rights. The meeting began with video clips of *Willowbrook: The Last Great Disgrace*, the 1972 exposé by Geraldo Rivera about the infamous institution which led to the deinstitutionalization movement, and a keynote by Michael Bach of Canada. After additional information about the project, the afternoon was spent in preliminary working groups organized by subject matter areas, including: legislation; the courts; education; service provision; and families and natural supports.

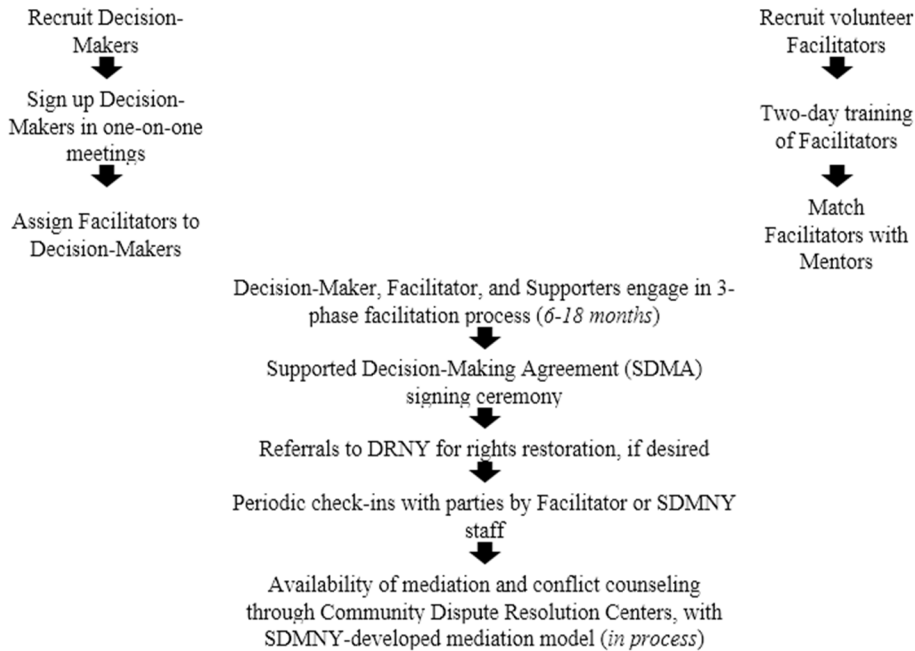
divided, albeit unequally, among the three collaborators over the five-year period, was in turn decreased by the modest salary and fringes⁵⁷ of core staff, located at the NYC site, who perform the project's substantial administrative work.

Even with the unparalleled dedication of project staff, there was simply not enough money to do what was necessary, or all that had been promised. This resulted in an unplanned-for institutional imperative, raising additional funds. A major, critical, and unfunded obligation was the cost of a full-time site coordinator in New York City. For the first two years, during which Hunter/CUNY was scheduled to be the primary player, that position was generously funded by Jennifer Raab, President of Hunter College, through the Hunter College Foundation. Thereafter, the Project Director assumed the additional role of fundraiser. To date, she has raised \$120,000 toward core New York City site functions, and \$150,000 for a separate campaign to educate legislators, policy makers and other stakeholders about SDM and the SDMNY facilitation model as New York begins to consider SDMA legislation.

C. Program Design

Overall, the SDMNY program design involves a number of steps, some occurring essentially simultaneously, in the following order. Those aspects of program that required significant conceptualization, design and implementation are described more fully below.

⁵⁷ RF employees receive fringe benefits of thirty-five percent of their salaries, so that, for example, the actual cost of the Project Coordinator, who was paid the relatively modest sum of \$70,000, was actually \$94,500.



1. Sources of the SDMNY Facilitation Model

The first and primary goal of the project was to design a model that would allow persons with I/DD to make their own decisions in a variety of areas, with support from trusted people in their lives whom they selected as supporters. In this work we were preceded and guided by pilot projects around the world and Western Massachusetts.⁵⁸ The unifying characteristic of all pilots which were then in, or had been in, existence was work done by the piloting entity with a Decision-Maker and her/his chosen supporters, a process variously referred to as training, education

⁵⁸ See ELIZABETH PELL & VIRGINIA MULKERN, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT (2016) [hereinafter HSRI REPORT 2016], <https://www.hsri.org/publication/supported-decision-making-pilot-year-2> (discussing the pilot program in western Massachusetts that involved nine participants, all of whom were clients of Nonotuck); *supra* note 45–46 and accompanying text.

or facilitation.

In Australia, the Decision-Maker and supporter or supporters were referred to as a “dyad,” and the six pilots there were described in terms of formation and support of the dyads:

With the exception of [one program] which worked with preexisting dyads, program staff helped to form dyads, from the decision makers’ own informal support network or by actively recruiting paid supporters or volunteers to the role. Once formed, program staff trained dyad members about decision making and provided ongoing support either individually or jointly to dyad members.⁵⁹

The program design of each pilot varied somewhat, with the pilot in the Australian Capital Territory focusing more on the skills of Decision-Makers than the other programs, “adopt[ing] a two-step process that included an initial decision readiness phase.”⁶⁰ This phase, which preceded recruitment of supporters, formation of and support to the dyad, aimed to develop skills in decision-making of the person with cognitive disability.

Pilots in Bulgaria,⁶¹ the Czech Republic,⁶² Latvia,⁶³ Israel,⁶⁴ and

⁵⁹ Bigby et al., *supra* note 48, at 226.

⁶⁰ *Id.* See Kris and Marieta Discuss the Bulgarian Center for Not-for-Profit Law’s SDM Pilot on June 14, 2017, SDMNY, 11:00–14:30, 16:13–19:10 (Jan. 2, 2020, 3:40 PM) [hereinafter Dimitrova Interview], <https://sdmny.org/about-sdmny/about-sdm/> (discussing how the “readiness phase” took a different and more expansive form in Bulgaria, where some participants had recently been released from institutions where they had been held for many years. As a result, they lacked both natural support systems, but also basic knowledge of how the “outside” world worked. For those decision makers, the pilot began with a yearlong “environmental facilitation” in which participants were introduced to modernity—buses, supermarkets, banks and ATMs, etc., and to a community of volunteers from whom they would eventually select their own supporters). For SDMNY, attention to the decision maker’s knowledge and experience of decision-making is akin to the “readiness phase.” See *infra* at Section II(D).

⁶¹ For a discussion of the Bulgarian experience, see Glen, *supra* note 16, at 84–89; BULG. CTR. FOR NOT-FOR-PROFIT LAW, SUPPORTED DECISION MAKING OR HOW PEOPLE WITH INTELLECTUAL DISABILITIES OR MENTAL HEALTH PROBLEMS CAN LIVE INDEPENDENT LIVES (2014), <https://inclusion-international.org/wp-content/uploads/2014/01/PodkrepEN.pdf>.

⁶² See Ieva Leimane-Veldmeijere, *Study Visit to Czech Republic Was Carried Out, to Explore Supported Decision Making Model in the Czech Republic*, ZELDA (Sept. 2, 2015), <http://zelda.org.lv/en/arh%C4%ABvi/2150>.

⁶³ See *Pilot Project for Introduction of Supported Decision-Making* [sic] in Latvia, SOC’Y INTEGRATION FOUND., https://www.sif.gov.lv/index.php?option=com_content&view=article&id=9389&Itemid=30&lang=en&skats=1 (last visited Mar. 5, 2020).

Western Massachusetts⁶⁵ also involved individual work—in differing degrees of intensity and formality—with the Decision-Maker, as well as her/his supporters. Together with the “capacity building” focus for supporters⁶⁶ that has characterized much of the experimentation in Australia, those pilots provided the inspiration and empirical grounding for our three-phase facilitation model, as did some theoretical underpinnings brought to the design by Hunter faculty.⁶⁷

2. The Three-Phase Model

Understanding that the end result of the process would be an SDMA, each of the three phases necessarily involved attention to what that agreement would need to contain, or what we came to call the “Big Four.” These were:

1. Which areas⁶⁸ (i.e. health, education, finances, relationships, community involvement, etc.) the Decision-Maker desired support in;
2. From Whom⁶⁹ s/he desired that support;

⁶⁴ See Arlene S. Kanter & Yotam Tolub, *The Fight for Personhood, Legal Capacity, and Equal Recognition under the Law for People with Disabilities in Israel and Beyond*, 39 CARDOZO L. REV. 557, 590 (2017); BIZCHUT, SUPPORTED DECISION-MAKING SERVICE FOR PERSONS WITH DISABILITIES: SERVICE MODEL (Maya Johnston trans., 2016), <https://en.beitissie.org.il/kb/item/supported-decision-making-service-for-people-with-disabilities-service-model>.

⁶⁵ See ELIZABETH PELL & VIRGINA MULKERN, HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE APPROACH: PILOT EVALUATION YEAR 1 REPORT (2015), <https://www.hsri.org/publication/supported-decision-making-pilot-year-1-evaluation-report>.

⁶⁶ See *infra* Section II(D)(2) (discussing this way of conceptualizing work with supporters and some practical consequences).

⁶⁷ Here we particularly drew upon the work of Deci & Ryan on intrinsic motivation brought to us by Professor Gina Riley. See *infra* Section II(D)(1). An additional influence was another article by Australian researchers: Michelle Browning, Christine Bigby & Jacinta Douglas, *Supported Decision Making: Understanding How Its Conceptual Link to Legal Capacity is Influencing the Development of Practice*, 1 RES. & PRAC. INTELL. & DEVELOPMENTAL DISABILITIES 34 (2014).

⁶⁸ Some pilots limited the areas in which support would be provided. See, e.g., BIZCHUT, *supra* note 64, at 16–18 (Israeli project limited to personal affairs, health issues, and financial affairs). In Australia, the first pilot in South Australia, the Australian Capital Territory, and Victoria excluded financial decisions. Bigby et al., *supra* note 48, at 229.

⁶⁹ The “who” was not intended to limit either the total number of supporters, or the choice of more than one supporter for any given area/domain, unlike some other pilots, including especially Israel where each Decision-Maker had a single

3. *What* kind of support s/he desired (i.e., gathering information; explaining information; considering the consequences of a particular decision, or of not making the decision; weighing alternatives; communicating the decision to others; implementing the decision, etc.); and
4. *How* s/he wanted to receive the desired support (i.e., in person; through meetings with all supporters; by phone; utilizing Skype or other web-based communication options,⁷⁰ etc.).

With continuing attention to the Big Four, the facilitation process proceeds as follows:

Phase One: The facilitator gets to know, and to develop a relationship with the Decision-Maker.⁷¹ They explore what kinds of decisions s/he is already making, what kinds of decisions might arise in the foreseeable future, how s/he makes decisions, who is important in her/ his life, etc. There are a number of materials available to the facilitator including an SDM worksheet, a Big Four Chart, “cheat sheets” with questions and topics to move Phase One forward, etc. The facilitator and Decision-Maker explore who the Decision-Maker may want as supporters and, at least preliminarily, for which areas, and what kinds of supports.⁷² The Decision-Maker is also given a preview of the SDMA template, in preparation for Phase Three.

Phase Two: Supporters whom the Decision-Maker has identified

supporter. See Tal Kahana & Shira Yalon-Chamovitz, *Schedule B: Article 12 Supported Decision Making Pilot: Summary of Assessment Study Findings*, in SUPPORTED DECISION-MAKING SERVICE FOR PERSONS WITH DISABILITIES: SERVICE MODEL, *supra* note 64, at 42, 43.

⁷⁰ This has been especially important when Decision-Makers have a large number of supporters with some located outside the city or the state, as in the case of one decision maker who had eight supporters, some of whom were in California.

⁷¹ See Telephone Interview with Michael Kendrick, Director of Initiatives on Supported Decision-Making, Center for Public Representation (Dec. 22, 2016) (transcript on file with author) (much attention is paid to consciously developing a “right relationship,” that is one which is not “up/down” but on an equal basis); Gina Riley, *What is Supported Decision Making?*, SDMNY (Nov. 16, 2017), https://www.sotaconference.com/uploads/1/0/3/4/103490714/d2s3_booth_glen.pdf (this is one of the ways in which facilitation differs from teaching or training, where the teacher/trainer is in an “up” position over the student/trainee to whom information and/or skills are imparted).

⁷² See Tina Minkowitz, *CRPD Legal Capacity – From Standards to Implementation*, ACADEMIA.EDU, <https://www.academia.edu/39776115/CRPD-legal-capacity-from-standards-to-implementation> (presentation delivered at conference in Basel, Switzerland on June 25, 2019). This exploration is consistent with what Tina Minkowitz refers to as the “opportunity to explore needs and design supports (support to seek support).” *Id.*

are invited to participate, with the Decision-Maker present or not (or present for some parts), all at her/his choice. The two primary goals of Phase Two are to educate supporters about SDM, and to “reposition” them from people who “know best,” make decisions for, and act to protect the Decision-Maker, to persons who support her/him in making her/his own decisions,⁷³ including accepting “the dignity of risk.”⁷⁴

Phase Three. Once the supporters have bought in to SDM principles, they and the Decision-Maker come together, with the assistance of the facilitator, to negotiate the contract that will become the SDMA. New, salient information may become available, aspects of the Big Four may change or be modified, but eventually, when the parties reach agreement, the facilitator prepares a draft, using the SDMNY template. The parties review the draft, which remains subject to modification until there is final agreement. The facilitator then submits the final draft to her/his mentor for comments, after which it goes to the Project Director and Coordinator, both of whom are lawyers, for final approval. A signing ceremony for all participants is then scheduled as the conclusion of the process.

Throughout all three phases the facilitator is “backed up” by her/his mentor, with mandatory check-ins after each meeting, and with the mentor available whenever issues or apparent impasses arise.

3. The SDMNY Facilitator Training Model

Another necessary aspect of program design was training for volunteer facilitators to understand the underlying principles of SDM and the right of legal capacity, what facilitation is, and is not,⁷⁵ the skills necessary for good facilitation, and the way in which those skills apply in each of the three phases. In addition,

⁷³ *Id.* Minkowitz helpfully describes support for legal capacity as “not protection of the person, rather accountability to the person served.” *Id.*

⁷⁴ See Robert Perske, *The Dignity of Risk and the Mentally Retarded*, 10 MENTAL RETARDATION 24 (1972). Because neurotypical people are free to take risks which may or may not have unfavorable results, denying persons with I/DD that same ability is to treat them unequally and to deny their dignity and personhood. See *id.* But, equally important, affording them the dignity of risk gives them the opportunity that we permit everyone else: to make mistakes, to learn from them, and to grow. See *id.*

⁷⁵ See SDMNY, FACILITATOR’S MANUAL 36–37 (2019), <https://sdmny.org/wp-content/uploads/2019/02/SDMNY-Facilitators-Manual-TOF6-Draft.pdf>.

they needed familiarity with the SDMA template, the various materials available for use in each of the three phases, and how to utilize the web-based SDMNY intranet for recording facilitation notes, communicating with mentors, etc.

The first Training of Facilitators (ToF) was only one day long, focusing on an introduction to SDM and the three phases of facilitation, illustrated by our first, not entirely successful attempt at live simulations, and the skills⁷⁶ relevant to those phases. Participants were excited but frustrated, and virtually unanimous in suggesting that the training needed to be longer, and to include more opportunities for practice.

The ToF format expanded with subsequent iterations, including, and to some extent propelled by development of a Facilitator's Manual, which itself has gone through several iterations to the relatively complete, 100-plus page version we are currently using. Trainings are now two full days. We found it more effective to teach the whole repertory of skills at the beginning, and to spend several hours on each of the phases, using new, more focused training videos⁷⁷ keyed to the skills and the manual. They include several simulations to enable participants to practice skills and develop comfort with the facilitation process overall, and a module specifically on the SDMA template⁷⁸ based on one of our guiding principles for training: "Begin with the end in sight."

4. SDMNY Mentor⁷⁹ Training

Initially we assumed that some number of facilitators who had successfully worked with one or more Decision-Makers would transition into mentors for new facilitators, while project staff

⁷⁶ We initially drew on a list of skills from Cher Nicholson's four-day presentation to us from November 9-12, 2016, including: framing; focusing; exploring; translating; connecting; bridging themes; checking in; setting limits; and gentle confrontation. *See id.* at 32-36. Cher Nicholson is one of the pioneers in training supporters in Australia and has taken her methodology worldwide. For a description of her training, *see* Piers Gooding, *South Australian Supported Decision-Making Training: Adelaide*, MELBOURNE SOC. EQUITY INST. (Mar. 5, 2016), http://supporteddecisionmaking.org/sites/default/files/South_Australian_Supported_Decision-Maki.pdf.

