

Supported Decision-Making: Lessons from Pilot Projects

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ABSTRACT: Supported Decision-Making is an emerging practice that has been widely discussed in scholarly literature, and advanced as a less restrictive alternative to guardianship, but with little empirical evidence as to how it actually works “on the ground”. The authors, from two organizations that have run the most extensive Supported Decision-Making pilot projects in the U.S. for persons with intellectual or developmental disabilities describe the projects, the respective lessons they have learned, and consider how Supported Decision-Making can be used to avoid guardianship in the first instance, and how it can provide the basis for restoration of rights for persons already subject to guardianship. Drawing on the National Guardianship Association Standards of Practice and Ethical Principles, they recommend what guardians need to know about Supported Decision-Making, and how using Supported Decision-Making can fulfill guardians’ obligations to enable the person subject to guardianship “to develop or regain his or her own capacity to the maximum extent possible,” including the potential goal of terminating the guardianship.

Authors' note: We are lawyers who have been involved in protecting the legal rights of persons with disabilities, and, over the past five to seven years, have been responsible for pilot projects that use Supported Decision-Making as an alternative to guardianship and a means of advancing the human right of legal capacity. We have moved from a primarily theoretical understanding of these issues and their importance, to empirical experimentation on how a diverse group of people with intellectual, developmental, or other disabilities and their supporters actually *practice* Supported Decision-Making. In imagining, planning, and carrying out these pilot projects, we have, of course, drawn on the larger scholarly conversation as well as the experience of pilot projects around the world. Our projects, in Massachusetts and New York, are related, but differ in a number of ways, as do the lessons and recommendations we draw from them. This article sets forth each of our experiences—Cathy Costanzo and Anna Krieger's experiences with pilots run or supported by the Center for Public Representation, and Kristin Booth Glen's experiences with Supported Decision-Making New York. While we do not all agree on everything in this article, we believe that there are valuable lessons from what have been, by far, the most extensive efforts in the United States to move Supported Decision-Making “from theory to practice” and that presenting these experiences together offers an important window into the work.

I. Introduction: the Context and Paradigm for Supported Decision-Making

Supported Decision-Making offers a new path forward for avoiding unnecessary and overly restrictive guardianship, and yet this alternative model is not a new idea. Supported Decision-Making has many definitions, but a widely accepted one is that Supported Decision-Making 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.”¹ As practitioners in this field, we see the transformative power of Supported Decision-Making. More than just a tool to prevent loss of rights, individuals who use Supported Decision-Making (“Decision-Makers”) have a chance, sometimes for the first time, to examine and reimagine their lives with themselves at the center. This preserves human rights and in turn, dignity, independence, and autonomy. There are a range of approaches to using Supported Decision-Making, which can be tailored to different populations and groups, though this article focuses mainly on people with intellectual or developmental disabilities.²

A. U.S. Guardianship and the Legal Framework for Supported Decision-Making through a civil rights lens

Guardianship³ is a surrogate or substitute decision-making model that is a pervasive aspect of the United States legal system. Guardianship is and has been central in the lives of

¹ 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*, HUM. RTS. BRIEF, Winter 2012, at 8, 10.

² For discussion of definitions of intellectual or developmental disabilities and historical use of the terms in the law, see National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* (June 10, 2019) https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf. [Hereinafter NCD TURNING RIGHTS INTO REALITY].

³ Guardianship is also referred to as conservatorship in some jurisdictions. *See, e.g.*, Cal. Prob. Code §§ 1400-1490; 1500-1611; 1800-1970; 2100-2893; 2900-2955. For the purposes of this article, we will use the term guardianship.

many people with intellectual or developmental disabilities, older adults, and individuals with mental health disabilities and labeled as having a mental health disability. Though the procedures vary by state,⁴ a guardianship is the process where a court makes a finding that an individual lacks capacity to make certain decisions such as those concerning housing, health care, financial matters⁵ and appoints a third-party to make decisions on behalf of the individual.⁶ A guardianship order can also restrict rights like the right to vote, to marry, to drive, or to work without transferring them to a third party.⁷ The scope of a guardianship is dependent on the court's order and the state or territory's law,⁸ but in all cases guardianship results in a loss of personal autonomy and dignity because the individual is stripped of the legal mechanisms necessary to express their will and preferences through decision-making.⁹ However, as

⁴ Most state guardianship statutes cover any individual who lacks capacity regardless of disability. *See, e.g.*, MASS. GEN. LAWS ANN. ch. 190B, § 5-101 (West 2020) (incapacitated person defined without reference to type of disability alleged); *see also* NCD TURNING RIGHTS INTO REALITY, *supra* note 2, at 37. However, some states have separate guardianship statutes for individuals with intellectual or developmental disabilities. *See, e.g.*, NY SURR. CT. PROC. ACT LAW §§ 1750-1761 (McKinney 2021) (Article 17-a. Guardians of Persons Who Are Intellectually Disabled and Developmentally Disabled); *see also* NATIONAL COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION, at 171 (Mar. 22, 2018) (listing eleven states with developmental disability specific guardianship statutes) [Hereinafter NCD BEYOND GUARDIANSHIP]; Appendix A, Analysis of ID/DD Specific Guardianship/Conservatorship Statutory Provisions, NCD TURNING RIGHTS INTO REALITY, *supra* note 2, at 85-93 (analysis of guardianship laws with different statutory procedures for people with intellectual or developmental disabilities)..

⁵ *E.g.*, Mass. Gen. Laws Ann. ch. 190B, § 5-309 (West 2020) (“a guardian of an incapacitated person shall make decisions regarding the incapacitated person's support, care, education, health and welfare...”).

⁶ *See, e.g.*, MASS. GEN. LAWS ANN. ch. 190B, §§ 5- 101 to - 107; §§ 5-301 to 5-431 (West 2020); N.Y. SURR. CT. PROC. ACT LAW § Ch. 59-a, art. 17-A (McKinney 2021); FLA. STAT. ANN. § 744.101 - .653 (West 2020) (“Florida Guardianship Law”).

⁷ For overview of the type of rights that can be removed by a guardianship, *see generally*, NCD BEYOND GUARDIANSHIP, *supra* note 4, at 28-30.

⁸ *E.g.*, FLA. STAT. ANN. § 744.2005 (West 2016) (The order appointing a guardian must state the nature of the guardianship as either plenary or limited. If limited, the order must state that the guardian may exercise only those delegable rights which have been removed from the incapacitated person and specifically delegated to the guardian. The order shall state the specific powers and duties of the guardian.)

⁹ Common features of substituted decision-making regimes have been described as “systems where (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective ‘best interests’ of the person concerned, as opposed to being based on the person’s own will and preferences.” Comm. on the Rights of Persons with Disabilities, General Comment on Article 12: Equal Recognition Before the Law, U.N. Doc. CRPD/C/11/4, at 27 (Nov. 25, 2014) [hereinafter COMM. ON RIGHTS OF PERSONS].

discussed *infra*, many state statutes and the new Uniform Law Commission’s Guardianship, Conservatorship, and Other Protective Arrangements Act¹⁰ (UGCOPAA) encourage guardians to respect the individuals’ autonomy to the maximum degree possible.¹¹

Many scholars have argued that current guardianship practices in the United States are a violation of human rights and civil rights.¹² The human rights analysis of guardianship centers around the concept of legal capacity—the human right to be recognized as a person before the law and as a legal actor.¹³ Legal capacity is the vehicle through which an individual can exercise the other legal rights that are essential for community life, including the right to make decisions about where a person lives and the right to make choices about a person’s bodily

¹⁰ Uniform Law Commission Guardianship, Conservatorship, and Other Protective Arrangements Act, Art. 3, Sec. 301(b) “ The court shall grant a guardian ... only those powers necessitated by the demonstrated needs and limitations of the respondent and issue orders that will encourage development of the respondent’s maximum self-determination and independence. The court may not establish a full guardianship if a limited guardianship, protective arrangement instead of guardianship, or other less restrictive alternatives would meet the needs of the respondent.” [Hereinafter UGCOPAA] See also discussion *infra* at 35.

¹¹ See, e.g., MASS. GEN. LAWS ANN. ch. 190B, § 5-309 (West 2020) (“A guardian shall exercise authority only as necessitated by the incapacitated person’s mental and adaptive limitations, and, to the extent possible, shall encourage the incapacitated person to participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage personal affairs. A guardian, to the extent known, shall consider the expressed desires and personal values of the incapacitated person when making decisions, and shall otherwise act in the incapacitated person’s best interest and exercise reasonable care, diligence, and prudence.”). For listing of all state guardianship statutes, see American Bar Association Commission on Law and Aging, Adult Guardianship Statutory Table of Authorities, (January 2021) https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-adult-guardianship-statutory-table-of-authorities.pdf (last visited March 19, 2021).

¹² See, e.g., Arlene S. Kanter & Yotam, *The Fight for Personhood, Legal Capacity, and Equal Recognition Under Law for People with Disabilities in Israel and Beyond*, 39 *Cardozo L. Rev.* 557, 560 (2017) (“Although guardianship began as a legal vehicle used to protect people whom society considered unable to protect themselves, it has become an outdated infringement on the human rights of persons with disabilities”); Dr. Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 *BERKELEY J. INT’L L.* 124, 126–27 (2014);

¹³ G.A. Res. 217 (III) A, Universal Declaration of Human Rights (Dec. 10, 1948) (“Everyone has the right to recognition everywhere as a person before the law.”). For further discussion of the human right of legal capacity, see, for example, Kristin Booth Glen, *Introducing A “New” Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 *COLUM. HUM. RTS. L. REV.* 1, 3–7 (2018); Kanter & Yotam Tolub, *supra* note 12, at 569 (discussing basis for legal capacity as a human right as established in various human rights instruments such as the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights); Tina Minkowitz, *The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions*, 34 *SYRACUSE J. INT’L L. & COM.* 405, 408 (2007); Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?* 34 *SYRACUSE J. INT’L L. & COM.* 429 (2007); Flynn & Arstein-Kerslake, *supra* note 12, at 126–27.

autonomy.¹⁴ Mental capacity is a distinct concept from legal capacity. An individual’s mental capacity is the individual’s cognitive decision-making ability.¹⁵ Mental capacity may be limited or impaired because of a disability, a cognitive condition related to aging, or due to an environmental or external factor. In the U.S. system, if a court finds an individual lacks *mental* capacity, the court can order a guardianship, so long as there is no less restrictive alternative. The guardianship restricts the individual’s *legal* capacity to have their will and preferences respected, therefore infringing on the individual’s autonomy, dignity, and personhood.^{16,17}

Supported Decision-Making addresses an individual’s mental limitations by using supporters to provide the individual with an accommodation and support with making decisions so that the individual can exercise their legal capacity. Because of the decision-making support from supporters, the individual’s mental capacity to make decisions is no longer impaired and a court would have no legal basis to infringe on the individual’s legal capacity via a guardianship order. In this framing, the Supported Decision-Making model protects the human right of legal capacity and, in turn, the individual’s personhood.¹⁸

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides a legal framework for the human right of legal capacity for persons with disabilities and for Supported Decision-Making.¹⁹ Article 12 of the CRPD recognizes the equal protection of

¹⁴ Glen, *Introducing A “New” Human Right*, *supra* note 13, at 4–5.

¹⁵ Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 *FORDHAM URB. L.J.* 495, 512 (2016).

¹⁶ Flynn & Arstein-Kerslake, *supra* note 12, at 126–27.

¹⁷ For discussion of personhood as it relates to Supported Decision-Making and legal capacity see Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of A Supported Decision-Making Project*, 39 *CARDOZO L. REV.* 495 (2017).

¹⁸ *Id.* 496 (2017) (“[O]ur personhood is the consequence of all the decisions we have made over our lives... That ability to make decisions and be recognized before the law is the human right of legal capacity.”).

¹⁹ Convention on the Rights of Persons with Disabilities, Gen. A. Res. 61/106, U.N. Doc. A/RES/6/106 (Dec. 13, 2006), available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>. For description of the drafting history of Article 12 and more detailed discussion of the

people with disabilities and the right to legal capacity on an equal basis with others.²⁰ Article 12 requires that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity,”²¹ which “requires both the abolition of substitute decision-making regimes and the development of Supported Decision-Making alternatives” not just the creation of parallel Supported Decision-Making regimes.²² Thus, Article 12 upended the existing legal norms and policies concerning people with disabilities and their right and freedom to make decisions and have these decisions be legally recognized, freedoms liberally granted to non-disabled adults.²³

B. History and Origin of Supported Decision-Making in the United States

While the CRPD provided the international law framework for Supported Decision-Making, over the last decade state legislatures and judges have begun to embed Supported Decision-Making into the law and jurisprudence of the United States. In 2014, federal funding from the Administration on Community Living of a National Resource Center on Supported Decision-Making run by the Quality Trust and partners was a major catalyst for Supported

implications for Supported Decision-Making, *see* Kanter & Tolub, *supra* note 12, at 574-579 (2017); Dinerstein, *supra* note 1 at 8-10.

²⁰ Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3 at 9 [hereinafter CRPD]. The concept of legal capacity was heavily debated in the adoption of the CRPD and is itself distinct from versus the idea of being a person before the law as described here: “The ‘capacity to be a person before the law’ endows the individual with the right to have their status and capacity recognised in the legal order. The concept of ‘legal capacity’ is a wider concept that logically presupposes the capability to be a potential holder of rights and obligations, but also entails the capacity to exercise these rights and to undertake these duties by way of one’s own conduct.” Ad Hoc Comm. on a Comprehensive & Integral Int’l Convention on the Protection & Promotion of the Rights & Dignity of Persons with Disabilities, Background Conference Document Prepared by the Office of the U.N. High Comm’r for Human Rights: Legal Capacity (Aug. 2015), <http://www.un.org/esa/socdev/enable/rights/ahc6documents.htm>.

²¹ CRPD Art. 12 para 3.