⁷⁷ *See* discussion *infra* Section III(B)(1) for a description of the videos and how they evolved.

⁷⁸ *See* discussion *infra* Section III(B)(1).

⁷⁹ *See infra* Section II(F)(6) for a discussion of our increasing appreciation of the importance of mentoring.

would serve as mentors to the original tranche of facilitators. This proved overly optimistic, and through the end of year three, staff carried virtually all of the mentoring load. At that point, and with the roll-out of three expansion sites, it became clear that we would need to pay for at least some mentoring. We would also need to develop training materials for prospective mentors., currently in process. Co-mentoring, where resources permit, has also been used successfully, especially in expansion sites where there was no cohort of experienced facilitators.⁸⁰

5. Post Agreement Activity and the Mediation Module

At the beginning, little thought was given to what would happen after a Decision-Maker signed her/his SDMA, although SDMNY's original proposal provided for development of a "mediation module" in year four. As more Decision-Makers reached or approached that benchmark, the need for some continuing process became apparent, especially because the grant—and SDMNY itself—would end in 2021.

We were fortunate to make a connection with the New York State Office for Court Innovation and its Community Dispute Resolution Centers (CRDCs),⁸¹ where it became apparent that the organizational structure, as well as the skill set of its volunteer mediators, made the CRDCs the perfect post-SDMA back up for SDMNY participants. Utilizing the mediation module that is currently under development by a highly regarded professor and practitioner in the field,⁸² CRDC mediators will receive a two-day training on SDM, the facilitation model, and potential disputes that may arise. These could be, as originally projected, between supporters, or the Decision-Maker and supporters. Experience

⁸⁰ For example, when the Rochester site began, the NYC Site Coordinator co-mentored the Rochester Site Coordinator.

⁸¹ *Alternative Dispute Resolution*, N.Y. UNIFIED COURT SYS., https://ww2.nycourts.gov/ip/adr/What_Is_ADR.shtml (last visited Mar. 4, 2020). The CRDCs, which operate in virtually every state in the country, are local not-for-profits that are court-affiliated, but not court controlled, and they provide mediation, arbitration, and other dispute resolution options as an alternative to court. *Id.*

⁸² Beryl Blaustone is a professor of law at CUNY School of Law, Director of the Mediation Clinic, and a mediator and mediation teacher with a national and international reputation. *Beryl Blaustone*, CUNY SCH. OF LAW, <https://www.law.cuny.edu/faculty/directory/blaustone> (last visited Mar. 4, 2020). She also has considerable experience with court affiliated mediation in New York, having incorporated mediation in the Housing, Civil and Small Claims Courts in the CUNY Law School Mediation Clinic for the past decade. *Id.*

now suggests other possible conflicts, between supporters and family members or others close to the Decision-Maker who were not chosen as supporters, and between the Decision-Maker and provider agencies who may be unwilling to accept her/his decisions about services they offer or withhold.

The CRDCs offer another useful service for Decision-Makers as they experience themselves in a different relationship to loved ones and others. Some CRDC mediators are trained in “conflict counseling,” with which they assist clients in advocating for themselves when disputes arise. We see this as valuable for persons who have always had decisions made for them, as they move toward greater self-determination and autonomy.

In addition, as a new aspect of program design, we have begun affinity groups for Decision-Makers with SDMAs, partly to explore and reflect on their experiences, partly to identify issues that might inform the facilitation process, or training of facilitators going forward.

6. The SDMNY SDMA Template

While other aspects of program design relate to the interactions of participants, one last aspect was design of a document, the SDMA template. As Decision-Makers moved through Phases One and Two of their facilitation, there was need for guidance as to what the resulting agreement should look like. Tensions arose between our commitment that the process should be Decision-Maker directed, with the SDMA looking like whatever s/he wanted, and the project rationale, to create an alternative to guardianship, which called for a more legalistic document.

Again, we noted what others had done, carefully reviewing virtually all of the SDMAs⁸³ that were then extant,⁸⁴ for eighteen separate issues, including setting out areas for support.⁸⁵

⁸³ We confined the search to existing form agreements, as opposed to descriptions of what an agreement might contain. A chart of all those forms agreements and the components they contain is on file with the author.

⁸⁴ See TEX. EST. CODE ANN. § 1002.031 (West 2015); DEL. CODE ANN. tit. 16, § 94A (West 2016) (Only two, Texas and Yukon, were connected to actual legislation, with, at the time, only Texas and Delaware having passed SDMA statutes, and only Texas including an actual form agreement. The remainder were aspirational, in the sense that, while people with I/DD were free to utilize them, there was no legal obligation for others to honor them).

⁸⁵ Three of the agreements, however, limited the availability of support to a single area: the ACLU/Quality Trust Sample SDMA (finances); ASAN (Autism

Anticipating its use in restoration proceedings, DRNY urged that our template look as much like a standard Power of Attorney (PoA) as possible so it would appear familiar to courts. Other advocates wanted the agreement to be more informal and individualized, and in “easy read” format.⁸⁶ There were spirited discussions among staff and partners, and drafts circulated to the Advisory Council, with a special, in-person review meeting with self-advocates.⁸⁷

In the end, while the SDMNY template resembles a legal document, it has, as requested by self-advocates, the Decision-Maker’s name in larger type than any agreement any of the lawyers among us have ever seen. It describes the process the Decision-Maker and her/his supporters have engaged in and is signed not only by the parties to the agreement, but also by the facilitator. It follows the “Big Four” architecture,⁸⁸ with an open-ended list of areas of support, as determined by the Decision-Maker, permits one or more than one supporter for each chosen area, with the possibility that supporters will offer one or more kinds of support, and specifies the kinds of support desired by the Decision-Maker. While the structure is prescribed, the content is intended to be individualized, with only a few exceptions, including a provision that the Decision-Maker can terminate or alter the agreement, including removing, replacing or adding supporters at any time.

The template contains a statement that the Decision-Maker wishes third parties to honor her/his decisions, provides that the Decision-Maker is not obligated to use support in making her/his decisions,⁸⁹ and that the Supporters sign an attestation that they will honor the Decision-Maker’s right to make her/his own

Self Advocacy Network) Supported health Care (healthcare); and District of Columbia Public Schools (education).

⁸⁶ See, e.g., *A Guide to Making Easy Read Information*, OFFICE FOR DISABILITY ISSUES, <https://www.odi.govt.nz/guidance-and-resources/a-guide-to-making-easy-read-information> (last visited Jan. 16, 2020).

⁸⁷ While meetings with other stakeholders could be held via teleconference, we found that in-person meetings better met the needs of most self-advocates and were considerably more productive.

⁸⁸ The one exception is the “how” support is to be delivered. Since this is basically a logistical issue, and subject to frequent, and frequently necessary change, it was thought to make any agreement too cumbersome.

⁸⁹ This was an important provision for self-advocates who feared that signing an SDMA might be used to show they were “incompetent,” and that services might be refused if they chose not to use support in a particular situation.

decisions, not substitute their own decisions, and not engage in conflicts of interest or undue influence.

Thus far the template has proved successful, with each of the ten signed SDMAs to date “customized” to meet the specific wishes of each Decision-Maker, as agreed to by her/his supporters, but also recognizable as the product of SDMNY facilitation. Decision-Makers have come up with areas for support (e.g., “support for bi-romantic, non-sexual relationships,” “career and professional development as an advocate,” “education as a life-long learner”), or particular kinds of support (e.g., “[h]elp [to] create the space for me to communicate my ideas and decisions to others [because t]here are times when I need assistance to speak in a group or meeting”) that had never occurred to anyone in the project, but that faithfully convey where, and in what ways the Decision-Maker wishes support.

Despite this success we have thus far declined to make the template public. Because SDMNY is a pilot project, intentionally creating an evidentiary base for SDM, intended to be independently evaluated, and utilizing an extensive and thoughtful structure for creation of its SDMAs, we are concerned about the template’s potential use with or by persons with I/DD without the benefit of a supervised SDMNY-style facilitation process.

D. Methods and Characteristics

Our three-phase facilitation model and facilitator training were developed using information available from pilots from around the world, and based in human rights principles of non-discrimination,⁹⁰ equality,⁹¹ and dignity.⁹² Over the next four years, our understanding and methodology deepened, based on our experience in the two pilots and on that of colleagues in other countries who were refining their work, and/or making it available in English.⁹³ These understandings and changes in

⁹⁰ See G.A. Res. 61/106, *supra* note 5, at art. 3(b) (“Non-discrimination”).

⁹¹ See *id.* at art. 3(e) (“Equality of opportunity”). Article 12(2) specifically provides that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” *Id.* at art. 12(2).

⁹² See *id.* at art. 3(a) (“Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.”).

⁹³ See, e.g., BIZCHUT, *supra* note 64 (providing extensive materials about the training model developed by Bizchut in Israel).

methods manifested most prominently in expanded conceptualizations about facilitators' relationships to Decision-Makers, to supporters, and about decision-making itself, with resulting refinement of our facilitation methods for each of them.

1. Decision-Makers

A substantial number of Decision-Makers recruited in the first year were transition-age youth still receiving educational services from the Department of Education (DOE)⁹⁴ and living at home with their families. The first real revelation was that, by and large, they had little or no conception of themselves as decision-makers. When asked, in information sessions, sign-up meetings, or during Phase One, what kinds of decisions they were currently making, they often drew a blank. The facilitator's task became to assist them to identify choices and decisions, however simple, that already existed in their lives, and to reflect on the ways in which they were made. Conversations might begin with something like "I see that is a nice shirt you are wearing. Who picked it out?" Or, "[w]hat did you have for breakfast this morning?" "How did you choose it?"

We realized that, in most instances, they had never been taught what decisions are, or how to make them. While neurotypical children learn decision-making "naturally," that is, without a conscious design, children with I/DD may require a more formalized practice and a "scaffolding," beginning with simple "choices" and building to more substantial decisions that have greater consequences.⁹⁵ Neurotypical children may learn

⁹⁴ Transition-age youth are persons with I/DD between the ages of eighteen, when they complete their secondary education, and twenty-one, when they complete "skills" training and transition from DOE services to services through the Office of Persons with Developmental Disabilities (OPWDD). Before they turn twenty-one, OPWDD is required to develop service plans for children referred to it by schools or social service programs if the OPWDD determines them "likely [to] need adult services." N.Y. MENTAL HYG. LAW § 13.37 (McKinney 2020).

⁹⁵ It should be noted, however, that the 1980s and 90s produced a period of relatively rich theoretical, and to a lesser degree empirical, scholarship about decision-making, and teaching decision-making to children and especially to adolescents. See, e.g., Ruth Beyth-Marom et al., *Teaching Decision Making to Adolescents: A Critical Review*, in *TEACHING DECISION MAKING TO ADOLESCENTS* 19 (Jonathan Baron & Rex V. Brown eds., 1991). But that work seems to have tapered off significantly and, with few exceptions, never addressed the specific needs of children, adolescents, and young adults with I/DD.

about consequences by trial and error, by making mistakes and learning from them. Families of children with I/DD tend, for good and obvious reasons, to be more protective of those children. A consequence is that their children's choices are limited in the service of preventing risk and harm. Education for young people with I/DD seldom includes explicit instruction on making decisions; rather, to the extent that a stated goal is self-determination, the emphasis is on "goals," often with professionals and/or family members making the decisions thought necessary for the person with I/DD to reach those goals.⁹⁶

In designing the facilitation model, we had not anticipated that we might need to actually teach Decision-Makers what decisions are, and how to make them. We did, however, consider what Decision-Makers would need in order to successfully participate. We built into the model basic self-determination theory⁹⁷ which promotes intrinsic motivation, as well as social development and well-being.⁹⁸ Because our process is Decision-Maker centered, the model had to foster and promote her/his intrinsic motivation, defined as "the inherent tendency to seek out novelty and challenges, to extend and exercise one's capacities, to explore and to learn."⁹⁹ That is, in order to facilitate a process with real integrity and that could last over time, Decision-Makers had to *want* to engage in the model and to learn how to utilize supports in making decisions in their lives (*intrinsic* motivation), not just to be there because parents or others told them to (*extrinsic*

⁹⁶ A recent article demonstrates how professionals dominate the IEP (Individual Education Program) meetings that are intended to move students to self-determination, with parents having only very limited participation, and with no mention at all of student participation. Jennifer A. Kurth et al., *A Description of Parent Input in IEP Development Through an Analysis of IEP Documents*, 57 INTELL. & DEVELOPMENTAL DISABILITIES 485 (2019).

⁹⁷ Self-determination and decision-making are not the same thing, but self-determination, which "foster[s] . . . positive human potential[]," is an important precondition for an individual's ability to make decisions about her/his life. Richard M. Ryan & Edward L. Deci, *Self Determination Theory and the Facilitation of Intrinsic Motivation, Social Development, and Well-Being*, 55 AMERICAN PSYCHOLOGIST 68, 68 (2000). See Alan Hoffman, *Teaching Decision Making to Students with Learning Disabilities by Promoting Self-Determination*, ERIC DIGEST (2003), <https://files.eric.ed.gov/fulltext/ED481859.pdf> ("If we support students in becoming more self-determined, we are, in essence, enabling them to learn how to make choices and decisions. . .").

⁹⁸ It is important to understand that self-determination theory is not confined to persons with I/DD; it applies to, and has been studied with, all the rest of "us" as well.

⁹⁹ Ryan & Deci, *supra* note 97, at 70.

motivation).

Cognitive Evaluation Theory (CET) is a subset of self-determination theory that looks at the environmental factors that promote or undermine intrinsic motivation, focusing on competence, autonomy and relatedness.¹⁰⁰ Competence, or the sense of personal efficacy, depends on, and can be fostered by external factors, including feedback, communication and rewards. For people to experience competence, they must also experience their behavior as self-determined, or autonomous, which requires contextual support for autonomy. Finally, and especially in the context of learning, intrinsic motivation is “more likely to flourish in contexts characterized by a sense of security and relatedness.”¹⁰¹

Applying these principles to the facilitation model meant establishing a “right relationship” between the facilitator and Decision-Maker that the Decision-Maker would experience as “safe.” The relationship had to be one of equality and mutual respect, rather than domination and subordination. The facilitator had to understand and treat the Decision-Maker as a capable and autonomous person, and provide a context for continuous feedback. The facilitator would need to explicitly acknowledge and show appreciation for the Decision-Maker’s competence in, for example completion of the Big Four Chart, and/or her/his exertion of leadership in Phase Three meetings.

We realized that the theoretical underpinnings of self-determination and intrinsic motivation that we were consciously building into the facilitation model and facilitator training were equally relevant to the actual process of SDM, because the latter also depended on the Decision-Maker’s sense of competence, respect and support for her/his autonomy by supporters, in a setting of trust and “right relationship.”¹⁰² We instrumentalized this confluence in an appreciation that the facilitation process should, as consciously as possible, actively model SDM practice to prepare the Decision-Maker for success and give her/him and her/his supporters the tools for going forward. As the Facilitator’s Manual puts it, “[t]hrough the SDMNY facilitation

¹⁰⁰ CET was first propounded by Deci & Ryan in 1985. See EDWARD L. DECI & RICHARD M. RYAN, INTRINSIC MOTIVATION AND SELF-DETERMINATION IN HUMAN BEHAVIOR 43 (1985).

¹⁰¹ Ryan & Deci, *supra* note 97, at 71.

¹⁰² See Telephone Interview with Michael Kendrick, *supra* note 71.

process, the DM and Supporters develop an appreciation for each other's knowledge, skills, and individual perspectives, while proceeding from a place of respect for the DM as an autonomous human being who is capable of making decisions."¹⁰³

In hindsight, although without setting out to teach decision-making, our facilitation process itself models that skill for Decision-Makers, and gives them opportunities to practice it in, for example, choosing supporters. It allows them to receive feedback that in turn enhances their sense of competence and autonomy. Generally available materials on teaching decision-making¹⁰⁴ also confirm that in presenting the kinds of support a Decision-Maker might want in a given area,¹⁰⁵ we have essentially described the elements and process of decision-making.

Understanding the possible choices in filling out the "What" portion of the Big Four chart has proven more difficult for Decision-Makers than anticipated, but working through that difficulty has provided an unexpected bonus. Rather than relying on the abstractions in the kinds of support we present, the facilitator can take a Decision-Maker through some decisions s/he has, or is about to make, utilizing the support typology. This more concretely demonstrates how decisions are made, and the steps a Decision-Maker needs to take, with or without support, in doing so.

For example, the facilitator might ask about how the Decision-Maker chose what to wear that day. What kind of information—the weather report, what clothes were clean and available—did s/he need in order to decide? Did she need to understand what the weather information on the tv news meant about the

¹⁰³ SDMNY, *supra* note 75, at 31.

¹⁰⁴ See, e.g., *Teaching Decision-Making Skills (For Parents of Children with Developmental Disabilities)*, SEXUALITY RESOURCE CENTER FOR PARENTS, http://www.srcp.org/for_some_parents/developmental_disabilities/activities_to_use_with_your_child/decisionDD.html (last visited Jan. 23, 2020); *Responsible Decision-Making Free Activity*, TEACHERS PAY TEACHERS, <https://teacherspayteachers.com/Product/Responsible-Decision-Making-Free-Activity-3767842> (last visited Jan. 23, 2020). There are also numerous other resources on teaching decision-making for teachers of various age groups.

¹⁰⁵ See SDMNY, *supra* note 75, at 15 (listing kinds of supports). While we do not want to unnecessarily curtail the kinds of supports any individual Decision-Maker might choose by utilizing a prescribed number of stated possibilities, we find it useful to present Decision-Makers with a manageable list, drawn both from the work of other pilots and our common experience of what we all use when we ask and receive support from others. Decision-Makers are, of course, free to add their own, and several have done so.

conditions s/he would encounter during the day? If s/he chose a particular outfit, might there be another one that could better accommodate the changes in temperature s/he would encounter at different times and in different places during the day? Or that might present her/him in a different manner? What was more important, comfort or fashion? Did you have to tell someone about your decision, or get help in carrying it out? (For example, a person with physical disabilities might need assistance in dressing). Facilitating a Decision-Maker in thinking about, and answering these questions is, it turns out, also teaching decision-making.¹⁰⁶

2. Supporters

When we designed the three-phase model, we were unaware of,¹⁰⁷ or oblivious to,¹⁰⁸ empirical research on the ways in which family members, caretakers and residential facility staff informally support decisions by persons with I/DD who are not under guardianship. That research, however, contains important insights that should inform any SDM facilitation. While it

¹⁰⁶ Learning does not occur on a one-off basis, so to make an impact, repetition utilizing different choices and decisions is critical. And, of course, this “unpacking” of decisions in the course of facilitation cannot compare with the kind of structured learning over time that should be part of any young person’s education. See *Curriculum for Teaching Decision Making*, DECISION EDUCATION FOUNDATION, <https://www.decisioneducation.org/curriculum> (last visited Jan. 23, 2020) (calling on educators and provides materials “to teach everyone how to make the best decisions possible in every decision-making situation”). See also Abigail Brenner, *The Importance of Making Decisions: The Basics of Mastering an Essential Life Skill*, PSYCHOLOGY TODAY, <https://www.psychologytoday.com/us/blog/in-flux/201505/the-importance-learning-how-make-decisions> (last visited Jan. 23, 2020) (“[d]ecision making is something we all need to learn how to do. This very essential life skill should be taught from very early on.”).

¹⁰⁷ One significant obstacle in accessing the work being done around the world (in addition to its being written in languages not translated into English) is that much of it is published in proprietary scholarly journals to which there is no open access. Unlike most law reviews, articles in these journals, which are the source of much research about intellectual and developmental disabilities, are only available, at considerable cost, frequently \$44.00 for 24 hours of web access without reprint capability. These specialized journals are often European or Australian, and in an age of ever-reduced budgets, are not available in most, if not all, U.S. libraries.

¹⁰⁸ We assumed we had enough information about how to work with supporters from what we knew of other pilots, and had we been aware of the existence of such research, we might not have understood its salience to our project.

confirms much of what we have done, it also provides a somewhat different lens through which to see the task that we originally labeled “repositioning,” also moving the model toward “capacity-building.”

One way in which we thought and spoke about “re-positioning” was to draw an analogy to the changing relationship parents almost inevitably experience with their neurotypical children as they reach adulthood. This move from being the protector, who knows best, and whose decisions are final, often happens with a great deal of *sturm und drang*. But as parents begin to see their adult children more as adults, and less as children, the relationship inevitably shifts to recognition, acceptance and appreciation of them as autonomous, and hopefully responsible, fully human beings.

This transition is far more problematic for parents of young adults with I/DD because of their perceived, and often real vulnerabilities. All parents protect their children, but as those children grow older, they learn to, and hopefully do protect themselves. Persons with I/DD have historically been seen as “eternal children,”¹⁰⁹ so the impulse and perceived need to protect and control is exponentially stronger and more difficult to relinquish. Parents are not the only ones who see persons with I/DD as in need of protection rather than supported in developing autonomy. Whether out of stereotype or fear of liability, caretakers and provider staff may similarly adopt a “protective parent” role.

“Repositioning” was intended to expose these dynamics, to offer a different, more hopeful vision of the person with I/DD as someone who could, and should, learn and grow, be afforded, and earn respect. It includes thoughtful consideration of “the dignity of risk” that encourages parents to see that an excessive emphasis on protection not only infantilizes their adult children, but also deprives them of the ability to experience responsibility for their actions, and to learn from their mistakes. As the Facilitator’s Manual points out,

By supporting dignity of risk and encouraging [Decision-Makers] to make decisions and take chances, Supporters can help combat learned helplessness and bolster [the] Decision-Makers’ self-

¹⁰⁹ See Janice Brockley, *Rearing the Child Who Never Grew: Ideologies of Parenting and Intellectual Disability in American History*, in MENTAL RETARDATION IN AMERICA 130 (Steve Noll & James Trent, Jr. eds. 2004).

esteem, self-respect, empowerment, and hope. And learning from her or his mistakes while [parents] are still around [can make them more confident] that s/he will have a good life and be able to make good and healthy choices, if and when the [parent] is not.¹¹⁰

This is what all parents want, and “re-positioning” was meant to help them see that it is possible for—and, indeed, owed—to their adult children, regardless of their disability.

The empirical research presented a more nuanced version of the barriers to meaningful support for parents and others. Researchers from LaTrobe University engaged in a four-phase research program including studies of support for decisions outside the realm of formally recognized SDM.¹¹¹ For example, in one study they interviewed a total of twenty-three family members and twelve workers in disability care services about how they supported persons with I/DD in making their decision. They found:

Supporters simultaneously drew on ideas about rights, practicalities, and risks, which one likened to “twirling two plates on a stick.” The juggling of these three concepts, and the influence exercised by supporters tempered the extent that the will, preferences, and rights of those supported were respected in the decision support process.¹¹²

Examples based on “paternalism, best interest, or values and self-interest of the supporter,”¹¹³ and “perceptions about available resources or support and issues of risk” suggest that, in developing an SDM practice for supporters, “[a]voiding premature foreclosure of options and finding ways to enable risk that minimise harm without changing a person’s preferred choice

¹¹⁰ SDMNY, *supra* note 75, at 60.

¹¹¹ These studies resulted in thirteen published articles. See Douglas & Bigby, *supra* note 47 (listing these thirteen studies).

¹¹² Christine Bigby et al., *Providing Support for Decision Making to Adults with Intellectual Disability: Perspectives of Family Members and Workers in Disability Support Services*, 44 J. INTELL. & DEVELOPMENTAL DISABILITIES 396, 406 (2017).

¹¹³ This typology was derived from Clare M. Dunn & A. Holland, *Living a Life “like ours” Support Worker Accounts of Substitute Decision Making in Residential Care Homes for Adults with Intellectual Disabilities*, 54 J. INTELLECTUAL DISABILITY RES. 144 (2010).

is a major challenge to be addressed.”¹¹⁴ Another takeaway from that study that suggests the need for our further attention was that “supporters whether family members or volunteers valued assistance from program coordinators to navigate the often complex issues they confronted in providing decision making support.”¹¹⁵

Reviewing all the studies, researchers found a diverse group of factors relating to how support is provided and what they term “strategies used.” Their findings demonstrated that

people with cognitive disabilities have a “positive” or “successful” experience of decision-making support, if support is provided by one or more individuals with whom they have a trusting relationship; who have a knowledge of their history and goals (including previous decisions and outcomes), and the nature of their impairments and level of functioning; who are flexible and use various strategies to tailor their support to . . . each individual; and who collaborate with the individual to reach their desired outcome.¹¹⁶

Some specific concerns were family members’ uncertainty about their roles and potential for their exclusion¹¹⁷ and, importantly as we begin planning an SDMNY mediation model, the need for mediation processes to resolve competing perspectives of formal and informal supporters.¹¹⁸

The goal of the LaTrobe effort was to create a model for how to effectively, and ethically, provide support to persons with I/DD¹¹⁹ The resulting six-step LaTrobe Support for Decision-Making Practice Framework¹²⁰ mirrors, in many ways, the content of our current training for facilitators, but suggests that attention might profitably be paid to providing more of a “capacity building”

¹¹⁴ Bigby, et al., *supra* note 112, at 406.

¹¹⁵ *Id.*

¹¹⁶ Douglas & Bigby, *supra* note 47, at 437.

¹¹⁷ This resonates with a finding from the Pell Report that parents may feel anxiety because the Phase One meetings between the facilitator and the Decision-Maker exclude them. PELL, *supra* note 7, at 17.

¹¹⁸ Bigby et al., *supra* note 112, at 406. Our initial plan for mediation failed to consider such potential conflicts as the subject of mediation.

¹¹⁹ The specific focus of their research and the resulting model was Persons with I/DD and, to a lesser extent, persons with TBI, but the authors suggest additional evaluation of the framework for older persons with dementia, etc., and persons with psychosocial disabilities. *Id.*

¹²⁰ *Id.* at 398, 399.

approach¹²¹ for supporters in Phase Two. This could include more explicit information about, and facilitation in, the *kinds* of support that Decision-Makers desire, and that they may be asked to give, even as we have come to understand the need for greater clarity in that area for Decision-Makers.

The LaTrobe project also proposed three principles to inform support: commitment, orchestration,¹²² and reflection and review. Although we have been conscious of, and attentive to, the need for reflection for facilitators,¹²³ the LaTrobe work foregrounds a similar need for supporters, especially if they are to function with fealty to a rights-based model of SDM over time.

A comprehensive review of the six Australian pilot projects¹²⁴ reinforced many of these lessons, noting the value of training and capacity-building for supporters, oversight of their role, and the availability of support and advice by program staff.¹²⁵ As a result we now plan a “Supporters’ Guide”¹²⁶ in Year Five, drawing on

¹²¹ For a thoughtful explication of capacity building for supporters and the importance of acknowledging (and correcting for) the potential for unnoticed and/or unconscious threats to a Decision Maker’s autonomy in making decisions, see Terry Carney, *Supported Decision-Making in Australia: Meeting the Challenge of Moving From Capacity to Capacity Building*, 35 *DISABILITY, RTS. & L. REFORM AUSTL.*, 44 (2017).

¹²² Orchestration here includes the ability to understand and coordinate with other supporters, as well as with other important persons in the Decision-Maker’s life. Bigby et al., *supra* note 112, at 406. This is, however, problematic, since the supporter’s overriding obligation is to support the Decision-Maker. This tension has been noted in another article that reported tension between the supporter’s role and consequent conflict with others involved in the Decision-Maker’s life that had to be negotiated. Supporters had to find a balance between respecting a person’s autonomy, supporting their dignity of risk, and ensuring their safety. The challenges of doing this were sometimes compounded by value clashes with others involved in the person’s life who might oppose a decision or assume it should simply be made for the person in their best interests. *Id.* at 406.

¹²³ This is provided both through constant interaction between facilitators and their mentors, and by “community of practice” monthly calls where facilitators exchange experiences, share issues that have arisen, and work toward developing ‘best practices.’

¹²⁴ See Bigby et al., *supra* note 112.

¹²⁵ Looking forward to potential expansion of our pilot, it will be important to think whether such support is feasible, and, if so, from whom it should come.

¹²⁶ Hopefully, that guide will “pinpoint[] practical strategies . . . underpinning [the] knowledge base used in decision-making support and identify[ing] aspects, such as being neutral, managing risk, avoiding influence, and foreclosing options by being realistic[,] . . . that are more challenging for supporters to navigate than practical support.” Bigby et al., *supra* note 112, at 406–07.

newer empirical research and proposals, and grounded in the experiences of supporters and, importantly, Decision- Makers, in our pilots.¹²⁷

E. Participants

We began, rather naively, with an assumption that it would be relatively easy to recruit both Decision-Makers and, to a lesser degree, facilitators. For the former, because of the enormous benefits we thought SDM would bring, it was a kind of “Field of Dreams”¹²⁸ view, which all too quickly proved seriously mistaken.

1. Decision-Makers

An initial decision, consistent with our core principle that the facilitation process be Decision-Maker centered, was that potential Decision-Makers should choose us, not be chosen *by* us. That is, rather than working with persons with I/DD who had been identified as appropriate for the project by others (provider staff, parents, etc.) we have insisted on a Decision-Maker’s affirmative choice to participate.

School information sessions are run simultaneously for parents and students. There have been occasions when enthusiastic parents set up a one-on one sign-up meeting with SDMNY staff¹²⁹ and their adult child, but, after that meeting, and despite a thorough explanation of SDM, the young person indicated that s/he did not want to be part of the project. Staff explained to the disappointed and sometimes disgruntled parent, that while we hoped that s/he might change her /his mind at some later time, and while we were available to talk again, it was the adult child’s choice, not theirs.

¹²⁷ Optimally, if resources permit, we will be able to convene a number of focus groups to explore these issues.

¹²⁸ “If you build it, they will come.” FIELD OF DREAMS (Universal Pictures 1989).

¹²⁹ When we receive an indication of interest, either in person, at an information session, by phone or through our website, we set up a meeting with the prospective Decision-Maker where SDM is explained, the facilitation process described, and any questions answered. If the DM chooses to go ahead, s/he signs a consent form if s/he is eighteen or over and not under guardianship, or an assent form if underage or under guardianship. By the same token, when parents of adult children not subject to guardianship are involved, they sign “assents”, while we have them sign consents if they have legal authority over the prospective Decision-Maker, either because of age or guardianship status.

Older persons with I/DD who we may first meet at an information session sponsored by a self-advocacy group, also have a sign-up meeting at which they may or may not continue on to sign a consent form and proceed. Where persons were under guardianship, we initially limited participation to those whose guardians were willing to give consent,¹³⁰ Over time we have softened that position and, under some circumstances, may have several Phase One meetings before the guardian is approached and asked for consent.

While this has been a principled position from the beginning, which seems important to the integrity of our process, it has also come at considerable cost. Recruiting Decision-Makers in this way has proven infinitely more time and resource consuming than we anticipated in the planning stage of the project.

2. Schools

Because transition-age youth were an obvious cohort from which to recruit, we had plans to work with three different kinds of schools: a private, “special needs” school; a public school that was part of New York City Department of Education (DOE) “District 75”¹³¹; and a charter school. Through personal contacts, we began with the first, Cooke School, which serves special education students from kindergarten to post-secondary “skills” training through age twenty-one and has a mission that resonates with SDM.¹³² At that time, we expected to move quickly onto the second two schools, but that never happened.

¹³⁰ This was largely a matter of resource allocation, as we assumed that an adversarial guardian would require enormous amounts of staff and legal time, and the “deliverables” required by our grant might be impossible to meet. In addition, we hoped to incrementally develop case law with good decisions on restoration where there was a strong record including successfully completing the SDMNY process, having a committed group of supporters, and the “blessing” (or at least not the opposition) of the guardian, and then to expand the cases we took to included potentially contested restoration petitions.

¹³¹ “District 75” is the non-geographically bounded school district that serves children and young adults with a variety of intellectual, developmental and learning disabilities, emotional impairments and multiple disabilities. See *District 75*, NYC DEP’T OF EDUC., <https://www.schools.nyc.gov/learning/special-education/school-settings/district-75> (last visited Feb. 24, 2020).