²² Committee on the Rights of Persons with Disabilities, General comment on Article 12: Equal recognition before the law, para 24, at 6 (Nov. 25, 2013) *available at* <https://www.ohchr.org/Documents/HRBodies/CRPD/GC/DGCArticle12.doc>.

²³ Kanter & Tolub, *supra* note 12, at 575.

Decision-Making practice in the United States.²⁴ State legislative change started in 2015 when Texas became the first state in the nation to pass a Supported Decision-Making bill.²⁵ At publication, a total of ten jurisdictions have passed a detailed Supported Decision-Making agreement statute,²⁶ and many other states have passed bills establishing Supported Decision-Making as an alternative to guardianship or otherwise including Supported Decision-Making in law.²⁷ The new UGCOPAA also includes a provision about Supported Decision-Making.²⁸

Starting in at least 1999,²⁹ U.S. courts have cited Supported Decision-Making as a basis for avoiding a guardianship with increasing frequency, including in many jurisdictions without a Supported Decision-Making statute at the time of the decision.³⁰ One example that is typical of

²⁴ About the National Resource Center for Supported Decision-Making, <http://www.supporteddecisionmaking.org/about> (last visited March 28, 2021); Supported Decision Making Program, Administration for Community Living, <https://acl.gov/programs/consumer-control/supported-decision-making-program> (last visited March 28, 2021).

²⁵ TEX. EST. CODE ANN. §§ 1357.001 - 1357.102 (West 2019).

²⁶ WIS. STAT. ANN. §§ 52.01-52.32 (West 2018); ALASKA STAT. ANN. §§ 13.56.010-13.56.195 (West 2018); DEL. CODE ANN. tit. 16, §§ 9401A-9410A (West 2016); D.C. CODE ANN. §§ 7-2131 – 7-2134 (West 2018); IND. CODE ANN. §§ 29-3-14-1 - 29-3-14-13 (West 2019); N.D. CENT. CODE ANN. §§ 30.1-36-01 - 30.1-36-08 (West 2019); 42 R.I. GEN. LAWS ANN. §§ 42-66.13-1 - 42-66.13-10 (West 2020); NEV. REV. STAT. ANN. §§ 162C.010 - 162C.330 (West 2020); WASH. REV. CODE ANN. §§ 11.130.700 et. seq. (West 2020) (effective Jan. 1 2022), 2020 Wash. Legis. Serv. Ch. 312 (S.S.B. 6287) Part VI § 601-612 (West 2020); LA. STAT. ANN. § 13:4261.101- 13:4261.302 (West 2020).

Note that these measures are typically called either a Supported Decision-Making Act (e.g., DEL. CODE ANN. tit. 16, § 9401A (West 2016); R.I. GEN. LAWS ANN. § 42-66.13-1 (West 2020); NEV. REV. STAT. ANN. § 162C.010)) or a Supported Decision-Making Agreement Act (e.g., Supported Decision-Making Agreement Act TEX. EST. CODE ANN. § 1357.001 (West 2015)). For discussion of many of these statutes, including four that were enacted in 2019, see Zachary Allen & Dari Pogach, *More States Pass Supported Decision-Making Agreement Laws*, 41 BIFOCAL 159 (2019) available at https://www.americanbar.org/groups/law_aging/publications/bifocal/vol-41/volume-41-issue-1/where-states-stand-on-supported-decision-making/#:~:text=Supported%20decision%2Dmaking%20agreements%20laws,Columbia%2C%20Alaska%2C%20A%20nd%20Wisconsin (last visited March 28, 2021).

²⁷ See MO. ANN. STAT. § 475.075 (West 2020); ME. REV. STAT. tit. 18-C, § 5-301 (West 2019) (requiring finding that Supported Decision-Making would no guardianship proceeding); ME. REV. STAT. tit. 18-C, § 5-401 (West 2019) (same for conservatorship proceeding).

²⁸ UGCOPAA Sec. 301(a)(1)(A).

²⁹ *In re Peery*, 727 A.2d 539 (Penn. Sup. Ct. 1999) (holding that a woman with a “circle of support” to assist her in making decisions did not need a guardian, even though she was incapacitated).

³⁰ For overview of Supported Decision-Making jurisprudence, including discussion of unpublished decisions, see NCD TURNING RIGHTS INTO REALITY, *supra* note 2, at 27 (“The first reported court decision terminating a guardianship specifically in favor of SDM occurred in 2012 in the state of New York and was followed by other cases in New York (2015, 2016, 2017), Virginia (2013), Massachusetts (2015), the District of Columbia (2016),

these decisions is *Matter of Robert C.B.*³¹ where the court dissolved a guardianship based in part on a finding that the individual was engaged in Supported Decision-Making.³² Courts continue to cite Supported Decision-Making as a reason guardianship is not appropriate even in states that have not yet passed Supported Decision-Making laws, such as in New York where the jurisprudence is particularly well-developed.³³

C. Supported Decision-Making in the Context of Guardianship

Supported Decision-Making has been discussed primarily as an alternative to guardianship—a less restrictive alternative that can divert persons whose capacity is questioned and avoid the imposition of a substitute decision-making regime. There is, however a significant way in which Supported Decision-Making can be useful to, and should be used by, guardians.³⁴

Guardians are not appointed only to make decisions, in perpetuity, for their “wards.” They are expected to maximize autonomy and, indeed, to do what is necessary and possible to restore the decision-making capacity of those over whom they have been given legal power.

Florida (2016), Vermont (2017), Kentucky (2017), Nevada (2017), Maine (2018), and Indiana (2018).”) and NCD BEYOND GUARDIANSHIP *supra* note 4, at 63-64.

³¹ 68 Misc. 3d 704, 732, 125 N.Y.S.3d 253, 274 (N.Y. Sur. 2020).

³² *Id.* at 732.

³³ *See, e.g.*, Guardianship of Dameris L., 38 Misc. 3d 570 (Surr. Ct., N.Y. Cnty., N.Y. 2012) (holding that a “support network” made a guardianship unnecessary); *In re D.D.*, 50 Misc. 3d 666, 677, 19 N.Y.S.3d 867 (N.Y. Sur. 2015) (rejecting guardianship petition where individual had a Supported Decision-Making network for 11 years); *In re Guardian for Michelle M.*, 52 Misc. 3d 1211(A), 41 N.Y.S.3d 719 (N.Y. Sur. 2016) (“The appropriate legal standard is not whether the petitioners can make better decisions than Michelle, it is whether or not Michelle has the capacity to make decisions for herself, albeit with supportive services.”).

For discussion the nationally recognized and widely publicized court cases involving Supported Decision-Making arrangements of Jenny Hatch of Virginia and Ryan King of the District of Columbia, see NCD BEYOND GUARDIANSHIP, *supra* note 4,, at 63-64; 90-92.

³⁴ This is not an entirely new idea. In a 2014 study by the Secretary of Health and Human Resources of the Commonwealth of Virginia, Initial Recommendation 2 proposed that “[i]ndividuals who are appointed to positions as guardians... should receive training in Supported Decision Making and Person Centered Planning. They should espouse the commitment to incorporating such practices in their roles.” REPORT OF THE SECRETARY OF HEALTH AND HUMAN RESOURCES, SUPPORTIVE DECISION-MAKING STUDY (HJR 190, 2014) HOUSE DOCUMENT NO.6 (2014).

This seldom noted obligation is, however, contained in many guardianship statutes as exemplified by the UGCOPAA, which provides that:

A guardian for an adult shall promote the self-determination of the adult and, to the extent reasonably feasible, encourage the adult to participate in decisions, act on the adult's own behalf, and develop or regain the capacity to manage the adult's personal affairs.³⁵

And, the Commentary notes, “in furtherance of the concepts of limited guardianship and least restrictive alternatives” subsection (f) requires a guardian to “immediately...notify the court if the condition of the adult has changed so that the adult is capable of exercising rights previously removed.”³⁶ Guardians are required to submit a plan for the “care of the adult” that includes goals for the adult including “the restoration of the adult's rights, and how the guardian anticipates achieving [that goal]”³⁷ Similar provisions relating to a guardian's plan and the obligation to notify the court if and when a person no longer needs a guardian exist in a number of state guardianship laws.³⁸

Consistent with the frequently stated statutory purpose to “afford the person the greatest amount of independence and self-determination and participation in all the decision affecting such person's life”³⁹ the clear trend of statutes enacted after the guardianship reform of the late 1980's and early 1990's⁴⁰ is to recognize that “incapacity” is not a fixed or necessarily permanent state, and that, to the extent possible, a guardian's role is to foster and increase

³⁵ UGCOPAA, Sec. 313(b).

³⁶ *Id.* Comment to Sec. 313.

³⁷ UGCOPAA, Sec. 316(a)(5).

³⁸ *See, e.g.*, NY Mental Hygiene Law Sec. 81.31(b)(10) (requiring the guardian to inform the court if termination or limitation of the guardianship is warranted.).

³⁹ *Id.* at Sec. 81.01.

⁴⁰ *See* discussion in Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond*, 44 COLUM. HUMAN RTS. L. REV. 93, 115-120 (2012).

capacity and autonomy, including, as a goal, termination of the guardianship and the restoration of the person’s rights.

Supported Decision-Making can be an important tool in fulfilling the guardian’s obligation to “maximize the self-reliance and independence of the person” as required by the National Guardianship Association Standards of Practice.⁴¹ The NGA Standards impose an affirmative obligation on the guardian to:

petition the court for limitation or termination of the guardianship when the person no longer meets the standard pursuant to which the guardianship was imposed, or *where there is an effective alternative available*”(emphasis added).⁴²

The National Guardianship Association has expressly recognized Supported Decision-Making as a “viable alternative to guardianship”⁴³ and, in addition to stating that, like other alternatives, “supported decision making should always be identified and considered, whenever possible prior to the commencement of guardianship proceedings” notes that

Modern day respect for individual rights dictates that we must allow each individual to make or participate to the extent possible in personal decisions. Therefore, incorporation of SDM into guardianship standards is essential to evolving practice.⁴⁴

A guardian’s goal should be to enable the person subject to guardianship to “develop or regain his or her own capacity to the maximum extent possible”⁴⁵ Supported Decision-Making is not only a *means* to doing so, but can become the “effective alternative [to guardianship] available”

⁴¹ National Guardianship Association, Standards of Practice, Standard 9(II) (2013). See also National Guardianship Association, Ethical Principles, 5, <https://www.guardianship.org/wp-content/uploads/2017/07/Ethical-Principles-2017.pdf> (last accessed March 30, 2021).

⁴² *Id.* at Standard 12(H)

⁴³ National Guardianship Association, Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making, https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision_Making_PositionStatement.pdf (last visited Feb. 14, 2021)

⁴⁴ *Id.*

⁴⁵ *Id.*

to accomplish the *end* that is termination of the guardianship and restoration of the person's rights.

D. Supported Decision-Making for Other Populations Whose Legal Capacity May Be Questioned

People often ask whether Supported Decision-Making, which has been used primarily with people with intellectual or developmental disabilities, is also feasible and/or available for other groups whose legal capacity may be questioned—persons with psychosocial (mental health) disabilities and people labeled as having a mental health disability; persons with Traumatic Brain Injuries (TBIs), and especially older persons with progressive cognitive decline, due to conditions such as dementia or Alzheimer's.

While the goal—to promote and preserve autonomy and dignity through the use of chosen supports, rather than substituted decision-making—is the same, Supported Decision-Making will, of necessity, look different for each of these groups, and there is a paucity of empirical evidence as to what that might be. In the human rights context, pilot projects around the world have focused on using Supported Decision-Making with people with intellectual or developmental disabilities, though some, including Bulgaria,⁴⁶ Israel,⁴⁷ and the Czech Republic⁴⁸ have also included persons with psychosocial disabilities and traumatic brain

⁴⁶ The Bulgarian pilot project began with half the participants persons with psychosocial disabilities, and continued to enroll them as the pilot continued. See LUBKA ALEKSANDROVA ET AL., BULGARIAN CTR. FOR NOT-FOR-PROFIT LAW, GLOB. INITIATIVE ON PSYCHIATRY, BULGARIAN ASS'N OF PEOPLE WITH INTELLECTUAL DISABILITIES & NAT'L ORG. OF MENTAL HEALTH SERV. USERS, SUPPORTED DECISION MAKING: GUIDEBOOK TO RIGHTS ENFORCEMENT 11-12 (2014).

⁴⁷ The Israeli pilot noted particular challenges with regard to participants who had experienced psychiatric hospitalization over the year the pilot was operative. In its Report, Bizchut wrote "In some of these cases, the need for the supporter became more acute during these emergency situations, when the person's needs enhanced support for making decisions during the hospitalization. Attention must be given to how support can be adapted to the changing circumstances of the participant's life." BIZCHUT SERVICE MODEL, *supra* n at 41.

⁴⁸ The pilot in the Czech Republic also enrolled persons with psychosocial disabilities but there is no published information in English specific to the experience of those participants.

injuries.⁴⁹ Unfortunately, there have been no U.S. pilot projects targeting the use of Supported Decision-Making for older persons.⁵⁰ For a thorough discussion of the potential use of Supported Decision-Making for older persons and recent pilot projects abroad, see the article by Rebekah Diller and Morgan Whitlach in this symposium issue.⁵¹

II. Supported Decision-Making Pilots: the Evolution of Supported Decision-Making Practice

There have been a small number of formal Supported Decision-Making pilots in the U.S. that have been purposefully designed to test out articulated hypotheses and identify best practices, and address questions raised by scholars.⁵² In addition, since adoption of the CRPD, a number of countries around the world, including Bulgaria, Israel, Australia,⁵³ the Czech Republic,⁵⁴ Latvia,⁵⁵ and Kenya⁵⁶ have created formal Supported Decision-Making pilot projects, with all employing a model for facilitating the Supported Decision-Making process with the person with the disability. Though these international pilots differ in many respects,

⁴⁹ Information about persons with TBIs has come primarily from Australia.

⁵⁰ The CPR Nonotuck pilot included one older adult with dementia, *see infra* at text accompanying note starting at 118. The SDMNY pilot had two participants in their seventies and three in their late sixties, but these were incidental to intellectual or developmental disabilities.

⁵¹ Morgan Whitlach & Rebecca Diller, *Supported Decision-Making: Potential and Challenges for Older Persons* [cite forthcoming].

⁵² *See, e.g.,* Karrie A. Shogren & Michael Wehmeyer, *A Framework for Research and Intervention Design in Supported Decision-Making*, INCLUSION (2015); Nina A. Kohn et. al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1114 (2013). (“Supported Decision-Making is thick on theory but thin on implementation and best practice guidance” and that “information is needed related to how, with whom, and with what supports Supported Decision-Making is most successful.”)

⁵³ Pilot projects and lessons learned in Bulgaria, Israel and Australia are discussed below, as are the presently undocumented pilots in Canada.

⁵⁴ For a description of the pilot project in the Czech Republic, denominated the "Black and White Project," see Black and White, QUIP, <http://www.kvalitavpraxi.cz/en/projects/current-projects/black-and-white/> [https://perma.cc/S6TH-9Q7N].

⁵⁵ For a description of the pilot project in Latvia, see *RC Zelda Has Published Handbook: FirstSteps in Implementation of Supported Decision Making in Latvia*, ZELDA (Apr. 26, 2016), <https://zelda.org.lv/en/news/rc-zelda-has-published-handbook-first-steps-in-implementation-of-supported-decision-making-in-latvia-2/> [https://perma.cc/428C-EZB8].

⁵⁶ *See* USERS AND SURVIVORS OF PSYCHIATRY IN KENYA, *Advancing The Rights Of Persons With Psychosocial Disabilities In Kenya*, 23-24 (2018), available at <https://uspskenya.org/wp-content/uploads/2017/08/Advancing-the-Rights-of-Persons-with-Psychosocial-Disability>.

they each demonstrated that Supported Decision-Making works to enable people with intellectual or developmental disabilities to make their own decisions with the support they need and desire. They also demonstrate, in fewer numbers, that Supported Decision-Making can assist people with psychosocial disabilities and people with traumatic brain injuries with decision-making. We have been fortunate to have worked, directly or indirectly, with a number of those pilots, and to have benefitted from what written material is available in English, and acknowledge our gratitude.

The remainder of this article will describe and analyze some of the major U.S. Pilots: (1) the first Massachusetts pilot, (2) the Massachusetts incubator pilots, (3) the Georgia pilot, all coordinated by Center for Public Representation, and (4) the New York pilot, run by Supported Decision-Making New York. We will describe how Supported Decision-Making worked for the participants, how the model was implemented, and discuss recommendations and observations about best practices. Like the international pilots, the U.S. pilots demonstrate that Supported Decision-Making is a viable alternative to guardianship that warrants ongoing dedication of resources and infrastructure to expand and embed the practice in the U.S.

A. Massachusetts Center for Public Representation and Nonotuck Supported Decision-Making Pilot

i. Initial Planning and Pilot Design

In 2014, the Center for Public Representation (CPR) decided to develop one of the first Supported Decision-Making pilots to generate information about the practice. CPR is a non-profit law firm based in Massachusetts and D.C. that uses legal strategies, advocacy, and policy to promote the integration and full community participation of people with disabilities in

society consistent with the values of self-determination and choice.⁵⁷ CPR's partner was Nonotuck Resource Associates, Inc. (Nonotuck), a Massachusetts shared living provider.⁵⁸ Human Services Research Institute (HSRI), a nonprofit national research and consulting organization, conducted an independent evaluation of the pilot.⁵⁹ At the outset, CPR conducted and published an environmental, international analysis of Supported Decision-Making.⁶⁰

In October 2013, to commence the project planning, the partners organized a one-day conference designed to learn about Supported Decision-Making practice in other jurisdictions and to get community input about the pilot design.⁶¹ The participants were carefully chosen to reflect a wide range of stakeholders and prioritized input from self-advocates and family members. Other participants included judges; international disability professionals; national disability advocates, scholars, and lawyers; government officials; and providers.⁶² Two explicit goals emerged from the planning meeting:

1. **Maximize individuals' independence:** By directing their own decision-making process and making their own decisions, pilot participants will gain confidence and

⁵⁷ CENTER FOR PUBLIC REPRESENTATION, <https://www.centerforpublicrep.org/> (last visited Feb. 9, 2021).

⁵⁸ *Who We Are*, NONOTUCK RESOURCE ASSOCIATES <https://www.nonotuck.com/who-we-are> (last visited Feb. 8, 2021).

⁵⁹ ELIZABETH PELL & VIRGINIA MULKERN, THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE APPROACH, PILOT EVALUATION YEAR 1 (Nov. 30, 2015) <https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-Supported-Decision-Making-HSRI-Evaluation-Year-1-Report-2015.pdf> (last visited Feb. 9, 2021); ELIZABETH PELL & VIRGINIA MULKERN, THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT (Nov. 30, 2015) <https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-SDM-HSRI-Evaluation-Year-2-Report-2016.pdf>.

⁶⁰ MARCIA BOUNDY & BOB FLEISCHNER, SUPPORTED DECISION MAKING INSTEAD OF GUARDIANSHIP: AN INTERNATIONAL OVERVIEW, TASC (Training & Advocacy Support Center), National Disability Rights Network (2013) (on file with author).

⁶¹ THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE APPROACH, PILOT EVALUATION YEAR 1, 8 (Nov. 30, 2015) <https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-Supported-Decision-Making-HSRI-Evaluation-Year-1-Report-2015.pdf> (last visited Feb. 9, 2021) [Hereinafter HSRI PILOT EVALUATION YEAR 1].

⁶² HSRI PILOT EVALUATION YEAR 1, *supra* note 62, at 8.

become better self-advocates. They will have both a voice and a presence in the community.

2. Identify best practices and factors that can be replicated as models that advance Supported Decision-Making as an alternative to restrictive guardianship: How can supported decision-making best be implemented to make a positive difference in an individual's life?⁶³

Participants also recommended that the project create an Advisory Council, provide for independent monitoring, conduct widespread community education, and recruit a small number of initial participants.⁶⁴ The judges also recommended that each Decision-Maker execute a Durable Power of Attorney and a Health Care Proxy to accompany the Supported Decision-Making agreement. They also recommended the written Supported Decision-Making agreements be notarized to give them the imprimatur of a legal process and confer formality, which would increase credibility of the model for third parties.⁶⁵

ii. Implementation

External advisors and evaluators: In addition to retaining HSRI for the independent evaluation, the partners established an Advisory Council composed of stakeholders, including Decision-Makers, family, providers, judges, and state agency representatives that met regularly to guide the pilot design and implementation.⁶⁶ The Advisory Council played an essential role in establishing pilot priorities and strategies, providing real-time feedback on implementation.

Recruitment of pilot participants: Guided by the principles developed through the one-day conference and Advisory Council recommendations, the pilot recruited a small number of

⁶³ *Id.* at 4.

⁶⁴ *Id.* at 9 (describing recommendations from planning meeting).

⁶⁵ *Id.* at 12.

⁶⁶ Advisory Council members included self-advocates, including both individuals under guardianship and pilot participants; family members; retired judges; a grantor; CEOs and directors of a large human services and advocacy agencies; health care providers; a guardian; and a representative from the Massachusetts' Public Defender agency. See *Initial SDM Pilot: CPR and Nonotuck*, SUPPORTED DECISION-MAKING <https://supporteddecisions.org/supported-decision-making-pilots/initial-supported-decision-making-pilot-cpr-and-nonotuck/> (last visited Feb. 9, 2021).

Decision-Makers to allow for careful study of the outcomes and challenges for each participant.⁶⁷ In recruiting participants, the partners prioritized identifying individuals with various diagnoses and differing levels of support needs.⁶⁸ First, Nonotuck staff reviewed the case files for close to 100 clients who met a set of targeted characteristics and identified twenty people as potential participants in the pilot.⁶⁹ Project partners then provided education about Supported Decision-Making in plain language to the individuals, their caregivers, family, and guardians.⁷⁰ Ten individuals initially joined the pilot and ultimately nine people participated in the entire pilot.⁷¹

The nine pilot participants represented a cross-section of people with varying support needs and from a range of demographics.⁷² All participants had an intellectual or developmental disability diagnosis and some participants had dementia.⁷³ All of the decision-makers used at least some speech, but reflected a wide range of ability and vocal expression.⁷⁴ Every participant lived with caregivers using a shared living or family caregiver model, and two had lived for several decades in Massachusetts state institutions.⁷⁵ The pilot participants' ages ranged from

⁶⁷ HSRI PILOT EVALUATION YEAR 1, *supra* note 62, at 9.

⁶⁸ *Id.*

⁶⁹ *Id.* at 15.

⁷⁰ *Id.* at 15.

⁷¹ One of older adult pilot participants passed away in the first year of the pilot before signing a Supported Decision-Making agreement.

⁷² HSRI PILOT EVALUATION YEAR 1, *supra* note 62, at 20 (table describing demographics of pilot participants).

⁷³ *Id.* at 20 (describing demographics of Decision-Makers and diagnoses).

⁷⁴ *Id.* (one pilot participant used “yes” and “no” with facial expression; another relied heavily on text messaging; and another Decision-Maker needed lots of extra time to process information and respond).

⁷⁵ *Id.* at 20.

twenty-three to seventy-eight years.⁷⁶ Many of the participants also had a behavioral health diagnoses⁷⁷ and two-thirds were women.⁷⁸

Given the time and complexities involved in terminating a guardianship, CPR and Nonotuck intentionally limited the number of pilot participants under guardianship.⁷⁹ Two participants had full guardians, one of whom was discharged during the pilot because of the individual's use of Supported Decision-Making, as discussed *infra* at 24.⁸⁰ Both of the pilot participants under guardianship were under court orders to take psychiatric medications.⁸¹ All of the other participants were at risk of guardianship.⁸²

Counseling pilot participants: Though CPR initially estimated that agreements could be developed over the course of one or two long meetings, in most instances more time was needed to understand the concepts fully and because a large number of individuals were typically involved.⁸³ Understanding Supported Decision-Making required repetition and extended conversation, and participant's communication styles need to be accommodated.⁸⁴

⁷⁶ *Id.*

⁷⁷ *Id.* (for example, participants' mental health diagnoses included Borderline Personality Disorder, Bipolar Mood Disorder, Anxiety Disorders, Depression, Attention Deficit Hyperactivity Disorder, Psychotic Disorder, Post-Traumatic Stress Disorder).

⁷⁸ *Id.*

⁷⁹ *Id.* at 29-30.

⁸⁰ *Id.* at 15, 28.

⁸¹ *Id.* at 28.

⁸² For example, one participant in the second year of the pilot was referred to the pilot because the Massachusetts Developmental Disabilities agency recommended preparing for a guardianship in the event his mother died, as she was his primary supporter. He instead chose to execute a Supported Decision-Making agreement that formalized his existing relationships with supporters including his mother so that he could demonstrate his capacity to make his own decisions with support and avoid a guardianship. His mother has since passed away and he continues to successfully practice Supported Decision-Making with his supporters.

⁸³ HSRI PILOT EVALUATION YEAR 1, *supra* note 62, at 16-17.

⁸⁴ *Id.* at 16-18.

Training: Training for all project staff, participants, and supporters was an essential aspect of the pilot and occurred in many forms throughout the two years and beyond.⁸⁵ Ultimately, all Nonotuck staff received training to embed the practice in the larger organization.⁸⁶ CPR also recognized the value of customized training, even for experienced disability lawyers, to learn how to facilitate personal, intimate conversations about participants' lives. A disability professional trained CPR and Nonotuck staff in facilitating discussions about what someone wanted in their life, the areas where they needed help, who they counted on, and the people they might want to support them.

Selection of supporters: A fundamental value of the project was that each participant was in charge of selecting their own supporters and identifying what assistance they wanted from each supporter.⁸⁷ The project staff gave counseling and advice about supporter selection as desired. Participants selected as their supporters a range of individuals including family members, friends, and providers.⁸⁸ Pilot participants also identified areas in which they wanted assistance making decisions, including healthcare, finance, employment, living arrangements, and relationships, and the supporters who would help with each area.⁸⁹

Six participants selected at least one supporter who was paid, either as a caregiver, respite provider, or Nonotuck staff.⁹⁰ Project partners concluded that it was consistent with the project principles of self-determination to honor Decision-Maker's selection of supporters. In all such

⁸⁵ ELIZABETH PELL & VIRGINIA MULKERN, THE HUMAN SERVICES RESEARCH INSTITUTE, SUPPORTED DECISION MAKING PILOT: PILOT PROGRAM EVALUATION YEAR 2 REPORT, at 41 (Nov. 30, 2015) <https://supporteddecisions.org/wp-content/uploads/2019/05/CPR-SDM-HSRI-Evaluation-Year-2-Report-2016.pdf> [Hereinafter HSRI PILOT EVALUATION YEAR 2] (discussing future training and referencing past training).

⁸⁶ *See id.*

⁸⁷ HSRI PILOT EVALUATION YEAR 1, *supra* note 62, at 21.

⁸⁸ *Id.*

⁸⁹ For more about how these arrangements were made, see *id.* at 26-27.

⁹⁰ *Id.* at 22.

cases, project staff had frank discussions with the Decision-Maker and supporters about any potential conflict of interest and how to draft an agreement to minimize the potential conflict, such as having paid supporters not assist with decision-making support for issues that concern services from the agency paying the supporter.⁹¹

Project staff also facilitated conversations about strategies for handling potential disagreements between supporters including how and whether supporters should communicate with each other or attempt to resolve differences, all while ensuring the Decision-Maker had the information they needed and retained ultimate authority.⁹²

Supported Decision-Making agreement: In consultation with project partners and the Advisory Council, CPR developed a model written Supported Decision-Making agreement that was intended to be flexible.⁹³ CPR revised the agreement with input from participants and families.⁹⁴ The agreement included language that: (1) laid out the role and responsibilities of each supporter; (2) made clear that the Decision-Maker could change their mind about the agreement at any time,⁹⁵ (3) allowed the individual to identify areas where they did not want decision-making support,⁹⁶ (4) described how multiple supporters would work together,⁹⁷ and (5) documented supporters commitment to respect the participant's decisions.⁹⁸ Over the course of several meetings, each participant, with support from project staff, developed an individualized,

⁹¹ HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 8, 13-14.