¹³² See *About Cooke*, COOKE SCHOOL, <https://cookeschool.org/about> (last visited Feb. 24, 2020) (“Cooke envisions a world in which all people with special needs are included as valued members of their communities, leading independent and purposeful lives.”).

Our experience with Cooke, though hardly proceeding as planned, has been enormously successful, and taught us valuable lessons. We began with several meetings with leadership and senior staff, and spent a day at the school, visiting classes, talking with students and teachers, and coming away deeply impressed with Cooke's commitment to nurturing and promoting the full personhood of their students. When we did our first information session for parents in December 2016, we expected an enthusiastic reception, and a number of sign-ups; instead there were doubts, concerns, and, alas, no Decision-Makers.

It took several more information sessions before the first sign up,¹³³ and still more time before the second. Throughout this period, we remained in contact with supportive staff. Over time there were more sign ups, and as Cooke Decision-Makers advanced through the facilitation process, word began to spread, with both students and parents becoming more receptive. Our first SDMA signing ceremony, on September 25, 2018, involved two Cooke students, and took place at the school, with teachers, staff and leadership present.¹³⁴ Consistent and repeated interaction with staff and teachers, many information sessions for students and parents, and the successes of the Cooke Decision-Makers to date have made SDMNY a valued partner in the Cooke family, but it has taken time, perseverance, and considerable commitment of limited resources.

Overtures to a number of other schools and school-connected programs,¹³⁵ ran into various obstacles—the departure of our contact person, non-cooperation by a provider agency that was serving students, staff overwhelmed by other demands, etc. Primarily for resource reasons, we were unable to commit the time and energy to “push through” those obstacles.

We have, however, been able to engage in an especially constructive way with another private special needs school. The Transition Director of the Rebecca School¹³⁶ became interested in

¹³³ This was a student whose parents had attended the first session and spent a considerable amount of time mulling over their son's participation.

¹³⁴ *Young Adults at Cooke SKILLS First to Sign Supported Decision-Making Agreements in New York State as Part of SDMNY*, SDMNY (Sep. 25, 2018), <https://sdmny.org/news> [<https://perma.cc/EER9-9H88>].

¹³⁵ See *College Programs*, AHRC, <https://www.ahrcnyc.org/services/school/college> (last visited Mar. 29, 2020). These included students in post-secondary education at CUNY Colleges through the Melissa Riggio Scholars Program.

¹³⁶ See REBECCA SCHOOL, <https://rebeccaschool.org> (last visited Mar. 29, 2020).

our work and he and his assistant both completed Facilitator Training. Information sessions at the school resulted in two initial sign-ups, with the “in-house” facilitators working with two young adult Decision-Makers. The Rebecca commitment has been more extensive, however, as the Transition Director is building on their experience and beginning to add SDM to the transition curriculum, a development we hope will bear fruit and can be expanded elsewhere.

3. Provider Agencies

Another source that we expected to be a major provider of Decision-Makers was the community of provider agencies, especially because of their close connections with the New York Alliance, of which most were members. We had meetings with leadership of four of the largest provider agencies in New York City whose values aligned with SDM. The “ask” was both the ability to hold information sessions for their clients with I/DD and the families they served, and for facilitators.¹³⁷ We subsequently held one or more sessions at each of the agencies, for participants in their self-advocacy or self-determination groups,¹³⁸ for family members, and in two instances, for staff. Over more than two years we expended a significant amount of effort with a number of different agencies with little or no return, and no Decision-Makers. In retrospect we might have been more successful by targeting one agency that seemed especially promising, and engaging in a more focused and ongoing relationship similar to what was successful with Cooke.

4. Self-Advocacy Groups

Not surprisingly, although with unanticipated complications, groups of self-advocates proved a fertile source of recruitment. Our Project Coordinator had a pre-existing relationship with SANYS, the statewide self-advocacy organization, and we did a number of information sessions for the SANYS New York City Chapter, as well as at its statewide convention. We have recruited a number of Decision-Makers through SANYS; our

¹³⁷ See discussion *infra* Section II(E)(7).

¹³⁸ We assumed that these were more focused recruitment targets because of their purpose to foster independence and autonomy, and would likely have a good “yield” of prospective Decision-Makers.

second SDMA signing ceremony, for three Decision-Makers, took place at its Manhattan offices.¹³⁹

We have also had an ongoing relationship with Outside Voices Theater Company, comprised of people with I/DD, that we initially approached to make training videos for our ToFs. Several members became interested in our process, and subsequently became Decision-Makers. Outside Voices has also become a source of referrals.¹⁴⁰

What we had not expected, but from which, with appropriate humility, we learned and profited, was skepticism about SDM, including from some prominent self-advocates. They said that they had managed, and managed successfully, without SDM, which they saw as yet another “service” to be foisted upon them. One leading self-advocate, Tony Phillips said,

At first, I was skeptical about [SDM]. For so long, I have had to prove to others that I can do things independently. I was very used to having to tell people I did things on my own, without others’ support. But then I had an experience that helped me to understand that I can be independent and also need support at the same time.¹⁴¹

Despite the potential he sees in SDM, he warns:

[I]t can’t be just another service. And that’s what going to happen if it’s something that only agencies do. It has to be something that persons with disabilities can do on their own, without agencies. Sure, I’m getting some help from the SDMNY program, but it’s different from working with an agency in lots of ways: most importantly, because once I have my agreement in place, and once my supporters are on the same page, it’s mine to do what I want with. I don’t have to depend on the program to do what I want to do the same way I have to depend on the agencies. And that’s important. That’s independence.¹⁴²

¹³⁹ *Second Supported Decision-Making Signings at SANYS New York City*, SDMNY (Dec. 17, 2018), <https://sdmny.org/news> [<https://perma.cc/EER9-9H88>].

¹⁴⁰ *See Videos: Voices of Self-Advocates*, SDMNY, <https://sdmny.org/sdmny-videos-voices-of-self-advocates> (last visited Mar. 29, 2020). We commissioned several short videos on aspects of SDM that have been very well received, and that are featured on our website. *See* discussion *infra* III(B)(i).

¹⁴¹ Tony Phillips, SANYS Board Member, Remarks at the United Nations Conference of State Parties to the CRPD (June 13, 2017) (on file with author).

¹⁴² *Id.*

5. Lawyers and the Court System

The SDMNY Project Director was involved in the American Bar Association (ABA) project to provide a tool for attorneys of persons seeking guardianship that provided for alternatives, the “PRACTICAL” tool,¹⁴³ the ABA Resolution on SDM,¹⁴⁴ and a Report of the Committees on Mental Health Law and Disability Law of the New York City Bar Association on reform of SCPA 17-A that stressed the use of less restrictive alternatives to guardianship, and is a recognized authority on the subject within the organized bar. She recruited several leaders of relevant committees of the state and city bar associations to the SDMNY Advisory Council, and presented on SDM and the SDMNY pilots at various bar association meetings.

We anticipated some resistance/opposition from attorneys whose practices were largely devoted to representing petitioners in guardianship cases, so we were not surprised when our outreach did not initially produce referrals. Over time, however, several private lawyers have begun to raise the possibility of SDM with their clients. More profitable thus far has been our relationship with Mental Hygiene Legal Service (MHLS)¹⁴⁵ the statutory entity, located within the NYS Court system’s Appellate Divisions. As a matter of law MHLS represents persons with I/DD and older persons with cognitive impairment living in institutions, but is often called upon to participate in pending or threatened guardianship proceedings. As such, they have made several referrals and, after a statewide training planned for April, we expect that there will be more.

The Project Director is also a retired Surrogate Judge and continues as a member of the NYS Surrogate’s Association. She

¹⁴³ See *PRACTICAL Tool*, ABA, https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool/ (May 8, 2016) (The “P” in PRACTICAL stands for “presume capacity,” and the “C” for “consider alternatives”).

¹⁴⁴ See COMM’N ON DISABILITY RIGHTS, *supra* note 6. The resolution affirmatively recognized and promoted SDM as a less restrictive alternative to guardianship, encouraging legislators to pass or amend statutes requiring SDM to be considered before guardianship could be imposed, and judges, in the absence of such legislation, to consider SDM as a less restrictive alternative, precluding guardianship.

¹⁴⁵ The Director of MHLS in one of the four Appellate Division Departments is a member of the SDMNY Advisory Committee and we have done a number of presentations on SDM both for MHLS leadership and its staff attorneys.

has presented on SDM and SDMNY at Surrogate's Association meetings, as has Advisory Committee member Prof. Arlene Kanter, and she and Brooklyn Law School Prof. Amy Mulzer have done SDM presentations at the annual NYS Judicial Training Institute. She has written articles on SDM for the ABA *Judges Journal* and the NYS Bar Association Elder Law & Special Needs Section.¹⁴⁶ Three Surrogate Judges are members of the SDMNY Advisory Council.

All of this has resulted in interest in SDM as an alternative to guardianship,¹⁴⁷ especially as reform of SCPA 17-A seems stalled. Several Surrogate's Courts have information about SDM and SDMNY in their Clerk's offices, resulting in referrals from those offices.¹⁴⁸ Several Surrogates have also referred Respondents who they thought might benefit from our program. While the petitioner parents in such referrals may be angry that their efforts to obtain guardianship have been delayed or thwarted, two such referrals have resulted in sign-ups, and several more are in process. As understanding the benefits of SDM for persons with I/DD and the courts expands, we look forward to more such diversions.

We are also excited about our first rights restoration case that will be based on the successful completion of the SDMNY facilitation process by one of our Decision-Makers, a person currently under guardianship, and the existence of an SDMA that was its culmination.¹⁴⁹

6. Faith-based organizations

We had been thinking about faith-based organizations for some time, when, by serendipity, two social workers from the Marlene

¹⁴⁶ See Kristin Booth Glen, *What Judges Need to Know About Supported Decision-Making and Why*, 58 JUDGES J. 26 (2019); Kristin Booth Glen, *Supported Decision-Making: What You Need to Know and Why*, 23 NYSBA HEALTH L. J. 93 (2018).

¹⁴⁷ See *Case Law*, SDMNY, <https://sdmny.org/downloads/case-law> (last visited Mar. 29, 2020). The work of educating judges about SDM is also beginning to appear in decisions denying 17-A guardianship petitions and/or terminating guardianships where there is an informal SDM system in place.

¹⁴⁸ One, Richmond County, has instituted information sessions for persons seeking to petition for 17-A guardianship which include information about SDM and SDMNY.

¹⁴⁹ See *SDMNY's Fifth Supported Decision-Making Agreement Signing Ceremony*, SDMNY (Aug. 20, 2019), <https://sdmny.org/news> [<https://perma.cc/EER9-9H88>].

Meyerson Jewish Community Center¹⁵⁰ (JCC) came to a Facilitator Training. There was, as well, a connection through one of our Decision-Makers who was active in programs there. We had several conversations about partnering and held a first information session in September 2018. The SDMNY Site Coordinator deepened our knowledge of the organization and our connection by attending a number of panels and presenting at one of the JCC peer-advocacy groups. Thus far we have recruited five Decision-Makers, and, as the relationship grew, JCC also became the field placement for our first BSW facilitator. In addition to recruitment, JCC is also including SDM in its programming for persons with I/DD, and is becoming a model partnership for SDMNY, which we hope to duplicate elsewhere.

7. Self-Direction Brokers

One way in which qualified persons with I/DD can receive Medicaid services in New York is through “self-direction.”¹⁵¹ On January 3, 2019, following several conversations with SDMNY, OPWDD authorized payment for facilitation services for persons using self-direction.¹⁵² Although we are committed to providing those service for free, the ruling opened up possibilities for sustainability after our grant ends. Equally important, it

¹⁵⁰ The JCC is a large community center on the Upper West Side of Manhattan that “serve[s] as a model of what’s possible in the ever-evolving and diverse Jewish community, incubating innovative programs that are shared nationally.” *About the JCC*, MARLENE MEYERSON JCC, <https://jccmanhattan.org/about-jcc> (last visited Jan. 26, 2020). It sponsors numerous educational, recreational and cultural programs, including the yearly Disability Film Festival, “Reel-Abilities.” JCC serves a non-denominational group of persons with I/DD through several specific programs including “Transitions” for young adults.

¹⁵¹ Self-direction is a way of receiving OPWDD services for persons with I/DD enrolled in the Home and Community Based Services (HCBS) Waiver that permits them flexibility in selecting supports and services that best meet their needs. Individuals can choose an agency to help them self-direct (agency-supported self-direction) or they can manage their budgets and staff with assistance from a Fiscal Intermediary and Support Broker (Self-Direction with Budget and Employer Authority). See OPWDD, SELF-DIRECTION GUIDANCE FOR PROVIDERS 10 (Mar. 8, 2018), https://opwdd.ny.gov/system/files/documents/2020/01/selfdirection_guidance_030818_0.pdf (last visited Mar. 29, 2020). HCBS Waivers are authorized by 42 U.S.C. §§ 1396(2)(A)(i) (2018).

¹⁵² E-mail from Chad Colarusso, Self-Direction Statewide Coordinator, OPWDD, to Desiree Loucks-Baer, SDM Coordinator, New York Alliance for Inclusion and Innovation (Jan. 3, 2019, 11:24 EST) (on file with author).

enabled us to think about a new cohort of non-volunteer facilitators,¹⁵³ qualified provider agency staff and Support Brokers.

Clearly, because of potential conflict of interest, Support Brokers could or should not facilitate their own clients. There is, however, nothing to prevent them from referring those clients to other Brokers who are SDMNY-trained facilitators. The OPWDD ruling also opened up a new partnership for us, with one of New York State's three University Centers of Excellence in Developmental Disabilities Education, Research and Service (UCEDDs),¹⁵⁴ the Westchester Institute for Human Development (WIHD).¹⁵⁵

The Director of the Community Support Network and Coordinator of Policy at WIHD is a member of our Advisory Council and, in the summer of 2019, we began discussions about a small "mini-pilot." Five WIHD Brokers received facilitator training in September 2019, with plans to refer clients interested in SDM to sign up and be assigned to another broker/facilitator. Other WIHD staff has designed, and will conduct an evaluation of this promising mini-pilot.

F. Facilitators

1. Educational Institutions and Professional Programs

Recruiting—and managing—facilitators has proven at least as challenging as recruiting Decision-Makers. From the beginning, with long-term sustainability in mind, unlike most other pilot projects, we committed to developing a cadre of volunteer facilitators.¹⁵⁶ One of our original Faculty Associates was a

¹⁵³ See discussion *infra* Section IV(B) (proposing expansion of the pool of facilitators).

¹⁵⁴ UCEDDs are funded in every state by the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services (HHS) pursuant to the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. §§ 15061–15066 (2018).

¹⁵⁵ See *About UCEDD*, WESTCHESTER INST. FOR HUMAN DEV., <https://www.wihd.org/about/ucedd> (last visited Feb. 21, 2020).

¹⁵⁶ For example, the CPR/Nonotuck pilot used Nonotuck employees as facilitators, while the large Bulgarian pilot paid its facilitators. See PELL & MULKERN, *supra* note 65, at 4; RADOSLAVA LALCHEVA & MIRYANA MALAMIN, COST BENEFIT ANALYSIS OF SUPPORTED DECISION-MAKING, 32 n.30, 33 n.39 (2014), http://bcnl.org/uploadfiles/documents/Cost%20Effectiveness_SDM.pdf. See also Dimitrova Interview, *supra* note 60, at 19:00–23:00.

professor at the Silberman School of Social Work at Hunter College (“the Social Work School”), and we naively assumed that we would have access to a substantial number of Master’s of Social Work (MSW) students as unpaid facilitators. We believed that educational institutions, especially graduate professional programs,¹⁵⁷ would and should be an important source of facilitators. There were several reasons for this belief.

First, programs like social work, occupational therapy, rehabilitation counseling, etc., would provide a pool of people familiar with, and committed to, persons with I/DD, and who would have, or be learning, useful skill sets. Second, if facilitation were connected to academic credit, students who chose to participate would be highly incentivized to complete their commitments to the project. Third, the pedagogical imperatives of fieldwork require a space for structured reflection that could be extremely useful to the project going forward, but that we might not otherwise be able to provide. Fourth, of enormous potential import for long term sustainability, if we can demonstrate that including facilitation in the fieldwork and/or clinical requirements of salient educational programs is beneficial to both students and the programs themselves, we will have created a rich,¹⁵⁸ reliable and renewable¹⁵⁹ resource for unpaid facilitators in the future.