⁹² *Id.* at 19-20.

⁹³ HSRI PILOT EVALUATION YEAR 1, *supra* note 62, at at 41-44 (Supported Decision-Making Agreement form).

⁹⁴ *Id.* at 12 (describing feedback and revisions to form).

⁹⁵ *Id.* at 43, Section F.

⁹⁶ *Id.* at 42.

⁹⁷ *Id.* at 43, Section E.

⁹⁸ *Id.* at 44, Section H.

written Supported Decision-Making agreement that memorialized the commitments that had been discussed with project staff and supporters.⁹⁹

Pilot participants then had a ceremony where they executed the agreements before a notary public who stamped, signed, and dated the agreement.¹⁰⁰ The ceremonies were followed by celebrations with supporters, family, and friends.¹⁰¹ These events were a rite of passage for the Decision-Maker and helped highlight the significance of the agreement.

Related decision-support documents: Pilot participants also used other legal forms to establish decision-making support and memorialize their wishes. For example, all but one participant designated a health care proxy, which is a form of an advance directive that allows an individual to designate an agent to make health care decisions for the individual when the principal is not capable to make them due to incapacity.¹⁰² Although a principal may revoke a health care proxy at any time,¹⁰³ the agent may petition the Massachusetts Probate Court to “affirm” the proxy upon a showing that the principal lacks the capacity to revoke,¹⁰⁴ which provided family members an additional level of comfort in using Supported Decision-Making.

Additionally, two participants executed a durable power of attorney, where an individual appoints a third party as an “Attorney-In-Fact” to manage the individual’s money, property, and business affairs and make financial decisions.¹⁰⁵ Finally, a number of participants had representative payees who managed their Social Security payments.¹⁰⁶ Some of the participants had these arrangements prior to the pilot, while others chose to put them in place as an

⁹⁹ *Id.* at 26.

¹⁰⁰ HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 8.

¹⁰¹ *Id.* at 11.

¹⁰² *Id.* at 34. *See* G.L. c. 201D

¹⁰³ G.L. c. 201D § 7.

¹⁰⁴ G.L. c. 201D § 17. *See Guardianship of Emma Mason*, 41 Mass. App. Ct. 298 (1996).

¹⁰⁵ G.L. c. 190B §§ 5-501 & 5-502; HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 34.

¹⁰⁶ HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 7.

accompaniment to creating a Supported Decision-Making agreement.¹⁰⁷ These tools were particularly important for pilot participants with advancing dementia, as they were a mechanism for capturing the participant’s present preferences before their symptoms progressed.

Evaluation findings about the practice of Supported Decision-Making during the pilot: During the evaluation, the researchers identified examples of seventy-two decisions¹⁰⁸ where Supported Decision-Making had been used.¹⁰⁹ Supported Decision-Making was most frequently employed in making health care decisions (nineteen decisions), followed by financial decisions (fifteen decisions),¹¹⁰ areas of concern that often trigger guardianship. The Decision-Makers expressed satisfaction with Supported Decision-Making, with their selection of supporters, and with the ways in which their supporters provided assistance.¹¹¹ The pilot participants also reported that their preferences and decisions were respected.¹¹² The researchers found that the pilot demonstrated that when individuals with disabilities are given opportunities to make decisions with input from committed and trusted supporters, it can be a satisfying experience with positive impact on both Decision-Makers¹¹³ and supporters.¹¹⁴ The evaluation also found that participants did not experience abuse, neglect or financial exploitation and many participants reported that they found “the structure of Supported Decision-Making—selecting

¹⁰⁷ *Id.* at 34 (table 3).

¹⁰⁸ Note that this is not a reflection of all the decisions made by the pilot participants during the two-year pilot, but rather those that the shared with the researchers in the interview. *See HSRI PILOT EVALUATION YEAR 2, supra* note 85, at 8, 13.

¹⁰⁹ *HSRI PILOT EVALUATION YEAR 2, supra* note 85, at 13-14 (describing number, types, and outcomes of decisions made by pilot participants).

¹¹⁰ *Id.*

¹¹¹ *Id.* at 24 (describing pilot participants’ satisfaction with decisions, supports, and decision assistance).

¹¹² *Id.* at 31-32 (“For all 72 SDM decisions, the preferences of adopters were reported as being respected and acted upon.”).

¹¹³ *Id.* at 24 (describing pilot participants’ satisfaction with decisions, supports, and decision assistance).

¹¹⁴ *Id.* at 25 (describing supporters’ satisfaction with decisions and responsibilities).

people one trusts to help make decisions and having more than one decision supporter—reduces such risks.”¹¹⁵

Post-pilot: Since the completion of the two-year pilot, Nonotuck has continued to support the participants, which is a significant resource investment. CPR has also provided periodic support and advice to participants, supporters, and Nonotuck staff. With this organizational support, the pilot participants have all sustained their practice of Supported Decision-Making.

iii. Impact of Supported Decision-Making on CPR-Nonotuck pilot participants’ lives

The pilot demonstrated and the evaluation found that Supported Decision-Making changed peoples’ lives in ways that are best understood through the participants’ own words and experiences.¹¹⁶

Cory: Cory is a young man from the Berkshires, who has worked for many years and is close with his family. Cory’s mother became his guardian when he turned eighteen. He had received services from Nonotuck for many years.

In January of 2015, Cory and his family first learned about the Nonotuck and CPR Supported Decision-Making pilot. Cory spent time learning about Supported Decision-Making with project staff and decided he wanted to practice Supported Decision-Making. With the help of CPR and Nonotuck, he identified the areas where he needed or wanted help making decisions and the supporters that he wanted to help with each one. Cory chose his mother, father, and his sister as supporters. These matters were memorialized in a Supported Decision-Making

¹¹⁵ *Id.* at 26-29 (describing evaluation finding that Supported Decision-Making did not result in abuse or exploitation from perspectives of participants, supporters, project staff), .

¹¹⁶ *Id.* at 5 (describing impact on Decision-Maker’s lives).

agreement with the help of CPR and Nonotuck. Cory also executed a health care proxy and durable power of attorney.

In 2015, CPR represented Cory in a proceeding to end his guardianship. As required by Massachusetts law, Cory's petition to terminate the guardianship was accompanied by reports from an MSW, MD, psychologist, and psychiatrist who each said that with support Cory could make his own decisions. The judge terminated Cory's guardianship in favor of his Supported Decision-Making agreement, the first such decision in Massachusetts.

While under guardianship, Cory was very withdrawn and did not feel in charge of his own life. After his the court terminated his guardianship, Cory stated:

[Ending the guardianship was] very special because I felt my own freedom for the first time.... [I learned] there were apartments available for independent living.... I met with my parents to help me make the decision....[They] gave me the big picture of what my life would look like, such as limited money, working more hours and independently doing laundry and cooking. I wanted this experience, and I took the risk. Supported Decision-Making is really important to me. I love my family and they will always be there to support me. This is my journey now.

Cory's mother described Supported Decision-Making as the "perfect storm for Cory, because we always wanted an alternative to guardianship from the beginning, but there was not such an option at the time when Cory turned eighteen."¹¹⁷

Agnes: Agnes, a woman in her late seventies, had been institutionalized for several decades in a state-operated institution for individuals with intellectual disabilities.¹¹⁸ She also had a behavioral health diagnosis. After Agnes was deinstitutionalized, she lived independently with supports for many years and had a cleaning business. As she aged, Agnes developed dementia and moved into a Nonotuck shared living arrangement. In recognition of her

¹¹⁷ MEET CORY, CPR SUPPORTED DECISION-MAKING, <https://supporteddecisions.org/stories-of-supported-decision-making/corys-story/> (last visited Feb. 9, 2021).

¹¹⁸ This is a pseudonym.

advancing dementia, she decided to participate in the CPR Nonotuck Supported Decision-Making pilot. She picked three individuals as supporters: a long-time friend who lived in another state and two providers.

After executing her Supported Decision-Making agreement, Agnes was hospitalized with a heart condition. Agnes' supporters helped her confer with her doctors and supported her in making health care decisions. Nonotuck nursing staff also provided Agnes and her supporters context and information about her options. The hospital physicians never questioned Agnes' ability to make decisions with the help of her supporters. This may be in part because Agnes' primary care doctor was so supportive and comfortable with her Supported Decision-Making arrangement. During the pilot, Agnes discharged the two providers as her supporters and retained only her long-time friend in the supporter role. Her friend checked in at least weekly with Agnes and Nonotuck to ensure she was available to support Agnes. Agnes also designated her friend as her health care proxy.

In the fall of 2020, Agnes was hospitalized with COVID-19. With the assistance of Nonotuck staff, her long-term supporter helped Agnes with all treatment decisions. Agnes lost the ability to walk while hospitalized and was admitted to a rehabilitation facility from the hospital, where she was kept isolated due to the infection. Agnes was unambiguous about wanting to return home and her supporter again assisted with decision-making. Together, Agnes, her supporter, Nonotuck, and CPR staff advocated with several state agencies to obtain additional funding and supports to allow her to return home, which she was able to do.

Subsequently, Agnes was re-hospitalized with an infection from a bedsore that she originally developed while in the rehabilitation facility. At this point, hospital physicians believed that due to her medical condition she was near the end of her life. During this time,

Agnes was still able to express her preferences. Her supporter was with Agnes during her hospitalization, making sure that Agnes' wishes were honored. Agnes' supporter held her hand as she took her last breath in 2021. Agnes' Supported Decision-Making arrangement continued working effectively throughout her life, despite the worsening of her dementia and the many complex medical conditions and interventions she navigated at the end of her life.

Molly: Molly¹¹⁹ is a middle-aged dually diagnosed woman, whose mother had been her guardian for her adult life. After her mother died, Molly's brother became her guardian. Molly and her brother learned about the pilot and she decided she was interested in trying out Supported Decision-Making while she remained under guardianship to see if it worked for her. Molly and her brother then planned to later reconsider whether guardianship remained necessary. Molly selected her brother and a number of other trusted individuals in her life as her supporters.

Molly successfully used Supported Decision-Making for about a year, and she and her supporters felt that it provided an adequate level of support. After much discussion, the family concluded that they supported the termination of the guardianship and were interested in going to court to restore her rights. The state developmental disability agency, however, strenuously opposed terminating her guardianship, and some of Molly's treating professionals were also reluctant. In part because of the resistance from the state agency, Molly and her family decided not to pursue the formal dissolution of the guardianship and instead to continue to practice Supported Decision-Making informally.

As these experiences show, the pilot demonstrated that Supported Decision-Making could be successfully practiced by individuals with a wide range of ages, life experiences,

¹¹⁹ This is a pseudonym.

disabilities and diagnoses, and family involvement. Pilot participants made their own decisions with support, gained confidence, and became better self-advocates.¹²⁰ CPR, Nonotuck, and HSRI were able to use the pilot to identify best practices that can be replicated as models to advance Supported Decision-Making as a less restrictive alternative to guardianship.¹²¹ The two-year independent evaluation confirmed that the pilot produced what scholars have called for—“evidence as to how decisions are actually made in supported decision-making relationships; the effect of such relationships on persons in need of decision-making assistance; or the quality of the decisions that result.”¹²²

B. Massachusetts Supported Decision-Making Incubator Pilots

i. Initial Planning and Pilot Design

In 2017, CPR designed and implemented a state-wide incubator Supported Decision-Making pilot that targeted transition aged youth and multicultural communities in urban and rural settings. The pilot was designed to gather information about whether Supported Decision-Making is an effective tool to disrupt the “school to guardianship pipeline,” a phenomenon that is a result of schools providing limited information to families as youth with disabilities approach eighteen, resulting in unnecessary guardianship due to lack of education about alternatives.¹²³

The incubator pilot also tested using an approach that was less resource intensive and more

¹²⁰ HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 31-34 (listing feedback on pilot impact from interviews with Decision-Makers, Supporters, and Nonotuck staff including one staff member who said impact of Supported Decision-Making “[s]he is taking leadership on her life, she wanted surgery, with work day decisions, making decisions for her life. Before SDM it would only have been mom’s decisions. She has opportunities for growth with finances and compulsion to buy”)

¹²¹ *Id.* at 4.

¹²² NINA A. KOHN ET. AL., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1114 (2013). *See* HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 17-19 (describing how decisions are made); 13-14 (describing types of decisions and outcomes of decisions made).

¹²³ NCD TURNING RIGHTS INTO REALITY, *supra* note 2, at 29-36.

replicable than the original pilot. CPR provided technical assistance, training, and support to five organizations of various types, with the goal of embedding Supported Decision-Making in the organization's practice. The five partners were: (1) Nonotuck, which targeted more racially and culturally diverse geographic regions in Massachusetts; (2) MassFamilies, a statewide, grassroots coalition of families of people with disabilities;¹²⁴ (3) Advocates, a progressive service provider for people with a range of disabilities, including mental health consumers;¹²⁵ (4) Multicultural Community Services, a service provider dedicated to providing culturally and ethnically responsive supports that enhance the capacities of individuals with developmental disabilities;¹²⁶ (5) the Northeast Arc, a service provider agency for people with developmental disabilities whose project was housed in a program serving autistic people and their families with a particular focus on Spanish-speaking populations.¹²⁷ The organizations were chosen because they had values and a track record of supporting people with disabilities in methods that promoted self-determination, dignity, autonomy, and were person-centered.

Each organization agreed to establish a pilot project that would serve between five and seven people in one year and committed to integrating Supported Decision-Making into the organization's ongoing programming and practice. CPR provided the five partners with a modest stipend to support the organizational investment in the project.

In April 2018 CPR again convened a group of advocates, thought leaders, and numerous stakeholders including self-advocates and family members, to assist with priority setting and the planning and implementation of the incubator pilot.

¹²⁴ ABOUT, MASSFAMILIES <https://massfamilies.org/about/> (last visited Feb. 10, 2021) (organization was formerly called Massachusetts Families Organizing for Change).

¹²⁵ WHO WE ARE, ADVOCATES, <https://www.advocates.org/who-we-are> (last visited Feb. 10, 2021).

¹²⁶ MISSION AND BELIEF STATEMENTS, MULTICULTURAL COMMUNITY SERVICES, <https://www.mcsnet.org/about-us/mission-belief-statements/> (last visited Feb. 10, 2021).

¹²⁷ AUTISM SUPPORT CENTER, NORTHEAST ARC, <https://ne-arc.org/services/autism-and-specialty-aba-services/autism-support-center/> (last visited Feb. 11, 2021).

ii. Implementation

CPR provided numerous trainings, technical assistance, and other oversight to the leadership and staff at each of the five partner organizations. In addition, with the five partners, CPR conducted group informational sessions for potential Decision-Makers and their families and supporters. Project staff also met with Decision-Makers and their families as needed. CPR created learning opportunities among the five organizations, such as meetings, joint trainings, and phone calls, that allowed the partner organization to discuss their respective challenges, successes, and experiences.

Approximately twenty-five people started using Supported Decision-Making during the incubator pilots, including transition age youth and people from diverse racial and cultural backgrounds. Most of the five partners embedded Supported Decision-Making into their organizational practice and the participants continue to use Supported Decision-Making to this day.

Some Decision-Makers from different racial and/or cultural backgrounds did not wish to use a written agreement to memorialize their Supported Decision-Making plans, though they embraced Supported Decision-Making as a way to avoid guardianship. Reducing personal matters and relationships—particularly family relationships—to a written document was inconsistent with some participants' cultural values. Similarly, they did not wish to execute decisional supports like a health care proxy or power of attorney. Some families of Russian, Latinx, and Southeast Asian descent reported Supported Decision-Making was also appealing because it was consistent with an interest in limiting government involvement in their lives, with guardianship epitomizing this interference. We do not suggest these perspectives are universal within any of these cultural groups, but rather they are significant because they demonstrate that

there is more than one approach to Supported Decision-Making and that cultural experiences can impact the way an individual and their family uses the model. A more structured approach to Supported Decision-Making may be warranted for individuals with more significant support needs.

The pilot has also been a catalyst for the five organizations to develop the internal capacity to offer Supported Decision-Making to people beyond the original pilot participants, indicating that the incubator approach is a valuable model.

C. Georgia Supported Decision-Making Pilot

Recognizing that early adopters of Supported Decision-Making in the U.S. either had involved family and/or a group of natural supporters, in 2018, CPR developed a Supported Decision-Making pilot that examined how the model could work for people without significant “natural supports.” The pilot partners were the Georgia Advocacy Office (GAO), the state’s federally funded Protection and Advocacy Program,¹²⁸ and the Georgia Council on Developmental Disabilities.

GAO runs a Citizen Advocacy program that initiates voluntary, one-to-one relationships between people with disabilities and community members.¹²⁹ The primary focus of the pilot was trying out Supported Decision-Making for individuals in the Citizen Advocacy program, and the secondary focus was using Supported Decision-Making to prevent or overturn guardianships,

¹²⁸ GEORGIA ADVOCACY OFFICE, <http://thegao.org/> (last visited Feb. 11, 2021).

¹²⁹ CITIZEN ADVOCACY, GEORGIA ADVOCACY OFFICE <http://thegao.org/what-we-do/programs/initiatives/engaging-georgia-citizens-in-protection-advocacy/> (Feb. 11, 2021) (describing Citizen Advocacy program to foster community connections for people with intellectual or developmental disabilities without natural supports).

building on a preexisting rights restoration initiative at GAO.¹³⁰ Like the other pilots, the Georgia pilot was guided by a state-wide Advisory Council.¹³¹

The Citizen Advocacy coordinators initially identified ten individuals who were at risk of guardianship and might benefit from Supported Decision-Making. Project staff met these individuals and their advocates about Supported Decision-Making. Twelve Citizen Advocacy participants adopted Supported Decision-Making as part of the pilot, half were women, and six participants were Black, and six were white. Participants ranged in age from twenty-one to fifty-three. Every participant selected their “citizen advocate” as a supporter. The pilot adopted a flexible approach for memorializing the agreements. None of the twelve participants chose to adopt a formal, written agreement, and none executed a health care proxy or a durable power of attorney.

Since the pilot began, GAO’s rights restoration project has successfully represented five individuals in terminating their guardianships and helped each set up a Supported Decision-Making arrangement.¹³² As part of the guardianship termination proceedings, each presented evidence to the court about their Supported Decision-Making arrangements, which the courts found weighed in favor of terminating their guardianships.¹³³ None of the five who had their rights restored chose to have a formal written agreement. This demonstrated that, like in other written decisions,¹³⁴ courts are willing to consider both written Supported Decision-Making agreements and informal arrangements in rights restoration proceedings.

¹³⁰ CPR SUPPORTED DECISION-MAKING, GEORGIA SDM PILOT, <https://supporteddecisions.org/supported-decision-making-pilots/georgia-supported-decision-making-pilot/> (last visited Feb. 14, 2021).

¹³¹ Council members included a wide range of stakeholders including self-advocates, a sitting judge, family members, and staff from the Public Guardian’s office.

¹³² *Id.*

¹³³ *Id.*

¹³⁴ See discussion *supra* at text accompanying notes 29 to 33.

The pilot also included on training and education component. For example, project staff presented on Supported Decision-Making at a statewide judicial conference.¹³⁵ One probate judge who attended the training subsequently contacted GAO for assistance on a pending guardianship petition for a young man who he believed could use Supported Decision-Making as a less restrictive alternative to guardianship. GAO assisted the man in developing a Supported Decision-Making plan that enabled him to avoid guardianship.¹³⁶

i. Impact of Supported Decision-Making on Georgia pilot participants' lives

Deborah: When Deborah¹³⁷ was seventeen she sustained a traumatic brain injury following an accident that killed her father and injured her baby. After the accident she was in a coma and at this time her mother became her guardian.

GAO advocated to get Deborah the services and supports so she could regain her independence and achieve her goal of living independently. Deborah was referred to the Citizen Advocacy Office and was matched with a community member, Lisa, as her Citizen Advocate. Lisa describes Deborah as “resilient, persistent, and determined.”

Deborah consistently maintained that she did not want to have a guardian. Lisa and Deborah tried for years to convince the Public Guardian Office to support ending Deborah’s guardianship. When this was not successful, Lisa temporarily became Deborah’s guardian with the ultimate goal of assisting Deborah with petitioning the court to remove the guardianship.

Deborah learned about the pilot and decided to adopt Supported-Decision-Making as an alternative to guardianship. With Lisa’s support, Deborah is now preparing to petition the court

¹³⁵ Center for Public Representation and Nonotuck invested a substantial amount of time and energy in outreach and activities. See HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 38-40 (describing outreach and education activities and associated investments).

¹³⁶ Email from Dana Lloyd, to author Cathy Costanzo, (Feb. 2, 2021. 1:27 PM) (on file with author).

to restore her rights. She plans to present information about her Supported Decision-Making arrangement to the court as evidence that her guardianship is not necessary.

John: John,¹³⁸ one of the self-advocates on the pilot Advisory Council, is autistic and did not use words to speak until he was nineteen. His parents became his guardians when he turned eighteen because they believed that their son did not have an effective way to communicate and were not sure of his level of understanding.

A year later, John began using an Augmentative and Alternative Communication system that he describes as “life changing.” After five months of training with the technology, John was able to communicate effectively with his family and others around him. John then recognized that Supported Decision-Making could help him become more independent and communicated that he no longer wanted a guardian. GAO worked with John to educate his doctor about Supported Decision-Making. John’s doctor supported terminating John’s guardianship. John also wrote a letter to the court describing the vision he had for his life. At the hearing to terminate the guardianship, John received assistance from his mother (who was his guardian and one of his chosen supporters) to communicate and the court restored his rights.

Since the termination of his guardianship, John’s consulting career has expanded and he is a sought-after speaker and trainer. John provides leadership to Uniting for Change and was selected to participate in an ACL Project of National Significance about guardianship alternatives for transition-aged youth. John stated:

You know that without a Supported Decision-Making plan I would still be under guardianship. The idea of making my own decisions was something I had started doing after I learned to spell to communicate. Then I just wanted to experience my full human rights. Under guardianship it feels oppressive. Like I'm "less" or "other". It feels great

¹³⁸ All information in the following section regarding John obtained from Email from Julie Kegley, to author Cathy Costanzo, (Feb. 2, 2021. 1:14 PM) (on file with author).

to know I have a plan and supporters who know I'm the one driving the direction of that plan.... I am more confident because I've taken control.¹³⁹

D. Center for Public Representation Lessons and Recommendations

Lesson 1: The three pilots demonstrate that Supported Decision-Making is a “viable means to provide people with I/DD and other disabilities customized decision-making assistance that allows people to keep their decision-making rights, has a positive impact on their self-respect, and can reduce society’s use of guardianship.”¹⁴⁰ Using Supported Decision-Making changed the lives of the pilot participants and resulted in “increased self-esteem and self-advocacy, more engagement in decision-making, and increased happiness.”¹⁴¹ The pilots also demonstrated that Supported Decision-Making can work for a wide range of demographics, including for people with different diagnoses including dementia and TBI, people across the age spectrum, people of different races and ethnicities, and people who use Augmentative and Alternative Communication, as well as people without natural supports. In order to adhere to person-centered principles while serving such a broad array of individuals with a range of preferences, experiences, and needs, the pilots needed to be flexible and creative about how Supported Decision-Making was offered and the structure of the pilots themselves. Different models for the practice of Supported Decision-Making from very proscribed to very flexible approaches have been successful and proven effective.

Lesson 2: Without dedicated funding, ample cash reserves or an extraordinary commitment to Supported Decision-Making it is very difficult for organizations to introduce, implement and help to support Supported Decision-Making for a large number of individuals. Supported Decision-Making is, by nature, highly individualized making it a

¹³⁹ Email from John McCarty, to author Cathy Costanzo, (Feb. 7, 2021. 11:29 AM) (on file with author).

¹⁴⁰ HSRI PILOT EVALUATION YEAR 2, *supra* note 85, at 5.

¹⁴¹ *Id.* at 5, 31.

major challenge to offer Supported Decision-Making to every individual who would like it in a state or locale. A significant investment is required to provide assistance along the lines provided in the pilots. Using federal or state dollars for such assistance unavoidably introduces bureaucracy into the lives of people with disabilities. This risks turning Supported Decision-Making into a paid service, which we believe undermines the informality and natural support features of the practice. We recognize that the authors are not in agreement on this conclusion, which further underscores the need to carefully consider the implications of Supported Decision-Making as a paid service, so that the fidelity of the Supported Decision-Making model is not compromised in an attempt to make the practice more widely available.

Lesson 3: With education and guidance, individuals under guardianship can practice Supported Decision-Making. Determining whether Supported Decision-Making is a viable less restrictive alternative to guardianship requires practice with the model, both for the individual and the guardian if the individual selects the guardian as a supporter. Courts have been receptive to considering evidence of Supported Decision-Making practice when ending a guardianship, meaning that Supported Decision-Making can be an essential pathway out of guardianship. However, education for guardians, supporters, and Decision-Makers is essential to understand the ethical and practical issues that arise when using Supported Decision-Making in this context.

Lesson 4: Training was effective and essential for promoting wide-spread community acceptance of a new model of decision-making. Key audiences for training included courts, self-advocates, families, health care providers, state agency officials, and other stakeholders.

CPR Recommendation: In the United States, the national Protection & Advocacy networks,¹⁴² the Developmental Disability Councils,¹⁴³ Area Agencies on Aging,¹⁴⁴ and equivalent counterpart networks serving older adults are obvious entities that could receive federal funding and to administer Supported Decision-Making in each state and territory. This would be consistent with these entities' missions and would minimize the likelihood of Supported Decision-Making becoming a paid, billable service and the attenuated risks to fidelity. Funding should support initiatives that explore best practices when serving different populations at risk of guardianship using a variety of models. Particular areas of focus should be initiatives for people under guardianship, BIPOC communities, people who use AAC, transition aged youth, elders, people without natural supports, and people with TBI, mental health diagnoses, dementia, all areas where it is important to explore how the model will work. In addition to funding pilots, training should be a significant investment, including training of judges and guardians.

E. The Supported Decision-Making New York (SDMNY) Pilot

i. History of the Project

SDMNY¹⁴⁵ was formed in 2016 as a consortium of Hunter College/CUNY; the N.Y. Alliance for Inclusion and Innovation (formerly NYSACRA), a statewide association of provider agencies; and Arc Westchester, a large provider organization. It was the successful applicant for

¹⁴² Administration for Community Living, State Protection & Advocacy Systems, <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems> (last visited Feb. 14, 2021).

¹⁴³ Administration for Community Living, State Councils on Developmental Disabilities, <https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities> (last visited Feb. 14, 2021).

¹⁴⁴ National Association of Area Agencies on Aging, Area Agencies on Aging (Mar. 2017) <https://www.n4a.org/Files/LocalLeadersAAA2017.pdf>.

¹⁴⁵ For a more granular discussion, see Kristin Booth Glen, *Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot Project*, 13 ALBANY GOV'T. L. REV. 94 (2019-2020).

a 5-year, \$1.5 million grant from the NYS Developmental Disabilities Planning Council ((DDPC) to educate a variety of stakeholders about supported decision-making (SDM) as an alternative to guardianship, and to pilot two projects: utilizing SDM to divert persons with developmental disabilities (DD) from guardianship, and to restore rights to those already subject to guardianship.¹⁴⁶

The first year was spent developing a facilitation model designed to serve the diversity of persons with DD in New York State—recruiting and training a corps of volunteer facilitators, and beginning to recruit and facilitate persons with DD, denominated “Decision-Makers”, at the NYC site. Additional sites, in Westchester County Rochester/Western New York, the Capital Region, and Long Island were added in Years 2 and 3. coordinated by SDMNY staff in NYC who, over the course of the project, utilized learnings from practice to revise, fine-tune and improve the facilitation process and facilitator training, developing new tools and materials along the way.