Unfortunately, despite all the imperatives to begin with MSW students who are located in the very building where SDMNY is

¹⁵⁷ We began by thinking only about students in Master’s degree programs, but learned there were non-graduate programs for persons who would be licensed to do work in the same field, primarily Bachelors of Social Work (BSWs), who, as their title implies require only a Bachelor’s degree plus certain post-degree practicum, and Occupational Therapy Assistants (OTAs) who need only complete a two-year Associate’s degree plus practicum. *See Occupational Therapy Assistants*, AMER. OCCUPATIONAL THERAPY ASS’N (AOTA), <https://www.aota.org/Practice/OT-Assistants.aspx> (last visited Mar. 29, 2020).

¹⁵⁸ There are twenty-seven MSW Social work programs. *See MSW Programs in New York*, MSWGUIDE.ORG, <https://www.mswguide.org/schools/new-york> (last visited Jan. 26, 2020). There are six BSW programs. *See Social Work Schools in New York with Degree Program Descriptions*, STUDY.COM, https://study.com/social_work_school_new_york.html (last visited Jan. 26, 2020). Finally, there are twelve OTA programs in New York State. *See OTA Associate-Degree-Level Programs – Accredited*, AOTA, <https://www.aota.org/Education-Careers/Find-School/AccreditEntryLevel/OTAPrograms.aspx> (last visited Jan. 26, 2020).

¹⁵⁹ Students matriculate, complete their professional programs, graduate, and are inevitably and reliably replaced by a new cohort that is ready to start the cycle—and provide facilitators—all over again.

housed, we were soon to learn that there was a much more serious impediment to utilizing them and, indeed, any professional students whose degrees were dependent on a specified amount of clinical or field work.

Time spent as a facilitator, once the two-day training has been completed, averages two to three hours a month, encompassing a one-hour meeting, preparation time, mentor check-in and recording notes on the SDMNY intranet. Clinical or fieldwork requirements for MSW, BSW and OTA students are in the twenty hour/week range, and assume a single placement, with a single supervisor. To assign a sufficient number of Decision-Makers to, for example, an MSW student, and then to provide mentoring for all those assignments, in order to make up twenty hours a week over the course of one or two semesters, was clearly impossible.¹⁶⁰

When we first approached the Social Work School this credentialing requirement seemed an insurmountable barrier. We then began conversations with the Director of the BSW program, where fieldwork requirements are different and somewhat less stringent. Again, however, the single placement/single supervisor “rule” was invoked, but in this case we were able to find a placement for a BSW student who had already trained as a facilitator at a site, JCC, where she was able to incorporate her facilitation within the scope of her work there.¹⁶¹

Meanwhile, we approached the Occupational Therapy Assistant (OTA) program at La Guardia Community College (LGCC), encouraged by the Occupational Therapy (OT) profession’s commitment to maximize independence and autonomy for their clients, and with core OT/OTA values.¹⁶²

¹⁶⁰ First, it would require that there were at least new twenty-five Decision-Makers available at the beginning of an academic semester, then that meetings would take place regularly and without interruption on a monthly basis, that each Decision-Maker would complete Phase Three by the end of the second semester, and finally that we had the resources to mentor that student for twenty-five or so hours a month. None of these factors was anywhere within the realm of possibility.

¹⁶¹ This, however, was not a solution that could be more broadly employed. To combine facilitation for an agency’s client with other work at that agency meant successfully recruiting Decision-Makers from agencies that were providing fieldwork sites, when, as discussed above, we had never been able to recruit a single Decision-Maker from any agency, and, to further complicate the process, sign-ups would have to happen simultaneously, or nearly simultaneously, with the beginning of a semester.

¹⁶² Occupational Therapy Code of Ethics (2015), 69 AM. J. OCCUPATIONAL THERAPY, Nov.-Dec. 2015, at 2 (“[t]he profession is grounded in seven long-

OTA education is also subject to stringent credentialing requirements,¹⁶³ but the Program and Fieldwork Directors saw the benefits that work with SDMNY could bring to their students, and wholeheartedly committed to finding a “way forward” to make it possible.

In March of 2018 both completed facilitator training along with six students and an Adjunct who would supervise the students in regular meetings for reflection on their work. The first tranche of students began facilitating in the spring of 2018 followed by a second in the following spring, with a third to be trained in February 2020. Although limitations relating to students’ schedules and graduation before completing facilitation led to issues for the NYC Site Coordinator,¹⁶⁴ we concluded that the enthusiasm, commitment and high quality of the students’ work, and the diversity and linguistic capability¹⁶⁵ they brought to the project, more than compensated.¹⁶⁶

Our success there encouraged us to renew efforts with MSWs at the Social Work School. A productive meeting with the Dean created an interesting possibility: if an existing placement site was willing to give up a few hours of the commitment it was owed, the Social Work School would provide a supervisor to allow the MSW student placed there to facilitate a Decision-Maker. Using the good offices of our partner, the New York Alliance who contacted the heads of several provider agencies in New York City, we were able to identify two possible sites, and two MSW students are now facilitating as part of their required fieldwork.

Building on the “mini-pilots” with MSW, BSW and OTA

standing Core Values: (1) Altruism, (2) Equality, (3) Freedom, (4) Justice, (5) Dignity, (6) Truth and (7) Prudence. . . . Freedom and personal choice are paramount in a profession in which the values and desires of the client guide our interventions . . . Justice expresses a state in which . . . diverse communities are organized and structured such that all members can function, flourish, and live a satisfactory life.”)

¹⁶³ See *Occupational Therapy Assistants*, *supra* note 157.

¹⁶⁴ Where facilitation had not been completed, new facilitators had to be assigned, and transition meetings arranged and managed. In some cases, students from the next tranche were able to take over from their LGCC colleagues, and in some the Site Coordinator herself had to take responsibility for continuation.

¹⁶⁵ Like many CUNY students, a number of the LGCC students were themselves immigrants, or first generation and, between them, spoke more than five different languages.

¹⁶⁶ We also continue to work on creative solutions to the scheduling issues in the LGCC program.

students, in late summer 2019, we opined that graduate students in education who were specializing in special ed might be another good source of facilitators. At that point there was inadequate time to explore how they might be able to earn academic credit within the existing curriculum. However, hoping to show the educational, professional and personal value to such students, we obtained a small grant from the New York Community Trust enabling us to pay modest stipends to five students currently facilitating and mentored by a Clinical Professor in the Hunter School of Education and SDMNY Faculty Associate. If this experiment is as successful as it already seems, we hope to find a way to incorporate facilitation into the placement requirements of the graduate education curriculum.

2. Provider Agency Employees

Despite our inability to successfully recruit Decision-Makers, we have had several volunteer facilitators from among the employees of AHRC, SUS, YAI, and HeartShare. By and large, the agency facilitators have done an excellent job, so it would be advantageous to have more of them as volunteers. Their work also suggests that if SDM is to go statewide, there is real capacity in agencies to provide quality facilitation under a mixed model.¹⁶⁷

3. Mediators from CRDCs

One of the initial members of our Advisory Council is a mediator at a CRDC, so we were enthusiastic about the possibility of recruiting volunteers from that community. We understand, however, that the very reasons that people take the time, training and energy to work as volunteer mediators are somewhat at odds with being facilitators.¹⁶⁸ We have come to believe that the unique role that the CRDCs already play in their communities can be best employed in advancing SDM, as already noted,¹⁶⁹ by providing a backup after SDMAs have been reached.

¹⁶⁷ See discussion *supra* Section II(B).

¹⁶⁸ Mediation may take considerable time, but it is essentially a one-off, as opposed to a year or so of one-hour meetings. The result is immediately clear, and when it is finished, there is probably another mediation waiting. For someone willing to give time in larger blocks, even aside from the difference between bringing resolution, and simply putting a process in motion, leads to a different kind of satisfaction.

¹⁶⁹ See *supra* note 81 and accompanying text (discussing the use of CRDCs and their mediators as back-up centers).

4. Parents

Although still in a relatively early stage, we hope to duplicate one of the accomplishments of the Bulgarian pilots; that parents of Decision-Makers who had completed their process became facilitators for other Decision-Makers.¹⁷⁰ Given the relatively small number of Decision-Makers who have completed our program, and the enormous demands on parents of persons with I/DD, we are delighted and encouraged that one parent is already volunteering as a facilitator, and hope that the future will result in more of the same.

5. Volunteers

Another assumption that has been shown to be, at the least, problematic, was that we could recruit and train “ordinary people” as facilitators.¹⁷¹ We decided to test this hypothesis by partnering with an organization, Re-Serve, that pairs retired professionals with non-profits and pays them a modest stipend for their work. There were a number of advantages to working with Re-Serve at the beginning of our process, not the least of which was that they provided liability insurance for volunteers that they placed and paid.¹⁷² They also had a large pool of volunteers with diverse backgrounds and interests who they could reach through social media.

After several meetings at which we explained our program and our needs, a call to their volunteers resulted in two ReServists being trained at our September 2017 Facilitator training with another ReServist trained later. Only one ultimately became a facilitator which we attributed, at least in part,¹⁷³ to their lack of

¹⁷⁰ See Dimitrova Interview, *supra* note 60, at 39:00-40:00.

¹⁷¹ See Glen, *supra* note 8, at 512.

¹⁷² The issue of insurance for facilitators, both in the event that they suffered injury while volunteering, and/or that injury might be caused to the Decision-Maker, has been a troublesome one throughout, and one which we have not entirely solved. When students are facilitating as part of their academic program they are covered by the University’s insurance, and to the extent that project staff are technically employees of the CUNY RF, they are also covered. Going forward, however, this issue clearly requires more, and more expert, attention.

¹⁷³ Another possibility was that ReServists were looking for more regular part-time employment, while facilitation was more sporadic and, if only one Decision-maker was involved, fewer hours than they were hoping to put in.

familiarity and/or discomfort with, working with persons with I/DD. We have, however, maintained a relationship with ReServe, utilizing one of their volunteers to translate some of our materials into Mandarin, and continue to see them as a potential source of specialized assistance.

There is an additional way in which we have sought volunteer facilitators. Each time we schedule a Facilitator Training, DDPIC sends out an email “blast” to all its subscribers, inviting participation. Over time, from the totality of these blasts, we have had eleven of these “true volunteers”¹⁷⁴ of whom seven are currently serving as facilitators, with four having begun, but subsequently dropped out. How viable these otherwise unrelated volunteers¹⁷⁵ are remains to be further explored and evaluated.

6. Mentors

When we began, we gave little thought to mentors for facilitators, except that they should be part of the program design.¹⁷⁶ There was an uninterrogated assumption that staff would initially mentor a number of facilitators, and some of those facilitators, having successfully concluded the process and reached an SDMA with their Decision-Maker, would become mentors. Over time, this early formulation changed in two ways.

First, the importance of mentoring became increasingly apparent. Facilitators who had little or no experience with persons with I/DD needed guidance and not a little “hand-holding.” Moving past Phase One also has presented an ongoing issue for many facilitators and/or their Decision-Makers, some of whom became too comfortable in Phase One, or became anxious about inviting supporters and moving to Phase Two.¹⁷⁷

¹⁷⁴ In early trainings we had persons sign up who were interested in what we were doing or who thought that it was something they might profitably include in their professional work. Because training involves a real investment of staff and financial resources, we now require those who take it to commit to facilitating at least one Decision-Maker. While obviously unenforceable, such requirement at least aspirationally limits participation to those who are genuinely interested in volunteering as facilitators.

¹⁷⁵ There are a number of facilitators who have come to us through connections with the project not enumerated in the categories above, for example, former students of Faculty Associates, staff members of funders with whom project personnel have worked on legal capacity issues over time, and CUNY staff who became aware of the project through their work in student services, etc.

¹⁷⁶ See Glen, *supra* note 8, at 510, 512.

¹⁷⁷ Rather than the three or so Phase One meetings we had planned for,

Increasingly, mentor check-ins serve not only to support the facilitator, and help her/him work through knotty issues, but also as a “nudge” to keep the process moving, sometimes requiring the facilitator to move out of her/his own comfort zone.

In addition, mentoring took on a more important role in documenting the project. The intranet capacity we designed on the SDMNY website includes forms for facilitators and mentors to fill out after every meeting. These forms enable the Project Coordinator and Site Coordinators to follow the progress of each facilitation in some detail, and spot issues that might require intervention.¹⁷⁸ The intranet entries, and the mentor notes in particular, create a record of the kind of problem solving that a pilot project optimally demonstrates, and as a resource for evaluation.

Second, the seamless transition from experienced facilitator to mentor simply did not happen, with one exception.¹⁷⁹ As the number of facilitators and active facilitations continued to increase, the burden on our limited core staff grew exponentially, and the challenge of locating mentors grew accordingly. One reason is that mentoring may lack the immediate gratification and benefits of working one on one with a Decision-Maker in facilitating her/his autonomy and self-determination. To be useful to the project, mentors need to work with a number of facilitators, with the time commitment substantially greater than the single facilitation for which they originally volunteered. For these reasons, we concluded, regrettably, that, unlike facilitators, mentors, other than paid staff, would themselves need to be paid.

G. Evaluators

Independent evaluators were important participants in the CPR/Nonotuck pilot, beginning with the initial project design.¹⁸⁰

some facilitators were holding as many as ten Phase One meetings, and/or stretching Phase One over twelve months.

¹⁷⁸ Sometimes this was the number of Phase One meetings, sometimes the time between meetings, and sometimes, unfortunately, a long absence in entries signaled that a facilitator had disappeared or at least ceased functioning in that position, requiring assignment of a new facilitator and some transitional “repair work” with the Decision-Maker and supporters, if any.

¹⁷⁹ This was the former HeartShare employee who had proven a superb facilitator before he moved to another state, and who is currently mentoring nine facilitators.

¹⁸⁰ The author was a member of the CPR/Nonotuck pilot and participated in

They wrote an extensive process evaluation after the first year¹⁸¹ that guided subsequent activities, and a program and participant evaluation after the second year,¹⁸² that has similarly informed CPR's recent efforts to expand the pilot.¹⁸³ We were excited that DDPC had allocated funds for, and had chosen an independent evaluator simultaneously with, the grant to SDMNY. We looked forward to a similarly helpful collaboration that was, of course, also appropriately respectful of the evaluator's independence.

One of the primary criticisms of SDM to date has been the lack of empirical evidence as to whether it really works, and whether the decisions made using SDM are, authentically, the decisions of the person utilizing the process. A leading and oft-cited article raising questions about the lack of an evidentiary base for SDM¹⁸⁴ concludes by listing a number of areas for future research necessary to allow policy makers "to actually design and implement practices which effectively empower persons with intellectual and cognitive disabilities to engage to the fullest extent possible in decisions about their own lives."¹⁸⁵

Some of those areas relate to the decisions that will be made utilizing SDM which, in our case, will require more time to have enough decisions¹⁸⁶ made pursuant to SDMA's. Others, however, go to the relationship between Decision-Makers and supporters, which has been a focus of our facilitation process¹⁸⁷ For example, the article's first "area[] for future research" asks how Decision-Makers and supporters interact, and the techniques utilized in practicing SDM.¹⁸⁸ The second asks about the possibility of coercion and/or undue influence, and how they may be influenced by the supported decision-making relationship.¹⁸⁹ Both of these

planning for design and implementation from the earliest days of that project.

¹⁸¹ See PELL & MULKERN, *supra* note 65.

¹⁸² HSRI REPORT 2016, *supra* note 58, at 8.

¹⁸³ CTR. FOR PUB. REPRESENTATION, *Massachusetts SDM Pilot*, <https://supporteddecisions.org/supported-decision-making-pilots/massachusetts-sdm-pilot> (last visited Mar. 25, 2020).

¹⁸⁴ Kohn et al., *supra* note 10, at 1112.

¹⁸⁵ *Id.* at 1155–56.

¹⁸⁶ We are beginning to have information about how Decision-Makers are using their SDMA through support group meetings we are holding and have suggested to the project evaluators that similar format might be useful when they begin their evaluation of the Decision-Makers.