SDMNY formed innovative relationships with stakeholder organizations and entities like the Cooke School in NYC; the Westchester Institute for Human Development (WIHD), one of 3 federally-funded University Centers for Excellence in Developmental Disability (UCEDDs) in New York; the NYS Office for Court Innovation; and AIM Services, a major provider of Medicaid HCBS waiver services through Self-Direction. Disability Rights New York (DRNY), the federally funded Protection and Advocacy Agency (P&A) for New York serves as SDMNY’s legal arm. It also drew on the knowledge and talents of the multiple stakeholders who make up its extensive Advisory Council.¹⁴⁷

¹⁴⁶ 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).

¹⁴⁷ See www.sdmny.org/the-sdmny-project/who-we-are/advisory-council/.

ii. Project Goals

Because the DDPC grant was focused on consideration and use of SDM as an alternative to guardianship, 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 SDMNY's 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 SDMNY's process, commitment to a rights-based approach required that the document would only be the *end*, but not the *means* for SDM. Here SDMNY immediately distinguished its objective from existing SDMA legislation which simply describes SDM, provides a form agreement or sets forth what must be contained in the agreement.

iii. Recruiting Decision-Makers

A significant decision was that prospective Decision-Makers had to choose SDMNY, not be chosen, by staff, parents, or others. Coupled with the focus on diversity, this dictated a recruitment strategy that ended up requiring literally hundreds of information sessions¹⁴⁸ and

¹⁴⁸ When, for example, these sessions were held in schools, there would be simultaneous meeting with parents in one room and students in another. In one case, there was a third, Spanish language session for parents.

one-on-one meetings with prospective Decision-Makers who found SDMNY on its website or were referred from a variety of sources.¹⁴⁹

The primary entry point for guardianship for people with I/DD in New York¹⁵⁰ occurs when they reach adulthood, and parents are encouraged to petition for guardianship.¹⁵¹ Because of this, we initially focused recruitment on transition age youth in public and private schools, but expanded efforts for older Decision-Makers through presentations at provider agencies, day programs, self-advocacy organization meetings, and faith-based organizations offering programming for people with DD. SDMNY ultimately enrolled over 140 racially and ethnically diverse Decision-Makers ranging in age from 17-78, with a variety of impairments¹⁵²

iv. The Three Phase SDMNY Facilitation Process

The SDMNY facilitation process proceeds in three phases and is centered on what is called “the Big Four”:

1. *which* areas the Decision-Maker wants support in;
2. *what* kinds of support they want;
3. *who* they want the support from, and;
4. *how* they want to receive that support.

¹⁴⁹ Over time, SDMNY has received referrals from, inter alia, the private bar, Mental Hygiene Legal Services, judges and clerks in court guardianship offices, parents of Decision-Makers, and Decision-makers themselves. Another source of recruitment was webinars done for various stakeholder organizations including Parent to Parent New York, INCLUDE New York, the Autism and Aspergers Association (AANE) etc.

¹⁵⁰ Unlike most states which have a single guardianship statute for persons who lack, or have lost “capacity” through a variety of disabilities, New York has a separate, diagnosis-driven statute for persons with I/DD, N.Y. SURR. CT. PROC. ACT LAW § 1701 (McKinney 2020). The statute has been subject to criticism for decades but efforts to reform or repeal it have, to date, been unsuccessful. *See, e.g.*, 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).; 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).

¹⁵¹ *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).

¹⁵² SDMNY never requested or noted diagnoses, but many Decision-makers self-identified as having autism, Asperger syndrome, Down syndrome, cerebral palsy, etc..

Phase 1: The Facilitator works with the Decision-Maker to learn about how they communicate, make decisions, the decisions that are likely to arise in both the short and long term, and the trusted persons in the Decision-Maker's life who they may want to choose as Supporters. The Facilitator guides the Decision-Maker through the steps of making a decision in order to identify the kinds of support (the "what") the Decision-Maker may want and need, and to build decision-making capability and intrinsic motivation.

Phase 2: The Facilitator works with Supporters the Decision-Maker has chosen, educating them about SDM, and helping them "re-position" from people who make decisions for the Decision-Maker, to those who are able to see the Decision-Maker as an adult capable of making their own decisions and to support them in doing so. In exploring the "dignity of risk" the Facilitator fosters "capacity building" for Supporters to maintain their commitment to the Decision-Maker's autonomy and growth after the facilitation process is completed.

Phase 3: The Facilitator works with the Decision-Maker and Supporters to negotiate the Supported Decision-Making agreement (the SDMA) which will reflect and memorialize their agreement on all aspects of the "Big Four." Phase 3 is also a time to ensure that all parties fully understand their roles, obligations and responsibilities.

Signing the SDMA: For most Decision-Makers and their family and Supporters, this is a time for real celebration: of the work everyone has put in, the Decision-Maker's growth, and an affirmation of the life-long process they have put into place

The SDMA is much more than a piece of paper. It is also an advocacy tool by which Decision Makers demonstrates to others how they make decisions, and why their decisions should be accepted on the same basis as those made by everyone else. Most importantly, the SDMA describes and memorializes the *process* of using support, from trusted persons chosen as

Supporters, that Decision-Makers developed in SDM facilitation, and that they will utilize for the rest of their lives.

v. The Form, Provisions and Flexibility of an SDMA

Like the facilitation process itself, the Decision-Maker is the “driver” of the SDMA. Although SDMNY provides a template, Decision-Makers are free to “customize” their agreements; every SDMA reflects the individuality of each Decision-Maker and their Supporters.

All SDMAs, however, provide that Decision-Makers are free to change or revoke them at any time, providing flexibility to make the SDMA a “living document” to be used as circumstances inevitably change. Supporters may move away, or die, or new trusted people may enter a Decision-Maker’s life. This ability to maintain active and committed groups of Supporters over time also reassures parents who worry about what might happen when they are no longer around.

vi. Facilitators and Mentors

Virtually all of the 200+ facilitators SDMNY has trained are volunteers. Some are students in University-connected and professional programs who may receive academic credit. Some are advocates for the rights of PWDD. Others work for provider agencies, or are Self Direction brokers, are retired professionals, or even parents of Decision-Makers who have found the process so valuable that they want to make it available to others.

All facilitators attend two full days of training by SDMNY staff, receive a comprehensive, 110+ page Facilitator’s Manual, extensive materials for use facilitation and participate in monthly Community of Practice calls. All facilitators have mentors, who are

experienced and successful facilitators who monitor and guide the work of the facilitators assigned to them through check-ins after every facilitation meeting. Mentors meet regularly meetings with their site coordinator, and quarterly with mentors from all five SDMNY sites.

To ensure consistency and quality, facilitators and mentors enter notes on all of their meetings on the SDMNY intranet. These notes are regularly reviewed by the site coordinators and again when an SDMA is finalized in order to verify the actual completion of the facilitation process.

vii. Resolving Disputes: Creating a Post-Facilitation Resource for SDMA Users

We can expect that, over time, there may be differences and/or disputes between or among parties to an SDMA and/or other important persons in a Decision-Maker's life. Anticipating such potential conflicts, SDMNY created a "Mediation Module"(MM) designed as a two-day training for mediators in the NYS office of Court Administration/Alternative Dispute Resolution- connected Community Dispute Resolution Centers (CDRCs)¹⁵³ that exist in every county in the state. The Mediation Module was designed by a nationally recognized ADR expert Professor Beryl Blaustone with assistance from students in the Mediation Clinic at CUNY School of Law.

Utilizing specially created materials on implicit bias around I/DD, the MM explores the unique problems, tactical, logistical and ethical, of mediation involving PWDD, educates mediators about SDM and SDMAs, and engages them in simulations designed around hard problems that might arise from use of SDMAs. It includes extensive written materials including lesson plans, learning goals, detailed instructions for role plays, etc., and specially created videos

¹⁵³ *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, are local not-for-profits that are court-affiliated, but not court controlled.

with PWDD in featured roles. CRDCs also provide “conflict counseling”. This a potentially valuable resource for Decision-Makers after facilitation has ended, so the MM includes a section directed to that separate skill/service for them.

Through its partnership with the CDRCs, SDMNY is working to create a vibrant, continuing resource for Decision-Makers and supporters as they utilize SDMAs. The MM can also be a valuable resource for SDM projects across the country, and SDMNY will make its materials available through open-source access.

F. Supported Decision-Making New York: Some lessons learned and implications for policy

Lesson 2: Parents are largely unaware of the actual consequences of guardianship for their adult children with I/DD, and lack information about, or knowledge of alternatives to guardianship.

We saw this repeatedly, confirmed by an independent evaluation¹⁵⁴ and reiterated by the National Council on Disability.¹⁵⁵ There are two major implications.

First, understanding how deeply the expectation of guardianship is embedded in the experiences of families with children with I/DD, and the number of sources that direct them toward guardianship, it is critical that information about alternatives, including especially SDM, be available through schools, transition counselors, health care professionals, and government agencies providing services. The court system should make prospective petitioners for guardianship aware of alternatives, through materials in clerk’s offices, information on court

¹⁵⁴ 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>.

¹⁵⁵ NCD BEYOND GUARDIANSHIP, *supra* note 4, at 90-92 (describing the “school to guardianship pipeline”).

websites or even, as is now being done in Richmond County, a required information session on alternatives before a petition can be filed.¹⁵⁶ The bar is also a critical resource and should be educated about the existence of alternatives like SDM, how they actually work, and why they might be a better alternative for clients who might otherwise seek guardianship.¹⁵⁷

Second, many parents who reflexively obtained guardianship when their children turned 18 now see that I/DD is not a static condition, but rather that PWDD can learn and grow. Almost certainly there are a large number of PWDD currently under guardianship for whom it may not have been appropriate or necessary, or for whom it is no longer necessary, especially if supports for decision-making exist or can be created through a process like SDMNY facilitation. Thanks to the pioneering work of the ABA Commission on Law and Aging, restoration of rights/termination of guardianship¹⁵⁸ has begun to receive significant attention. In New York, DRNY has successfully terminated 17-A guardianships by demonstrating a combination of existing support systems and growth in capabilities over time of PWDD.¹⁵⁹ This suggests the need to educate guardians and persons subject to guardianship about restoration, and provide access to facilitation and other less formal iterations of SDM for them.

¹⁵⁶ Personal communication with Iri Bekhet, Guardianship Supervisor and Court Attorney, Surrogate's Court, Richmond County.

¹⁵⁷ A tool developed by the American Bar Association Commissions on Law and Aging (COLA) and Disability Rights (CDR) provides a useful framework for practitioners and courts. See AMERICAN BAR ASSOCIATION, *PRACTICAL Tool*, (May 8, 2016) https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool/ (The "P" in PRACTICAL stands for "presume capacity," and the "C" for "consider alternatives").

¹⁵⁸ See, e.g., Restoration in Adult Guardianships (Statutes), available at https://americanbar.org/content/dam/aba/adminstrative/law_aging/2013_CassidyRestotationofRightsChart7-13.pdf, Jenica Cassidy, Restoration of Rights in the Termination of Adult Guardianship, 23 ELDER L. J. 83 (2015)

¹⁵⁹ See, e.g., *Matter of Capurso*, 63 Misc. 3d 725 (Surr. Ct. Westchester Co. 2019); *In re Robert C.B.*, 2020 NYLJ LEXIS 934 (Surr. Ct. Dutchess Co. 2020); *Matter of Michael J.N.* 58 Misc. 3d 1204(A), 94 N.Y.S. 539 (Surr. Ct. Erie Co. 2017).

SDMNY Decision-Makers currently under guardianship¹⁶⁰ will soon be going to court for restoration,¹⁶¹ and we anticipate that evidence of their SDMA's, the process by which they were reached, and the decision-making support they provide will demonstrate that a “less restrictive alternative”¹⁶² is in place. We have seen previously skeptical guardians persuaded, through the facilitation process, that guardianship is no longer necessary, and a new and different relationship, based on respect and the recognition of rights, is possible and desirable.

Recommendations (1):

Make information available to parents and other potential petitioners about alternatives, especially SDM, available at all the points where guardianship may be discussed or recommended.

Educate guardians, the bar and the court system about restoration of rights and how a viable system of decision-making supports, whether informal or the result of a facilitated SDMA can provide grounds for restoring rights.

Lesson 2: PWDD aren't taught to make decisions and don't think of themselves as decision-makers.

We were surprised at how little Decision-Makers thought about the decisions that they were or might be making in their lives when they first enrolled in SDMNY. Not only did they

¹⁶⁰ Initially SDMNY only enrolled persons subject to guardianship with the consent and support of their guardians; these were often precisely the parents who had obtained guardianship with little thought or understanding, and who were now appreciative of the availability of an alternative that aligned with their own hopes for their children, and belief that they could make their own decisions with support. Subsequently this policy was somewhat relaxed, especially for older persons whose guardians, though still legally empowered, were less directly involved in their lives.

¹⁶¹ The Covid-19 “pause” in New York has caused major delays in such proceedings, but several are currently in process. On the brighter side, the delay has also caused a number of families already in the process to “try” SDM during the interim and to consider, or actually withdraw, pending petitions.

¹⁶² See discussion *supra* at notes 30 to 33.

not think of themselves as decision-makers, that is, agents of their own lives, but they also had no real conception of how decisions are made, or how someone could ask for and utilize support in doing so.