¹⁸⁷ See *supra* notes 66–67 and accompanying text (discussing our use of salient theoretical and empirical knowledge in structuring our work with supporters).

¹⁸⁸ Kohn et al., *supra* note 10, at 1156.

¹⁸⁹ *Id.*

are subjects that we have thought about deeply, and about which we continue to learn from the experience of our participants.

Given the project's remit from DDPC to test SDM as an alternative to guardianship, there is at least one other area that calls for interrogation and evaluation. We need to know what concerns cause parents and others to seek—or actually obtain—guardianship in the first instance. We need to know whether, during the facilitation process and thereafter, they gain confidence in the ability of their loved one to make her/his own decisions with support. We need to know whether, after facilitation has been completed, earlier concerns have been ameliorated, and plans for guardianship abandoned. We need to know whether those who already hold guardianship see the facilitation process and the Decision-Maker's use of SDM as grounds for terminating the guardianship.¹⁹⁰

Unfortunately, after two years, the initial evaluator left the project. DDPC then issued a new RFP, eventually selecting the Burton Blatt Institute of Syracuse University (BBI)¹⁹¹ which began its three-year contract in April 2019. Prior to that date, and in the lacunae that followed departure of the first evaluator, we were able to commission a small independent evaluation to raise the “additional questions” described above. We were fortunate to retain Elizabeth Pell, one of the authors of the highly regarded evaluations of the CPR/Nonotuck pilot,¹⁹² and a person already well versed in SDM “on the ground.”

The evaluation was initially planned to include interviews of parents in the SDMNY pilot who were, or had been, considering guardianship, and current guardians. Interviews were to have been conducted at the beginning of facilitation, and again after completion. Ultimately funding issues made this impossible, limiting the evaluation to single interviews. While we hope to see further research on these important questions, the Pell

¹⁹⁰ We also need to know, whether, over time, those who might have petitioned for guardianship and/or actual guardians remain reassured that SDM is an effective, less restrictive alternative to guardianship, but that requires a study of longer duration than available under the strictures of our grant.

¹⁹¹ A recognized leader in disability research, “BBI engages in multi-method empirical research by blending quantitative, qualitative and archival methods of data collection using evidence-based measures from multiple disciplines.” *Research & Publications*, BURTON BLATT INST., <http://www.bbi.syr.edu/research/index.html>.

¹⁹² See HSRI REPORT 2016, *supra* note 58.

evaluation provided a trove of information that has informed our current practice and lessons learned.

III. LESSONS LEARNED

Pilot projects are inevitably challenging because they begin from untested premises. They are also exciting because they call for experimentation and see temporary failures as constructive opportunities to try something else, and to do better. That has been our experience, many lessons learned over the past four years. Some have already been incorporated in our practice, and others provide important information for future planning and expansion. What follows are among the most useful; those that have clear policy implications are bolded for consideration by legislators and others in government.

One pervasive lesson, which we gratefully acknowledge, is the critical importance of self-advocates at every stage of SDMNY's work, from the initial proposal, through all stages of our program design and implementation. They are truly our "experts by experience" and whenever they were involved, what we did was the better for their contributions. They have been generous with their time and talents, but it is neither fair to them, nor consistent with our basic principles,¹⁹³ that their work should go uncompensated. We have been able to offer small stipends when they speak on behalf of, and/or for, the project, but going forward, self-advocates and persons with I/DD should be hired as paid staff so that they are true partners, engaged in all future planning and work toward systemic change.

A. *Recruitment*

1. Decision-Makers

In information sessions held for parents, we briefly explained guardianship and its consequences for persons with I/DD subject to it. Our independent evaluation revealed how little parents who may or do seek guardianship actually understand and

¹⁹³ As a staff member wrote for the Pell evaluation, "[t]hrough this project I have become more acutely aware of the ethical dimensions of a project with clear objectives of systemic change built into the project's [five]-year work plan and grant agreement with the donor that at best is inclusive of persons with IDD but not necessarily tasked with developing a policy or systems-change agenda that is directed primarily by them." PELL, *supra* note 7, at 79.

internalize those consequences,¹⁹⁴ as well as how few are aware of less restrictive alternatives.¹⁹⁵ As a policy matter, institutions charged with providing information about the transition process, when persons with I/DD legally become adults at age 18, should be required to give complete and accurate information about the legal implications of, and loss of rights entailed by, guardianship, as well as accurate information about alternatives, including SDM.

We found that a useful, and often persuasive, way of talking about both guardianship and SDM was through the use of a historical lens on the ways in which society has “protected” persons with I/DD over time.¹⁹⁶ This history includes movement away from segregated residential “schools” like Willowbrook, to guardianship, established by statute in 1966 when parents were faced with mass de-institutionalization. It continues to the present day, with the enormous changes in how society views people with disabilities, as reflected in the Americans with Disabilities Act (ADA),¹⁹⁷ the Individuals with Disabilities Education Act (IDEA),¹⁹⁸ and the Supreme Court’s *Olmstead* decision¹⁹⁹ which have led to the emergence of SDM as a “new way.”²⁰⁰ One of the advantages of such a presentation is that it avoids “blaming” parents who have already chosen guardianship, understanding that they did so because it was presented to them

¹⁹⁴ See *id.* at 55 (“Most guardians and potential guardians ([sixty percent]) reported awareness but not a real understanding of the specific loss of rights that accompanies a guardianship order for those with IDD in New York.”).

¹⁹⁵ See *id.* at 56–57.

¹⁹⁶ See *id.* at 59.

¹⁹⁷ Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12101–12213 (2018).

¹⁹⁸ 20 U.S.C. §§ 1400–1482 (2018).

¹⁹⁹ See *Olmstead v. L. C. by Zimring*, 527 U.S. 581, 589 (1999).

²⁰⁰ The story begins with the rise of well-intentioned residential schools for the “feeble-minded,” that all too soon became, although not acknowledged as, terrible institutions that were exposed in the 1960s. See NAT’L COUNCIL ON DISABILITY, *supra* note 22, at 42–44 to be reminded of that exposé. See also THE STORY THAT REVEALED WILLOWBROOK’S HORRORS (PBS television broadcast Jan. 5, 2016) <https://www.pbs.org/video/metrofocus-story-revealed-willowbrooks-horrors> (including the famous Geraldo Rivera videos from Willowbrook); JAMES W. TRENT JR., *INVENTING THE FEEBLE MIND: A HISTORY OF INTELLECTUAL DISABILITY IN THE UNITED STATES* (2017). With massive deinstitutionalization, parents of children now in their thirties and forties converged on Albany to seek legislation that would allow them to continue the legal control they had when their now adult children were still, literally, children, and so Article 17-A was enacted in 1969. See Bailly & Torok, *supra* note 27.

as the best—and often only—way to protect their children with I/DD.

Another especially impactful lesson for us has been that successful recruitment depends on relationships, and that those relationships must be built, cultivated, and constantly reinforced, a time and resource intensive process. One-off information sessions or recruiting events simply do not result in sign-ups by potential Decision-Makers. Entities or institutions (schools, advocacy groups, etc.) with which potential Decision-Makers are connected need to understand what SDM is, and why the person might benefit from it. Even where SDM clearly aligns with the institution's values, as it does with Cooke School, or SANYS, investing time with teachers, staff, leadership, etc., ensures that, as the prospective Decision-Maker thinks about and considers SDM, s/he (and in the case of transition age young adults, her/his parents) will find support from people they most trust.

A critical issue, with strong policy implications, is the enormous importance of SDMA legislation. We have heard, over and over, “What is the point of going through this whole process if, at the end, a doctor or someone else can still say that they won't accept [name]'s decision and that we have to get guardianship?” Pell's report confirmed our anecdotal evidence, finding that *every* respondent responded affirmatively to whether formal, legal recognition of SDM would affect the guardian or potential guardian's confidence in the Decision-Maker's use of SDM. “‘Absolutely!’ and ‘Definitely’ were frequent responses.”²⁰¹ Current Decision-Makers and their families are hopeful that legislation is on the horizon, and conscious of the role their participation in SDMNY may play in encouraging the legislature to act.²⁰² Legislation recognizing SDM, and SDMA is critical to encouraging the use of this less restrictive alternative to guardianship.

²⁰¹ PELL, *supra* note 7, at 66. One potential guardian said “[i]f the legislature adopts this, it would give us a lot more confidence of what could happen in the future,” while another parent, worrying about how her son might someday be taken advantage of without recognition of SDM opined “I would feel more secure [about the future] knowing that his rights and desires are protected by a law.” *Id.*

²⁰² One parent exclaimed, in supporting the idea of SDMA legislation, “[t]hat's why I'm participating in this evaluation, for [SDM] to be all over, not just in New York.” *Id.*

2. Facilitators

Although sustainability strongly favors volunteer facilitators, we learned firsthand that there was also a substantial cost: interrupted or, even more common, incomplete facilitations, requiring substitution of a second, or even third facilitator for a single Decision-Maker. This was hardly an optimal situation for anyone involved, and required large and un-planned-for time commitments by already overburdened staff. Without some external incentive to see facilitation through to the SDMA signing, volunteers prioritized other obligations in their lives, and, all too frequently, either “disappeared,”²⁰³ or informed the Site Coordinator that they were unable to continue.

The demonstrated need for external incentives other than payment reinforced our original instinct that University-connected²⁰⁴ educational programs, especially those with fieldwork or clinical requirements, are an optimal source of facilitators if facilitation can be connected to academic credit. As described, we have experimented with various programs, often encountering obstacles related to credentialing requirements.

We are encouraged to have found viable work-arounds, and will continue to build on them to solidly incorporate SDM facilitation in formal curricula. The even more encouraging outcome has been that students who participated found facilitation to be rewarding, educationally valuable, important in changing their views about people with I/DD and aligned with the values of the programs they were pursuing.²⁰⁵ They are also poised to be “ambassadors” for SDM, and to carry it into their post-graduation professional lives and workplaces.

We need to demonstrate to other educational institutions that both graduate and undergraduate professional programs and their students can benefit from including SDM facilitation in

²⁰³ “Disappear” here is not literal, but refers to the situation in which SDMNY and the Decision-Maker lost contact with their facilitators.

²⁰⁴ “University-connected” is used to include four-year colleges and two-year community colleges with appropriate programs.

²⁰⁵ Pell’s report found “Facilitators [including OTA students] who participated in this evaluation reported that the SDMNY training and experience changed their perspective and removed some stereotypes about people with IDD. These facilitators are incorporating SDM into their professional work activity.” PELL, *supra* note 7, at 74.

their curricula, thus creating a large, geographically diverse²⁰⁶ and well-trained pool of unpaid facilitators.

B. The Program

1. Facilitator Training

Beside needing more time, more simulations and practice experiences, and an expanded Facilitators' Manual, the major "learning" has been about the tendency/danger of focusing on goals *for*, rather than decisions *by* Decision-Makers. As an example of this recurring "trap": the initial videos created for facilitator training portrayed the Decision-Maker as wanting support in the area of finances and money, and discussion with "supporters" focused on helping him reach his goals, not making decisions. The tasks for supporters were perceived as who would help him set up a bank account, and who would help him make a budget, rather than what kinds of decisions he might need to make in setting up a bank account (What kind? In what bank? With what kind of limitations, if any? Joint or individual? etc.). Similarly, in the area of housing, a supporter's assistance was described as attending open houses with him, as opposed to decisions necessary to moving out (Do I have enough money? How will I find the money? What neighborhood? Roommates or living alone? etc.).

We understand where this comes from—in most interactions with helping entities, whether schools or service providers, Decision-Makers and their parents are asked to focus on goals,²⁰⁷ not decisions, and it is easy and familiar to fall into that discourse. We came to call this "goalspeak," and now consciously work to have facilitators break down goals articulated by the

²⁰⁶ See discussion *supra* note 157 and accompanying text. Schools with relevant programs are located from Buffalo to Syracuse and Rochester, Rockland and Westchester Counties, to NYC and Long Island.

²⁰⁷ Schools are required to create Individual Education Program (IEP) that set out goals for students with I/DD, while provider agencies are also tasked with creating plans for the Decision-Maker. See 20 U.S.C. § 1414(d)(2)(A) (2018); N.Y. COMP. CODES. R. & REGS. tit. 14, § 635-99.1 (2020). Although in both instances the decisions about how to reach those goals are made largely by others, the written document that is developed by an individual's chosen service coordinator, the individual and/or the parties chosen by the individual, often known as the person's circle of support, that describes the services, activities and supports, regardless of the funding source, and that constitutes the person's individualized service environment.

Decision-Maker into the many decisions, large and small, that might be necessary to reach those goals. We have replaced the original training videos with a new set that clarifies the distinction between decisions and goals, and reiterates and models that SDM is about the former, not the latter. Much as we all, facilitators, mentors and supporters, might want to help Decision-Makers achieve their goals, we have neither the capacity nor the remit to do so, and so are constantly and consciously vigilant about the tendency to slip into “goalspeak.”

2. Facilitators

If, as we have found, “pure” volunteer facilitators are difficult to work with, and often unreliable, any expansion of the pilot has to seriously engage with alternatives. If, by the conclusion of the pilot, we have been able to work with graduate and undergraduate professional programs to devise and test models that include facilitation as part of the curriculum, as it would be beneficial to collectively approach the many schools in New York State that offer such programs, through conferences, associations, and in the case of SUNY and CUNY, through University administration.

3. Time of Facilitation

We began, based on reports from other pilots, assuming that the facilitation process would take somewhere between six and nine months of monthly facilitation meetings. In fact, our experience has shown that a more realistic timeline is twelve to eighteen months. In part this has been due to the need to replace facilitators when volunteers left the project with their facilitations incomplete, in part because of the gap between signing Decision-Maker up, assigning facilitators and actually getting to the first facilitation meeting,²⁰⁸ and in part simply because of the many conflicting time demands on all parties to the facilitation, especially in New York City.²⁰⁹

²⁰⁸ Technically this is not all time spent in facilitation, but Decision-Makers and their families tend to measure their participation in the pilots from the time at which they sign up.

²⁰⁹ It will be interesting, when we have more data from the expansion sites, to see whether our experience of the time necessary for facilitation is different in other parts of the state.

One consequence of this experience is that we now share the more realistic estimate in formation sessions with prospective Decision-Makers, parents, and others. Facilitating persons with I/DD to truly make their own decisions with support, and supporters to support rather than relapse into paternalism or otherwise overly influence Decision-Makers takes time; it is not a one-off and, for the integrity of the process, it cannot be rushed.

4. Mentors

We have learned that mentors are far more important than originally contemplated and, at the same time, that our initial expectation that facilitators would morph into mentors has not materialized. The concentration of mentoring within staff that has occurred as a matter of necessity suggests, however, that volume may add to the richness of the mentor's relationship²¹⁰ with any individual facilitator, and the tools available to make the facilitator successful. Fewer mentors, mentoring more facilitators, also promotes greater consistency in the process, as well as a certain degree of "quality control." Given all of this, it is unrealistic to plan for, or rely on volunteer facilitators. Any expansion of the pilot should include adequate provision for staff mentoring and additional paid mentors.

5. Supporters

The "re-positioning" that the facilitation process seeks to accomplish takes more than just discussion and requires more thoughtful and explicit "capacity-building" for supporters. Although we do not yet have sufficient experience with post-SDMA decision-making, we suspect that, over time, supporters will need reinforcement, especially when they strongly disagree with decisions of the Decision-Maker they support. Any expansion of the pilot should include ongoing assistance/support to supporters.

6. Decision-Makers

We have been consistently reinforced in our determination to place Decision-Makers at the center of the process, despite the discomfort this apparently causes some parents and family

²¹⁰ See discussion *supra* notes 176–79 and accompanying text.

members.²¹¹ Doing so models what SDM is, and how the Decision-Maker can and should utilize SDM going forward. It also demonstrates her/his growing capabilities in making decisions to supporters, so increasing their confidence in the process.

We also now see the desirability of continued support for Decision-Makers after signing their SDMA's. We are currently exploring ways in which that might occur, both through Post-SDMA affinity groups,²¹² and through plans for training CRDC mediators to provide "conflict counseling" to Decision-Makers when necessary.

We have been surprised at how little understanding Decision-Makers initially have about making decisions, and how they see—or don't see—themselves in that process.²¹³ In practice, this means much more explicit focus on, and modeling of, decision-making, especially in Phase One, where it is important to name the steps in making decisions, and facilitate the Decision-Maker in practicing them. This learning is essential to ensuring the integrity of the decision-making process, and must be a fundamental requirement of any SDMA legislation. Without a serious and thoughtful facilitation process, there is no certainty that decisions purportedly made with SDM or SDMA's will reflect the will and preference of the Decision-Maker, or ensure that supporters are not actually engaged in substitute decision making or undue influence. Any legislation that relies on a signed "form" alone favors form over substance and undermines the efficacy of SDM as a process the Decision-Maker can use throughout her/his life to make her/his own decisions with the support s/he chooses.

²¹¹ Pell's report found "Initiating meetings between facilitators and people with I/DD without others does place the individual at the center of the process. It has also raised anxiety for some family members." PELL, *supra* note 7, at 17.

²¹² One such group, comprised of students and graduates of Cooke School and the Cooke SKILLS program is currently meeting on a monthly basis, and there are plans for another, comprised of older self-advocates.

²¹³ This may also be true about neurotypical young adults, but the presumption of their "capacity" will allow them to try and fail, try and succeed, try again over the course of their late teens and twenties, until they understand and consistently practice their own decision-making and take full control over their lives. The perceived vulnerability and lack of "capacity" of young adult persons frequently invokes over protection by parents and other involved adults, so that the "normal" process of individuation does not occur. Guardianship constitutes an even more dramatic constraint on the development of autonomy and personhood. See Glen, *supra* note 8, at 498.

C. Questions going forward

Although we worked with every Decision-Maker who “chose” us,²¹⁴ logistical and institutional issues kept us from recruiting in various locations, limiting the cohort of potential Decision-Makers we might serve. Persons with I/DD residing in restrictive group homes or other facilities to which we did not have easy access, including persons with multiple and/or more severe impairments, were not available as participants in the pilot. Thus, we cannot claim experience with persons with severe impairments, as we were not able to ascertain their interest in SDM, or whether and how working with such persons might be different and/or more resource intense.

Nor were we able to develop strategies for educating and obtaining buy-in for SDM from that cohort’s institutional service providers and their employees. Where persons with I/DD are almost totally dependent on direct service providers, their ability to utilize SDM, to make their own decisions and to have those decisions recognized, is dependent on acceptance of their legitimacy by the workers and administrative structure that wield so much power.

There is another issue, which we have not directly confronted, but are often asked about. Decision-Makers who are part of SDMNY are fortunate to have trusted persons in their lives available and willing to be their supporters. Often, especially for younger Decision-Makers, these will be parents and other family members, but they may also be neighbors, teachers, friends or trusted service providers.²¹⁵ How can SDM be made available to, and work for, persons who have no natural supports in their

²¹⁴ We consciously chose not to ask for or consider diagnoses, and we did not limit participation based on kind or degree of impairment, and the pilot has included non-verbal Decision-Makers and Decision-Makers with multiple disabilities.

²¹⁵ There is a debate among those who work on and with SDM as to whether direct service providers (DSPs) should be able to serve as recognized supporters, primarily because of potential conflicts of interest. Some SDMA laws (Rhode Island, Delaware and Alaska, and the District of Columbia) have actually adopted a prohibition on persons providing services to Decision-Makers. Because SDMNY’s process is Decision-Maker centered, we believe that the choice of supporters belongs to the Decision-Maker alone. In addition, for some Decision-Makers there may not be, at least not presently, anyone else in their lives who they can ask. We note, however, that where DSPs are prospective supporters, there are a number of legal and ethical questions, involving relevant labor law, that need to be addressed and resolved. *See* discussion of existing SDMA legislation *supra* note 51 and accompanying text.

lives? One possibility, which raises many additional issues, is to provide paid supporters.²¹⁶ Another is the use of “Citizen Advocates,”²¹⁷ the subject of a new pilot in Georgia that is a collaboration between C.P.R. and the Georgia Advocacy Agency.²¹⁸

In terms of both expansion and legislation, these so-far unaddressed issues require attention and thoughtful consideration.

D. Conclusions

The biggest “learning” and the overall conclusion of SDMNY’s work thus far is that it really works. A well planned, theoretically grounded and thoughtfully supervised facilitation process enables diverse persons with I/DD, with impairments of varying severity, to make their own decisions authentically, with the supports they choose themselves.

SDM is a process, not simply a piece of paper or a signed form. It is a process that must be learned, practiced and honored by all

²¹⁶ Israel’s initial pilot program, which was limited to support on financial issues, provided for assigned, albeit unpaid, supporters rather than persons chosen by the Decision-Maker, and the SDM law and regulations subsequently enacted anticipate. Both “volunteer” and “professional,” (and so presumably paid) supporters. See BIZCHUT, *supra* note 64, at 43; Legal Capacity and Guardianship Law, 5722-1962, § 67b (Isr.).

²¹⁷ Person-to-Person Citizen Advocacy is a movement started by esteemed disability scholar and activist Syracuse University Professor Wolf Wolfensberger in 1967. Citizen Advocacy aims “to promote, protect, and defend the welfare and interest of those who have a developmental disability through one-on-one voluntary commitments.” *About Us*, PERSON-TO-PERSON CITIZEN ADVOCACY, <https://www.ppcadvocacy.org/about-2/> (last visited Mar. 25, 2020). There are Citizen Advocacy groups in many states, *see, e.g.*, Georgia (*About Us*, MACON BIBB CITIZEN ADVOCACY <https://www.maconbibbcitizenadvocacy.org/about-us/> (last visited Mar. 25, 2020)), Nebraska (*What is Civilian Advocacy?*, HEARTLAND CITIZEN ADVOCACY, INC. <https://heartlandcitizenadvocacy.org/what-is-citizen-advocacy/> (last visited Mar. 25, 2020)), as well as Canada (*Introduction to Civilian Advocacy*, CIVILIAN ADVOCACY <https://www.bmartin.cc/CAN/intro.html> (last visited Mar. 25, 2020)). In New York, the umbrella group, Person-to-Person: Citizen Advocacy, is headquartered in Onondaga County. See *About Us*, PERSON-TO-PERSON CITIZEN ADVOCACY <https://www.ppcadvocacy.org/about-2/> (last visited Mar. 25, 2020).

²¹⁸ See *Supported Decision-Making*, GEORGIA COUNCIL ON DEVELOPMENTAL DISABILITIES, <https://gcdd.org/partnerships/supported-decision-making.html> (last visited Mar. 25, 2020), and at CPR’s SDM website, *Georgia SDM Pilot*, C.P.R. SUPPORTED DECISION-MAKING, <https://supporteddecisions.org/supported-decision-making-pilots/georgia-supported-decision-making-pilot/> (last visited Mar. 25, 2020).

those involved, Decision-Maker and supporters alike. When that happens, it is appropriate and just that the Decision-Maker should be recognized as having legal capacity—the right make her/his own decisions, and to have them legally recognized.

Through its five-year grant to SDMNY, New York has made a significant investment in testing the efficacy of SDM, and the most effective way for persons with I/DD and their supporters to practice SDM, preliminary to considering SDMA legislation. Unlike other states,²¹⁹ New York has invested in an evidentiary base for its consideration and determination in that legislative process. What SDMNY has learned thus far should provide a critical component of what comes next.

IV. NEXT STEPS

The question posed by DDPC's grant to SDMNY was: “[c]an, and if so how, might SDM provide an alternative to guardianship for persons with I/DD?” As this article has shown, the answer to the first part of that question is “yes,” and, to the second, “[t]hrough a serious and thoughtful facilitation process, such as that designed and piloted by SDMNY.” Making this happen requires both legislation that incorporates what we have learned, and expansion of the SDMNY pilot to make facilitation available to everyone who wants it, regardless of ability to pay.

A. Legislation

1. The Pressing Need (redux)

We have heard again and again about the need for legislation recognizing SDMA's so that for example, parents can avoid the painful choice between getting necessary medical care for their adult child, and removing all of her/his legal and civil rights by seeking guardianship. A recent communication from the Rochester SDMNY Site Coordinator brings this conundrum to life. She wrote

Doctors up here can be really concerned about accepting consent from a person with [I/DD] when the person doesn't want to speak the decision themselves . . . [a potential Decision-Maker] has difficulty expressing herself and is fearful of medical procedures.

²¹⁹ See discussion of existing SDMA legislation *supra* note 51.

The family worries that she won't receive routine care that requires her consent due to symptoms of autism . . . and may go to guardianship [despite serious concerns about doing so].²²⁰

SDM may empower this young woman to make her own medical decisions and communicate them with support, but, without SDMA legislation, her health care providers are not required to honor them, and guardianship becomes the otherwise unnecessary result. To make SDM a viable and compelling alternative to guardianship for potential petitioners, SDMA must have formal legal recognition.

2. The limitations of existing legislation and an alternative approach

Legislation in other states generally defines SDM, gives supporters legal status, provides for an SDMA, details what the SDMA must contain—or actually provides a form SDMA—and then requires third parties to accept that SDMA, relieving those third parties from liability for good faith reliance on the agreement.²²¹ While these latter provisions solve the problem that so often militates for guardianship, existing statutes make no provision for the work necessary to empower the Decision-Maker authentically to make decisions with support, or to provide the “re-positioning” and capacity-building that enables supporters to move out of old roles and accept the Decision-Maker as an autonomous and self-directed adult.

The experience of Israel provides a useful contrast. Unlike U.S. legislation to date, Israel's SDM legislation grew out of a well-planned and evaluated pilot based on facilitation.²²² The SDM statute, enacted in 2016 as part of Israel's existing guardianship law, is quite “bare bones,” recognizing the existence and validity of SDM, but delegating the details of its operation to the Ministry of Justice.²²³ Regulations issued two years later drew on the experience and recommendations of the pilot project,²²⁴ adopting a capacity-building model for supporters,

²²⁰ E-mail from Maureen Philips, Rochester SDMNY Site Coordinator, to Kristin Booth Glen (Jan. 16, 2020) (on file with author).

²²¹ See Glen, *supra* note 23, at 81.

²²² See sources cited *supra* note 64.

²²³ See Legal Capacity and Guardianship Law, 5722-1962, § 67b(f) (Isr.)

²²⁴ The organization that designed and ran the pilot project, Bizchut,

requiring fifteen hours of training for family members and other volunteer supporters chosen by the Decision-Maker, and sixty hours for “professional supporters” who, presumably, would be paid.²²⁵ Two pilot programs were authorized and are currently under way. What is missing, of course, is equal attention to the needs of the Decision-Maker, although we understand that this remains a possible subject of consideration.²²⁶

The Israeli experience provides support for what has become apparent in the SDMNY pilot. If policy makers and legislators are to ensure legal capacity—the right to have their decisions legally recognized—to persons with I/DD based on SDMA, there must also be confidence in the integrity of those agreements, and the process by which they were reached.

3. Why the legislature should require “more”

People with I/DD have always made decisions informally with supports of various kinds, and they will continue to do so. Third parties are, and have been, free to accept those decisions, to question them, or to refuse to honor them. However, for the legislature to intervene and *require* recognition of those decisions, based entirely on the existence of an SDMA, there should be evidence of an actual process in place, reflected in the SDMA, that will ensure the integrity and authenticity of such decisions.

As an “intentional pilot,” presciently funded by DDPC,

published an extensive description of its model with recommendations for wider adoption, noting in particular that “[t]he training and hands-on counseling provided to the supporters along the way [similar to SDMNY’s facilitator training and mentoring of facilitators as they work with supporters] is of great importance,” and continuing with “guiding principles” and a detailed *supra* summary of the “hands-on counseling provided during the pilot.” BIZCHUT, *supra* note 64, at 29.

²²⁵ See, e.g., *id.* at 46 (describing the recommendations for expansion of the pilot programs, including the need to adapt the provision to services to the needs of the Decision-Maker).

²²⁶ E-mail from Yotam Tolub, former Director of Bizchut, to Kristin Booth Glen (Jan. 24, 2020) (on file with author). Notably, the official designated by the Ministry of Justice to oversee SDM regulations visited SDMNY and wrote that SDMNY’s “understandings concerning the capability of disabled persons to make choices of their own with adapted assistance as well as the tools they are developing in order for this process to take place are a huge contribution . . . and some of the tools developed by SDMNY have been translated into Hebrew and are being used in our work here in Israel in the various training processes of Decision-Making Supporters.” Letter from Ornit Dan, Department of the Administrator General and Official Receiver of the Ministry of Justice, Israel, to CUNY Chancellor James B. Milliken (April 22, 2018) (on file with author).

SDMNY's experience and learnings are available to New York lawmakers, in contrast to how other states have passed SDMA statutes. This empirical evidentiary base should provide an important grounding for legislation that ties recognition of SDMA to a facilitation process that engages and empowers persons with I/DD and their supporters. The alternative is reliance on a document that may or may not reflect whether SDM is actually happening, and which is also subject to potential abuse.²²⁷

B. Expansion of the Pilot Project

Another decision confronts government in New York, whether and how to expand the SDMNY pilot into a permanent, statewide program. This decision is inextricably connected to whatever SDMA legislation may be passed. Legal recognition of SDMA cannot be tied to a requirement of completing a recognized facilitation process unless that facilitation process is available to everyone who desires it, regardless of ability to pay. Here the experience of SDMNY provides a model for consideration, as well as justifications for the cost that model would involve.

Although this article has concentrated on the SDMNY NYC site, there is already enough experience in the project as a whole to see the value of geographically diverse SDM project sites, overseen by a central resource and training entity. Hunter/CUNY has filled that role with respect to the expansion sites in Westchester, Rochester/Western New York, the Capital Region and Long Island, while the sites themselves have been responsible for recruiting and matching Decision-Makers and facilitators.

Expansion of the pilot could, and as a political matter, should also expand the pool of persons who can facilitate Decision-Makers and their supporters.²²⁸ Whether the facilitators are

²²⁷ Without a facilitation process, there is no way of knowing that the Decision-Maker understands what it is that s/he has signed, how the supporter(s) might utilize the SDMA, and to what ends, and nothing to suggest that the supporter(s) is/are avoiding substituting their own decision for that of the Decision-Maker, to her/his potential detriment.

²²⁸ The organized bar, including many lawyers with substantial guardianship practices, is an important stakeholder in the conversation about SDM. Providing those lawyers an opportunity to incorporate SDM into their practices would not only increase the choices available to families, and the number of available facilitators, but also forestall opposition to SDM legislation

unpaid volunteers, service providers paid by Medicaid waiver funds, or private practitioners—lawyers or their employees²²⁹—should not matter as long as all receive the same high-quality training, and are effectively and uniformly mentored. Both those functions would be the responsibility of the central Resource and Training entity. This model would provide choice for parents and other potential petitioners, but would also assure consistency and accountability and provide a degree of quality control.

An obvious concern is, of course, cost. The SDMNY pilot has, we believe, demonstrated that SDM weighs heavily in favor of the “human” and social benefits to Decision-Makers and their families in the form of greater self-determination, possibility for growth, autonomy and dignity,²³⁰ as opposed to the costs of guardianship, under which persons subject to guardianship can, according to the National Council on Disability, “‘feel helpless, hopeless and self-critical’, experience ‘low self-esteem, passivity, and feelings of inadequacy and incompetency’ as well as significantly decreased ‘physical and mental health, longevity, [and] ability to function.’”²³¹ There are almost certainly economic benefits as well, but these are difficult to quantify.

1. Lessons from Other Pilot Projects

There is currently no existing cohort of persons who have been utilizing SDMA's for any meaningful period of time, so there is no direct way of comparing costs attributable to them with the costs incurred by a control group of otherwise similarly situated

that has occurred in other states. See Eliana J. Theodorou, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973, 992, 1003 (2018) (describing initial opposition from the Real Estate, Probate and Trust (REPTL) section of the bar association).

²²⁹ Lawyers who now have a substantial guardianship practice could be trained as facilitators or, more likely, send a paralegal in their offices for training, and then charge for those services, on a stand-alone basis, or as part of a package of advance personal and financial planning.