Through research¹⁶³ and trial-and-error, SDMNY has developed a framework and materials to enable Decision-Makers to “take apart” how decisions are made, and the places where, and how, support might be utilized in a large variety of decisions. Facilitators are trained to help Decision-Makers “map” decisions they are already making, from simple¹⁶⁴ to more complicated or impactful, with the basic structure/ process of making any decision essentially the same: gathering information; understanding that information; exploring possible alternatives; considering the consequences of making a particular decision—or not making it; weighing alternatives; communicating the decision to third parties;¹⁶⁵ and implementing the decision.

Through repetition, and use of tools we have designed, Decision-makers learn how they make decisions, which steps they can do on their own, and where they might need support. They also develop a more nuanced appreciation of how these may vary from one decision-making

¹⁶³ Ironically, there is now a niche industry in teaching decision-making to neuro-typical adolescents and adults. 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.”).

¹⁶⁴ See discussion of how this issue can be used to “map” an apparently simple decision at Glen, *From Theory*, *supra* note 145, at 122-23

¹⁶⁵ Here support may be especially helpful for persons with I/DD who do not communicate verbally or in other reasonably recognizable/understandable ways.

domain to another. The “mapping” process is also useful for supporters,¹⁶⁶ “normalizing”¹⁶⁷ the idea of support, and assisting in re-orienting their relationship to the Decision-Maker.

But giving Decision-Makers the tools to learn/understand how decisions are made is not enough: they must *want* to use those tools, to make their own decisions, and ultimately to take responsibility for them. This is something we have learned, especially through the concept of “intrinsic motivation” and research around Cognitive Evaluation Theory¹⁶⁸ which we have incorporated in facilitator training and reiterate through the mentoring process.

These theoretical underpinnings are critically important in practice, developing a PWDD’s identity as a decision-maker, part of the “transformation” that good facilitation creates. They are also useful for parents and guardians in teaching decision-making over time, whether to avoid guardianship, or to help prepare a person for restoration of their rights.

Recommendation (2)

Persons with I/DD can and should be taught how decisions are made, and facilitated in determining what kinds of support they might need/desire in specific areas.

Any process utilized to teach and encourage the use of supports in decision-making must also enable PWDD to see themselves as decision-makers, promoting intrinsic motivation with what that entails.

¹⁶⁶ Facilitators are encouraged to use mapping in Phase 2 (with supporters) and Phase 3 (modeling and practicing mapping by the Decision-Maker with their supporters).

¹⁶⁷ See Wolf Wolfensberger, *NORMALIZATION: THE PRINCIPLES OF NORMALIZATION IN HUMAN SERVICES* (1992) (defining normalization as “[u]tilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics that are as culturally normative as possible).

¹⁶⁸ 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). It 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, see Glen, *From Theory, supra* note 145, at 121

Lesson 3: Supporters may mean well, but transitioning from their prior relationship with a Decision-Maker is difficult, and they need capacity building to do so over a long period of time, especially when a Decision-Maker makes a “bad” decision.

We initially underestimated what would be necessary to effectively “re-position” chosen supporters from their prior (understandably) protective/paternalistic roles. We have been influenced by the thoughtful research of a number of Australian scholars¹⁶⁹ who describe multiple barriers and constraints, often unconscious, that can limit supporters’ ability to respect and support, rather than second guess, or attempt to overrule, a Decision-Maker’s own decision.¹⁷⁰

Capacity-building for supporters is more than a conversation. We are committed to creating and sharing a “Supporters’ Guide” that explains and illustrates the “dignity of risk” and provides supporters with tools for maintaining their commitment to the principles of SDM and will draw on the Australian model¹⁷¹ for additional resources.

Recommendation (3)

Supporters need capacity-building tools and resources to sustain them in their role.

¹⁶⁹ They studied 13 pilots ranging 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>

¹⁷⁰ 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).

¹⁷¹ See The LaTrobe Support for Decision-Making Framework, available at <http://www.supportfordecisionmakingresource.com.au/>.

Lesson 4: Meaningful SDMAs, with real integrity, take time and hard work, and should represent a well thought out and agreed upon practice for decision-making that Decision-Makers can use with supporters throughout their lives.

Innumerable PWDD use SDM informally with enough success to avoid guardianship and lead reasonably inclusive lives.¹⁷² Many say they have no need for formal facilitation or a written SDMA¹⁷³. We have also heard from Decision-Makers, supporters, and family members that the facilitation process has been transformational, that the relationship between Decision-Makers and their supporters, especially family members, has changed from protection and dependence, to one of mutual respect. We have heard the relief of parents whose adult children now have SDMAs, and a process for making decisions with support into the future about what will happen when they are no longer around.

Without time-consuming and often expensive evaluation,¹⁷⁴ it is difficult to quantify what we “know” or to present it in an academically rigorous fashion. What we are able to do is to record and amplify the voices of those with whom we have been privileged to work through videos available on our website.¹⁷⁵

What we know, after 5 years, is this: quality facilitation is necessary to develop an authentic SDM process that leads to an SDMA with real integrity; quality facilitation requires

¹⁷² 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 Glen, *Introducing A “New” Human Right*, *supra* note 13, at 8 n.28.

¹⁷³ It is important to understand that SDMAs, while they serve many purposes, are, or should be, primarily the memorialization of the process agreed on between the Decision-maker and their supporters. As long as no one questions decisions made by people using informal SDM, there is no pressing need for an SDMA. The actual written document is, however, necessary, to ensure that decisions made pursuant to SDM are legally recognized by third parties on a basis equal with all others—something that takes legislative recognition.

¹⁷⁴ The two HSRI evaluations of the CPR-Nonotuck pilot project, supported by the Open Society Foundations, are an excellent model.

¹⁷⁵ See www.sdmny.org/resources/SDMNYvideos.

hard work by Decision Makers, supporters and facilitators, expert supervision and guidance by experienced mentors, and time .¹⁷⁶

We do not claim that our model is the only way to ensure the integrity of the SDM process, or to legitimize legislative recognition of decisions made pursuant to SDMA. We did, however, consciously build on the available research and lessons from functioning pilots,¹⁷⁷ taking into account questions raised as to the validity and practicality of SDM.¹⁷⁸ After 5 years of experimentation, recalibration, repetition and constant reflection, what we have learned is based on a sufficient number of participants, over a sufficient period of time to warrant serious notice, and, we hope, respect.

Recommendation (4)

Good facilitation is necessary for authentic SDM and should be planned and executed with sufficient time and effort.

Lesson 5: “Doing” SDM is not enough. SDMA legislation is necessary to effectively empower many PWDD and to overcome discrimination based on stigma, prejudice and ignorance about I/DD

Much has been said about the importance of SDM, and, increasingly, PWDD and their families are encouraged to use or practice ‘it’, with SDM often presented simply as” making

¹⁷⁶ The average facilitation takes between 9 and 14 hour-long meetings. Meeting remotely has allowed for more frequent meetings and shortened the overall time. But as we learn more about what makes an effective supporter over time,¹⁷⁶we are also considering devoting more time to capacity building during Phase 2..

¹⁷⁷ The SDMNY Director had the benefit of visiting and working with pilots in Bulgaria, Kenya and the Czech Republic, served on the Advisory Board of the CPR-Nonotuck project, and through the efforts of OSF, was able to meet (and remain in contact) with principals in pilots in Israel, Australia, Columbia, and Latvia. The principal designer of training for SDM pilots in Australia spent 4 days with SDMNY staff and Advisory Council members at the beginning of the SDMNY project, and SDMNY visited and learned from the CPR-Nonotuck pilot.

¹⁷⁸ See, for example Kohn, *supra* 122, Terry Carney, *Clarifying, Operationalising, and Evaluating Supported Decision Making Models*, 1 RES.& PRAC. INTELL & DEVELOPMENTAL DISABILITIES 46 (2014)

one's own choices.” Our experience suggests that more than good intentions or enthusiasm are required to ensure the authenticity of SDM that critics like Professor Kohn¹⁷⁹ have interrogated, We also see how the separate but related issue of SDMA often becomes confused with exhortations that “Everyone has a right to decide for themselves!”

The human rights lens clarifies why a more formal process, including an SDMA, may be necessary for some, though not all, PWDD. The right of legal capacity crucially includes both the right to make one's own decisions, but also *to have those decisions legally recognized by others*.¹⁸⁰ Encouraging, teaching, or even facilitating PWDD to use SDM does not, without more, accomplish legal agency. Empowering someone to use SDM in order to *choose* a certain medical procedure is not enough when the doctor refuses to treat her because they believe she lacks capacity to give informed consent. This is why *SDMA legislation*, as distinguished from legislation that inscribes SDM as a less restrictive alternative to guardianship¹⁸¹, is necessary.

Because of stigma, prejudice, ignorance, or fear of liability, third parties may refuse to accept decisions by, or enter into transactions with, PWDD. They may demand or require that a guardian be appointed to be certain they are dealing with someone with unquestioned legal authority.¹⁸² This is the problem SDMA legislation is designed to solve, doing so by *requiring* third party acceptance of decisions made pursuant to a “recognized”¹⁸³ SDMA and, in turn, providing immunity to the third party for good faith reliance on the decision.¹⁸⁴

¹⁷⁹ *Id.* at X. Nina A. Kohn, *Legislating Supported Decision-Making*, Harvard Journal on Legislation (forthcoming 2121).

¹⁸⁰ Legal capacity involves legal recognition of a person's right and power “to engage in transactions and...create, modify or end legal relationships” Convention on the Rights of Persons with Disabilities, General Comment No. 1 (2014) Para. 9, U.N. Doc. CRPD/C/GC/1 (May 19, 2014).

¹⁸¹ This use of SDM is exemplified by the recently revised UGCOPAA, *supra* note 10.

¹⁸² We have heard this story, or some version of it, repeatedly from parents and others, *see* Glen, *From Theory*, *supra* note 145, at 156-157.

¹⁸³ That is, an SDMA that conforms to the requirement of the particular SDMA statute.

¹⁸⁴ See discussion *supra* at

SDMA statutes are not necessary to enable PWDD to practice SDM, nor are SDMA. But without such legislation (and, thus, SDMA) many PWDD will be discriminated against in transactions ranging from informed consent, to making a binding contract, to getting married.¹⁸⁵ In this respect, it may be more appropriate to understand SDMA statutes as civil rights or anti-discrimination laws for PWDD¹⁸⁶ than as laws about SDM.

Our experience shows that SDMA legislation can also serve a practical purpose, incentivizing parents and PWDD to engage in a more formalized SDM process, even if it does not end in an SDMA. It confirms our belief that SDMA legislation is critical to actualize the right of PWDD to make their own decisions. But because of what we know about how much time and effort goes into making an SDMA that authentically represents adherence to a process by which a Decision-Maker uses support to make their own decisions, we are skeptical of SDMA legislation that appears to require nothing more than signatures on a form with some prescribed formality.¹⁸⁷ Based on our experience, such a “piece of paper,” with nothing behind it, also raises the possibility of exploitation or abuse, echoing criticism in a recent article by Professor Nina Kohn.¹⁸⁸

¹⁸⁵ For an extensive discussion of the many ways, other than guardianship in which PWDD may be discriminated against based on alleged lack of “capacity”, see Kristin Booth Glen, *Not Just Guardianship: Uncovering the Invisible Taxonomy of Laws, Regulations and Decisions that Limit or Deny the Right of Legal Capacity for People with Intellectual and Developmental Disabilities*, 13 Albany Gov’t. L. Rev. 25 (2019-2020) For a discussion of the importance of equal, non-discriminatory treatment of PWDD in consumer transactions, see Yvette Maker et. al., *Ensuring Equality for Persons with Cognitive Disabilities in Consumer Contracting: An International Human Rights Law Perspective*, 19 Melbourne J. of Int’l Law 178 (2018)

¹⁸⁶ Legislative recognition of decisions made pursuant to recognized SDMA removes the ability of public and private third parties to utilize their own views of a person’s capacity to deny them access to services or goods, in the same way that traditional civil rights legislation denies them the ability to withhold access based on race or gender.

¹⁸⁷ The integrity of SDMA legislation, to the extent that it genuinely promotes the goals of SDM, including self-determination, autonomy and dignity, depends in part on the motivation behind it. See Eliana J. Theodorou, Note, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973,979-980, 989–94 (2018) (describing how the Texas SDMA statute appealed to a conservative agenda by reducing the costs associated with monitoring guardianships).

¹⁸⁸ Kohn, *Legislating Supported Decision-Making*, *supra* n.

Part of the charge of DDPC’s grant to SDMNY was to develop an evidentiary base for possible SDMA legislation. Based on our experience, in a lengthy and iterative process, we created “*Principles for An SDMA Law.*”¹⁸⁹ that were “workshopped” at 6 focus groups convened by Parent-to-Parent New York, and 6 groups of self-advocates and PWDD convened by the Self-Advocacy Association of New York State (SANYS). Other experts and stakeholders, including Professor Kohn and the NYC Bar Association Committee on Mental Health¹⁹⁰ were consulted, resulting in still further refinement.

We hope that, unlike states that have passed SDMA laws without pilots or other empirical evidence, New York legislators will benefit from our “on-the-ground” experience and learnings, including that legislative recognition of decisions by people with developmental disabilities made pursuant to SDMAs should be tied to a process of facilitation that provides confidence in their integrity.

Recommendations (5)

SDMA legislation is necessary to promote the values, and encourage the use, of SDM, to ensure legal agency, and to prevent discrimination against PWDD

SDMA legislation should ensure the integrity of SDMAs when affording legislative recognition to decisions made pursuant to those SDMAs

Lesson 6: Sustainability depends on creating cost-effective models and embedding SDM into existing systems

¹⁸⁹ Because SDMNY is governmentally funded, we are prohibited from lobbying, and so cannot either draft legislation or support or oppose any specific bill. For the “Principles” with Commentary, *see* <https://sdmny.org/supported-decision-making-legislation/principles-for-supported-decision-making-agreements-in-new-york/principles>

¹⁹⁰ That committee is currently drafting a report on a report on Prospective SDMA legislation in NY.