²³⁰ Based on our experience to date, we have every reason to expect that the results of BBI's evaluation of the SDMNY pilot will demonstrate these benefits for pilot participants, as have other investigations into SDM's benefits. See, e.g., KARRIE A. SHOGREN, ET AL., SUPPORTED DECISION-MAKING: THEORY, RESEARCH AND PRACTICE TO ENHANCE SELF-DETERMINATION AND QUALITY OF LIFE 234–235 (2019) (“supported decision-making, when implemented well, increases the self-determination of people with disabilities across the life course” and “people who exercise more self-determination tend to enjoy better life outcomes in employment, daily independence, and quality of life.”).

²³¹ NAT'L COUNCIL ON DISABILITY, *supra* note 22, at 103.

individuals who do not use SDM or SDMA. To make any calculation even more difficult, the “costs” and potential “savings” may come from many different sources, or “baskets.” These might include, for example, Medicaid services utilized—or not; the time spent by judges and the court system in guardianship proceedings time—or not; time spent by health care providers, hospital emergency rooms, etc., dealing with informed consent issues—or not, etc.

There appear to be only two studies of cost saving associated with SDM, or “enhancing legal capacity.” One, is a study of the use of “support” in improving outcomes for persons with cognitive disability accused of crimes.²³² It utilized a rigorous cost-benefit analysis²³³ to explore whether a project to decrease the number of persons with IDD, especially Aboriginal and Torres Strait Islander people who are over-represented in the Australian criminal justice system, provided economic, as well as social benefits. The study concluded that it “provides evidence of how a tailored programme intervention at a critical point in legal proceedings can lead to economic savings in police, courts, justice and custody costs in addition to improving the timeliness and quality of outcomes for accused persons with disabilities.”²³⁴

The Bulgarian pilot project commissioned an extensive, professional, independent evaluation examining both social and economic costs and benefits of its work promoting legal capacity through an SDM facilitation model.²³⁵ As to the former, it noted

Quality of life, equal recognition before the law, independent living and inclusion in the community . . . are the benefits of SDM which cannot be measured with monetary units. They have a higher value for the society than any purely financial benefit and are in fact the main goal and outcome of SDM.²³⁶

As to the latter, it employed recognized economic methodology

²³² See Ruth McCausland, et al., *The Economic Case for Improving Legal Outcomes for Accused Persons with Cognitive Disability: An Australian Study*, 15 INT'L J. L. CONTEXT 367, 367 (2019). The underlying project utilized several forms of “support,” none specifically denominated SDM. All were, however, tied to CRPD Article 12, and, in their effort to enhance capacity for persons with IDD, provide a useful analogy.

²³³ *Id.*

²³⁴ *Id.*

²³⁵ LALCHEVA & MALAMIN, *supra* note 156, at 6.

²³⁶ *Id.* at 11.

to ask and answer the question: “As SDM results in increased self-determination, personal development and independency [sic] of ID and persons with mental problems, does this lead to reduced intensity of the support and consequently reduced price of social services (monetized benefit) for the society?”²³⁷

Analysis of the costs and usage of existing services found that, in the following categories, SDM resulted in substantial cost savings.

a. Housing

More than half of persons with I/DD in institutions could live in less restrictive [and expensive] living arrangements in the community with the use of SDM;²³⁸ utilizing SDM, more than half of those residing in the equivalent of group homes could successfully live with less supervision and services than provided in that housing option;²³⁹ utilizing SDM would very substantially decrease the costs related to housing with accompanying services.²⁴⁰

b. Services provided in the community

Persons utilizing SDM need “less daycare/in terms of hours or intensity/, need only consultative services instead of daycare or even do not need any daycare or consultative [services] as a result of increased independency [sic].”²⁴¹

c. Health care services

This section of the analysis considered only the cost of psychiatric care for persons with psychosocial disabilities with no analysis of healthcare costs for persons with I/DD. To the extent that it is possible to analogize, the finding that “[t]he effect of SDM . . . led to reduced intensity of usage of healthcare services . . .”²⁴² seems at least partially transferable to healthcare costs for persons with I/DD.²⁴³

²³⁷ *Id.* at 36.

²³⁸ *Id.* at 28–39.

²³⁹ *Id.* at 40, 41.

²⁴⁰ *Id.* at 45.

²⁴¹ *Id.* at 46.

²⁴² *Id.* at 60.

²⁴³ See discussion *supra* Section IV(B)(1) (discussing the costs of obtaining “informed consent” through substitute decision-making).

d. Employment

The short period of SDM implementation precluded direct evidence of the number of persons with I/DD using SDM who had achieved employment. Instead, the analysis used information provided by the research on the “level of readiness” for full or part-time employment (and, in some cases, supported employment) finding “over 85% of participants in the pilot projects able to have [employment]”²⁴⁴ with the very substantial savings that employment would produce.²⁴⁵

2. Application to the U.S. Context

Obviously, the social conditions and service provision to people with I/DD are very different in Bulgaria than in the United States, but the thoughtful and well-researched analysis suggests some level of confidence in the likelihood of similar economic benefits from well facilitated SDM. Here are some preliminary thoughts about what could be expected if the SDMNY pilot were expanded statewide:

a. Housing

There are at least two reasons to expect that persons using SDM will be able to move from certified facilities²⁴⁶ to, or continue in, community-based housing, rather than moving to such service-intensive and costly residences. First is the general research tying increased self-determination to the ability to remain in the community, and SDM to greater self-determination.²⁴⁷ Second is the considerable anecdotal evidence that aging parents, concerned about what will happen to their adult children with I/DD when they are no longer able to care for them, pre-emptively place their adult children in certified facilities, hopeful that their care and safety has been secured. If, instead of total dependency on parents, whether under

²⁴⁴ LALCHEVA & MALAMIN, *supra* note 156, at 61.

²⁴⁵ *Id.* at 62–64.

²⁴⁶ OPWDD issues operating certificates to the following types of residential facilities: “community residence,” “individualized residential alternative/free standing respite,” “intermediate care facility for individuals with intellectual disabilities,” “private school,” “family care home,” and “specialty hospital.” N.Y. COMP. CODES R. & REGS. tit. 14, § 619.2 (2020).

²⁴⁷ *See* LALCHEVA & MALAMIN, *supra* note 156, at 11, 18.

guardianship or otherwise, those adult children had participated in facilitation, signed SDMAs, used SDM to learn and grow, and had a circle of trusted supporters of their choice, parents would be spared the painful, but what they might see as the only choice to secure their children's future. And, of course, every year that a person does not reside in a certified facility means substantial monetary savings to the state.

b. Services provided in the community

There is at least some evidence that more self-determined persons who use "self-direction"²⁴⁸ use fewer, and more targeted services than persons receiving "legacy services" from provider agencies. We could expect Decision-Makers with SDMAs to be at least equally as discerning, and so less expensive, consumers. And, related to housing, services provided in the community are less costly than those required in certified facilities. For example, when a number of persons with I/DD residing in a New York City certified facility at Coler Hospital were transferred to community-based housing, the cost of services decreased dramatically.²⁴⁹

c. Healthcare

In general, it has been shown that persons with I/DD who are more self-determined are healthier, so it is reasonable to assume that persons with and using SDMAs will require fewer healthcare interventions. But there is another, mostly hidden cost connected to healthcare that flows from the determination by a healthcare provider that a person with I/DD "lacks capacity."

Such a determination sends the provider, the person with I/DD, and her/his parents or caregivers into a morass of

²⁴⁸ N.Y. OPWDD, SELF-DIRECTION GUIDANCE FOR PROVIDERS 8 (June 8, 2017), <https://opwdd.ny.gov/sites/default/files/documents/self-direction-guidance.pdf> ("Self-Direction is the practice of empowering people with developmental disabilities to manage the supports and services they receive, determine who provides the supports, and how and where they are provided. In Self-Direction the person with developmental disabilities chooses the mix of supports and services that work best for them, how and when they are provided, and the staff and/or organizations that provide them.").

²⁴⁹ See, e.g., N.Y.C. HEALTH & HOSP.'S CORP., THE COLER GOLDWATER LONG TERM ACUTE CARE HOSPITAL (LTACH) 1, 7 (2013), <https://www.nyhealthandhospitals.org/coler/wp-content/uploads/sites/6/2016/08/chna-goldwater-2013.pdf>; N.Y.C. HEALTH & HOSP.'S CORP., COLER-GOLDWATER'S INNOVATIVE VOLUNTEER EXTENDED SELF-CARE PROGRAM 14, <http://www.nyc.gov/html/hhc/coler-goldwater/pdf/fohwinter1314-2.pdf> (last visited Feb. 23, 2020).

conflicting laws and regulations, with differing coverage, requirements and procedures for obtaining substituted consent, which they—and even most lawyers —are ill-equipped to navigate. The possible choices include the Family Health Care Decisions Act (FHCDA),²⁵⁰ Article 80 of the Mental Hygiene Law,²⁵¹ OPWDD regulations,²⁵² and, for life-sustaining treatments, the Health Care Decisions Act for Persons with Intellectual Disability (HCDA).²⁵³ The legal department may be called in, a physician with specialized credentials may be required to make the capacity determination, and a great deal of time and energy is almost inevitably expended.²⁵⁴ In health care, time is money, and getting substitute consent for a person with I/DD deemed to lack capacity is a costly process for the health care provider, which is often a public facility.

Where the setting is a doctor or dentist's office and the issue is routine care, if the practitioner refuses to accept the consent of the person with I/DD, or misinterprets the web of potentially applicable laws and regulations,²⁵⁵ s/he must either forego

²⁵⁰ N.Y. PUB. HEALTH L. § 2994-a (McKinney 2020). The FHCDA applies to routine, major medical and life-sustaining treatment in hospitals, nursing homes and hospice. However, the FHCDA does not apply to residents of a facility operated or certified by OPWDD or who receive any services operated or certified by OPWDD since such persons are subject to OPWDD's surrogate decision-making regulations. N.Y. COMP. CODES R. & REGS. tit. 14 § 633.11 (2020).

²⁵¹ N.Y. MENTAL HYG. L. § 80.01 (McKinney 2020) (establishing the need for a surrogate decision-making committee with regard to major medical decisions); N.Y. EXEC. L. § 553.15 (McKinney 2020) (granting the justice center power and duties to make medical decisions as organized under the auspices of the New York State Justice Center for the Protection of People with Special Needs Advocacy and Support).

²⁵² N.Y. COMP. CODES R. & REGS. tit. 14 § 633.11 (2020).

²⁵³ N.Y. SURR. CT. PROC. ACT § 1750-b (McKinney 2020).

²⁵⁴ E-mail from Beth Haroules, Senior Staff Attorney, New York Civil Liberties Union, Plaintiff's Counsel for the Willowbrook Class, to Kristin Booth Glen (Jan. 25, 2020) (on file with author).

²⁵⁵ See, e.g., N.Y. DEPT. OF HEALTH, HEALTH CARE PROXY: APPOINTING YOUR HEALTH CARE AGENT IN NEW YORK STATE 8 (2017), <https://www.health.ny.gov/publications/1430.pdf>. The New York State Department of Health's health care proxy form contains a witness attestation that the patient "appears to be of sound mind," even though the New York Health Care Proxy Law does not provide a statutory form and merely requires that a proxy both "(i) identify the principal and agent; and (ii) indicate that the principal intends the agent to have authority to make health care decisions on the principal's behalf." N.Y. PUB. HEALTH L. § 2981(5)(a) (McKinney 2020). This has led health care professionals to deem certain patients with I/DD who have never been appointed guardians ineligible for appointing a health care agent. E-mail from

treatment, with the possibility of adverse (and costly) consequences later, or her/his parent or other caregiver must commence a guardianship proceeding with attending costs to the court system. These costs, though difficult to measure, are not insubstantial, not to mention the non-monetary cost of the loss of rights entailed by guardianship.²⁵⁶

With SDMA legislation, all of these costs can be avoided. The patient's SDMA would authorize the provider to accept her/his consent and be relieved of liability for doing so. Expansion of the SDMNY pilot would make facilitation available to persons with I/DD to enter into SDMAs with their chosen supporters. The aggregate savings to the healthcare system could and should result in significant economic benefit to the state.

d. Employment

Even as it was too soon to assess whether SDM increases employment and employment opportunities in Bulgaria when the Cost/Benefit Analysis was written, so too it is not yet possible to make any claims that persons with SDMAs will be more likely to obtain jobs that contribute to the economy. Again, however, the more likely it is that Decision-Makers are included in community, develop confidence and exercise self-determination, the more likely it is that they will be "employment ready." This is an area that requires tracking and a commitment to meaningful data collection and analysis over time.

C. Opportunities to Leverage Expansion of SDM and the SDMNY Pilot

The importance and efficacy of SDM is not limited to persons who have been the focus of the SDMNY pilot. Other pilot projects around the world have combined working with people with I/DD and those with psychosocial disabilities²⁵⁷ and utilized synergies to better serve both groups. A number of small studies out of

Janine Belfast, Westchester Institute for Human Development, to Kristin Booth Glen (Jan. 23, 2020) (on file with author).

²⁵⁶ See N.Y. MENTAL HYG. L. § 81.15 (McKinney 2020) (requiring that a guardianship petition must be filed); N.Y. MENTAL HYG. L. § 81.16(b) (McKinney 2020) (explaining that guardianship is not the only or necessary outcome, permitting the court to "authorize a transaction or transactions," i.e. grant consent for the treatment or procedure, without appointing a guardian).

²⁵⁷ See, e.g., Glen, *supra* note 16, at 86–87 (discussing the pilot project in Bulgaria); ZELDA, *supra* note 62 (discussing the pilot project in Czech Republic).

Australia have also focused the use of SDM with persons with TBIs.²⁵⁸ While it seems clear that the model SDMNY has successfully piloted for persons with I/DD cannot be applied “as is” to these other groups,²⁵⁹ our work is a valuable “jumping-off” place from which to begin, and could provide valuable social and economic benefits for both cohorts.

Another large and growing group for whom some version of SDM could be game-changing is older persons with progressive cognitive decline, dementia, Alzheimer’s, etc. This is a group that uses a large percentage of Medicaid funding and is the subject of growing concern and activity about elder abuse. Until recently, despite expansion of efforts beyond persons with I/DD, older persons have been virtually invisible in any on-the-ground work in SDM.²⁶⁰ Now, however, there is interesting and potentially promising work coming out of Australia.²⁶¹ Expansion of the SDMNY pilot could provide a rich trove of experience and learnings to promote and protect the rights and autonomy of older New Yorkers, and to provide a model for other states around the country.

V. CONCLUSION

In its four years of existence, SDMNY has designed and piloted a successful facilitation model embodying a process through which SDM is actualized for Decision-Makers and their chosen supporters. That model has proven to be a viable, less restrictive alternative to guardianship for persons with I/DD, benefitting participants by promoting autonomy, self-determination and inclusion. The SDMNY model, and the experimentation that has produced it, form a solid evidentiary basis for lawmakers as they

²⁵⁸ See, e.g., Lucy Knox et al., *Becoming a Decision-Making Supporter for Someone with Acquired Cognitive Disability Following Traumatic Brain Injury*, 3 RES. & PRAC. INTELL. & DEVELOPMENTAL DISABILITIES 12, 13 (2016); Glen, *supra* note 16, at 45–49.

²⁵⁹ See Glen, *supra* note 16, at 38–40, 47–48.

²⁶⁰ See Diller, *supra* note 2, at 520; Jennifer Lansing Pilcher et al., *Supported Decision Making for Elders with Dementia: A Deep Dive*, J. AGING LIFE CARE (Summer 2019), <https://www.aginglifecarejournal.org/supported-decision-making-for-elders-with-dementia-a-deep-dive/>.

²⁶¹ See, e.g., *Research on Supported Decision-Making in Dementia*, COGNITIVE DECLINE PARTNERSHIP CENTRE, <https://cdpc.sydney.edu.au/> (last visited Feb. 23, 2020); Craig Sinclair et al., “A Real Bucket of Worms”: Views of People Living with Dementia and Family Members on Supported Decision-Making, 16 J. BIOETHICAL INQUIRY 587 (2019).

consider legislation recognizing SDM and requiring acceptance of SDMA's by third parties. Similarly, SDMNY's "lessons learned," should serve to inform policy makers exploring expansion of the SDMNY pilot to serve all New Yorkers who would benefit from SDM to live more self-directed, inclusive lives, with the autonomy and dignity to which every citizen is entitled.