It is all well and good to show that a meaningful facilitation process, requiring both time and hard work, is necessary for authentic, SDM, but what if the cost of that process is prohibitive, as it has been in existing pilots?¹⁹¹ Sustainability” was one of the intended goals of the SDMNY project, and we struggled mightily to find an answer to this critical question. Even though much of our budget went to developing the model, start-up and experimentation,¹⁹² the cost per Decision-Maker¹⁹³, much less completed SDMA¹⁹⁴ was more than we believed the state would fund if the goal were simply to expand SDMNY to serve anyone in the state who wanted facilitation services.¹⁹⁵ We conducted numerous experiments aimed at reducing the cost of facilitation but learned that, despite our best efforts, relying entirely on volunteer facilitators and mentors was not sustainable.

In discussions with OPWDD, and incorporating these learnings, however, we have developed a model for providing facilitation to everyone who wants it, that, although hardly “free,” will, we believe be highly cost effective.¹⁹⁶

¹⁹¹ See Terry Carney & Fleur Beupert, *Public & Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making*, 36 U. NEW SOUTH WALES L.J. 175, 178 (2013).

¹⁹² The beauty of a pilot project is that it encourages trying a variety of options, understanding that many will fail, but learning from, and building on those failures. We are grateful for DDPC ‘s farsightedness in designing the grant to cover 5 full years.

¹⁹³ We enrolled approximately 140 Decision-Makers over the 4 years we were actively facilitating, but as of this writing, 40 had officially dropped out and a significant number were in “pause”, some because of problems associated with the Covid-19 pandemic, but others because of changes in their lives.

¹⁹⁴ We expect a total of 31 signed SDMAs by the project’s end on March 31, 2021, although this is a somewhat misleading number; many Decision-Makers are still in the pipe-line, and many of them would have concluded the process and signed their SDMAs by the closing date but for the pandemic. Another 27 are expected to sign by June, and, with funding for a “bridge year” now in place, we expect 100 signed SDMAs by February 2022.

¹⁹⁵ Since SDMNY’s “Principles”, n. *supra*, tie legal recognition of decisions made pursuant to an SDMA to SDMAs made with an approved facilitation process, equity requires that such a process must be available to everyone who wants it, regardless of ability to pay.

¹⁹⁶ With a generous grant from the New York Community Trust, we have commissioned an independent cost/benefit analysis from a highly regarded financial consulting firm; preliminary findings suggest that making facilitation and SDMAs available, with SDMA legislation, will save the state millions of dollars more than providing the service. When completed, the study will be available on SDMNY’s website.

A majority of PWDD who might want this service already receive Medicaid-funded services through OPWDD. Authorization currently exists allowing people receiving services through Self Direction to use funds from their budgets for SDMA facilitation, and we hope to expand that to everyone (or even to include SDMA facilitation as a “free” piece of Self Direction¹⁹⁷). If SDMA legislation is passed, and more people know about it, experience suggests that many families will want to do facilitation and use Medicaid dollars to pay for it.

But we do not see SDMA facilitation as only for poor people or those receiving services through OPWDD. Private counsel presently provide many advance planning services to families of PWDD, including Supplemental Needs Trusts (SNTs), Health Care Proxies and, of course, guardianship. It is important that they should be able to offer SDMAs as one of the “tools in the toolkit.” They, or a paralegal in their office, could be trained as a facilitator, charging a fee for facilitation and making an SDMA, just as they would otherwise have done for a guardianship.

There are additional possible entry points for facilitators. Many colleges and universities offer a “college experience” to people with developmental disabilities aged 18-22. They may want to include SDMA facilitation as part of this non-matriculated “inclusive education” regulated by the federal Department of Education¹⁹⁸ that requires curricular attention to self-determination and independent living. An inclusive education program could offer SDMA

¹⁹⁷ ¹⁹⁷ If it turns out that PWDDs with SDMAs in Self Direction spend substantially less, and/or make better choices with better long-term results for their self-determination and inclusion, OPWDD might be able to justify including facilitation as a benefit of signing up for Self Direction, whether they can bill all or part of the cost to Medicaid.

¹⁹⁸ For a discussion of post-secondary educational opportunities for PWDD, see Erin Vinoski Thomas ID, Bridgette M. Schram and Daniel Crimmins, *College as Community for Students with Intellectual Disabilities*, 40 *Jrnl Legal Medicine* 53 (2020).

unpaid facilitation by MSW students from the university's social work school¹⁹⁹— students would get academic field work credit²⁰⁰, and are the perfect “renewable resource”.

Finally, (but not exhaustively, a community-based organization like the YM or YWCA, or a faith-based organization that provides social services might also want to provide facilitation, possibly using volunteers from their community²⁰¹. And, of course, it would be wonderful to have guardians trained as facilitators, adding to their own “toolkit.”

With a number of sectors from which facilitators might come, and different models of how they would be paid or otherwise compensated, what is needed to make it all work is a central SDMA Facilitation Training and Resource Center (FTRC). This entity would be responsible for all facilitator training and materials²⁰², and providing mentors for every facilitator, regardless of the source from which they come. A state-funded and directed FTRC would ensure uniformity, accountability and a reasonably high degree of quality control.

We estimate the cost of such an entity at approximately \$3.5million/year to facilitate 500 Decision-Makers to their SDMAs. While \$7000 per Decision Maker is hardly a negligible amount²⁰³, unlike other services provided over long periods of time²⁰⁴ it is a one-time expense that should be amortized, and can be expected to save the state far more over a period of years.

¹⁹⁹ We have developed a model for this that meets credentialing requirements for MSWs and BSWs with Hunter's Silberman School of Social Work. Similar programs could use students in Occupational Therapy (OT) or Occupational Therapy Assistant (OTA) programs; we have also developed a model for the latter with the OTA program at LaGuardia Community College.

²⁰⁰ Like monetary payment through Self Direction or the private bar, giving academic credit ensures accountability and completion, both of which were problematic with volunteers.

²⁰¹ We have had success working with the Jewish Community Center (JCC) in Manhattan, several of whose staff we have trained, and are now engaged in a collaboration with Jewish Family Services of Lehigh Valley, Pennsylvania.

²⁰² Much of what would be needed-- training materials and videos, a facilitator's manual, materials for use with Decision-Makers, a mentor's guide, etc., have already been developed and tested by SDMNY.

²⁰³ In 2019, Medicaid payments for services and supports administered by OPWDD totaled more than \$8 billion, *see* <https://opwdd.ny.gov/people-receiving-opwddd-medicaid-services#age-group>

²⁰⁴ In 2019 OPWDD provided HCBS waiver service totaling approximately \$6.4billion to approximately 86,000 individuals, or approximately \$74,400 per person, *see* <https://opwdd.ny.gov/services-funded-fee-service-medicaid-2019#home-waiver-services>

And, of course, if one were to build in the benefits gained in enabling people with developmental disabilities to live more inclusive, self-determined, autonomous lives, it would be a small price, indeed.

There is one final and important lesson, critical to the sustainability of an authentic model of SDM. It grows in part from our understanding how, in effectuating the kind of paradigm shift that the conversation around SDM envisions, it may be necessary not only to design and build new models, but also to find ways to embed them in existing systems.

The most obvious choice, apparent almost from the beginning, is the special education system. Children and young adults with developmental disabilities receive services through the Department of Education until they are 21 under the Intellectual Disabilities Education Improvement Act (IDEIA)²⁰⁵ that requires schools to provide students receiving special education with “education and related services designed to meet their unique needs and *prepare them for further education, employment, and independent living.*”²⁰⁶ An important requirement of education under the IDEIA is “transition planning” which generally occurs as students approach 18, to “facilitate the child’s movement...to independent living and community participation.”²⁰⁷

Unfortunately, in actual practice, transition planning falls far short of this goal and is often counterproductive, especially in its reflexive emphasis on guardianship as students approach 18.²⁰⁸ Instead, schools could incorporate SDM into their curricula, teaching students how to make decisions, when they need support, and how best to obtain it. This could be

²⁰⁵ 20 U.S.C. § 1400(d) (1)(A).

²⁰⁶ *Id.*

²⁰⁷ *Id.* at

²⁰⁸ Arlene S. Kanter, *Guardianship for Young Adults with Disabilities as a Violation of the Purpose of the Individuals with Disabilities Education Improvement Act*, 8 J. INT’L. AGING L. & POLICY 1 (2015).

incorporated into of the transition planning process²⁰⁹ or more gradually and organically, over many years,²¹⁰ so that by the time students reach their majority, they will have a SDM process in place.

Because schools are already required to move their students to independence and self-determination, and are compensated for doing so, they need only change *how* they approach that obligation.²¹¹ Embedding SDM within special education can not only improve outcomes for students, and eliminate the imposition of guardianship for at least a large percentage of them,²¹² it is basically fiscally neutral/cost free. There would, of course, be start-up costs, including curricular development²¹³ and teacher training,²¹⁴ but they would be negligible, especially spread over time.

If SDM were embedded in special education, the need for guardianship—and the concomitant deprivation of rights for people with developmental disabilities—would, over the next decade or so, virtually disappear. There would be little need for, and little cost associated

²⁰⁹ SDMNY is planning a mini-pilot on transition planning curriculum development with the Cooke Academy and Institute, having received foundation funding for a final “bridge” year necessitated by the pandemic.

²¹⁰ Teaching decision-making to neurotypical students from an early age is incorporated in the educational system of a number of Scandinavian countries. For an example, see Gisli Thorsteinsson & Brynjar Loafsson, A Survey on Students Design Decisions in Design and Craft Education in Icelandic Schools, available at http://scholar.google.com/scholar_url?url=https://journals.oslomet.no/index.php/techneA/article/download/37/158&hl=en&sa=X&ei=prNgYNKpJJGPmwHblq-oCA&scisig=AAGBfm0r7bGs4oOcTa0AvuYv3eEF0Hm8Ag&nossl=1&oi=scholar

²¹¹ SDM is already being incorporated into the District of Columbia school system. See District of Columbia Public Schools, Office of Specialized Instruction. (n.d.) Available at http://supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_faqs_0.pdf

²¹² Studies increasingly show that parents would prefer alternatives to guardianship, including especially SDM, if they were available. If their children had a supported decision-making process in place by the time they turned 18, it is likely that most families would not feel compelled to seek guardianship and, to the extent that schools had facilitated that process, equally likely that they would no longer recommend guardianship as the default position for all their students.

²¹³ Presumably DOE could commission this and then make it available nationwide.

²¹⁴ For teachers already in the system this could be incorporated into professional development; schools of education could include it in the curriculum for students intending to teach special education. SDMNY has begun a mini-pilot with the Hunter School of Education to explore including an appropriately modified model of SDM facilitation into the graduate special education curriculum.

with providing SDM facilitation because an increasing percentage of PWDD would already have had it.

Recommendations (6)

Consider the cost saving from SDM facilitation and fund a statewide Facilitation Training and Resource Center.

“Embed” SDM and SDM facilitation into Self-Direction of Medicaid HCBS waiver services

Develop a plan for incorporating SDM in the curriculum and transition planning process for special education, and create a model for doing so.

Develop a model for schools of education to incorporate SDM in teacher training for students intending to teach special education, and incentivize them to do so.

III. Conclusion & Recommendations Regarding Guardianship and Supported Decision-Making

While there is growing consensus *that* SDM is important—as an alternative to guardianship, as a means to the human right of legal capacity, as a recognition of how we all make decisions—there is a diversity of views as to what it looks like, or should look like in practice. Pilot projects allow us to test the various ways in which people with disabilities are using Supported Decision-Making and how they and their supporters might be facilitated or educated to do so.

Drawing on the experiences of our pilot Supported Decision-Making projects and in light of our observations of Supported Decision-Making and guardianships discussed *supra* at I.C, we have the following recommendations on the potential use of Supported Decision-Making for

avoiding unnecessary guardianships, and to aid guardians in discharging the obligation to increase capacity and terminate guardianship wherever possible. We recommend:

1. Prospective petitioners for guardianship should be supplied with information about alternatives, including Supported Decision-Making.
2. Guardians should be educated about Supported Decision-Making and the resources available in the jurisdictions where they work.
3. Guardians should strongly consider using Supported Decision-Making to practice decision-making that can lead to the restoration of rights to those under their care.
4. The National Guardianship Association and the U.S. Department of Education should jointly undertake to train local guardianship associations, school districts and educators about SDM as a viable alternative to guardianship.
5. Supported Decision-Making pilots should strive to collect the demographic and outcome data and stories that inform establishing best practices, statutes, and guiding principles with maximum fidelity.

In addition, while there is no single model, nor should there be, questions about the integrity of any Supported Decision-Making practice, and the decisions made utilizing it, need to be addressed, and analyzed. Pilot projects allow the necessary context to find these answers. There are also, understandably, questions about the cost of implementing Supported Decision-Making, and pilot projects can test more or less cost-intensive alternatives and innovate delivery systems. Pilot projects also can provide an evidentiary base from which cost-benefit analyses can be made, comparing the monetary costs of facilitation to the financial savings that a jurisdiction or locale can expect in areas of health care, services utilized, employability, and related areas. In addition, pilot projects can, and do, demonstrate the "priceless" human benefits of affording

people with disabilities the self-determination and autonomy that comes from making their own decisions.

The very first pilot project, in Bulgaria, was conceived as necessary to overcome deep-seated prejudice and stigma against people with disabilities by demonstrating that, with support, they are able to make their own decisions and lead lives of inclusion and dignity. Given the unfortunate but continuing discrimination against people with disabilities in the United States, pilot projects are no less necessary to accomplish the social and cultural “paradigm shift” that Supported Decision-Making promises. The “lessons learned” from pilots to date are an important contribution to that ongoing work. However, embedding Supported Decision-Making into carefully constructed statutes that reflect evidenced based standards and best practices will also advance its acceptance. Finally, the federal government’s support for Supported Decision-Making, in the provision of dedicated resources, is critical to the widespread adoption of Supported Decision-Making by people with a range of intellectual, cognitive and psychosocial disabilities, and including older persons.