

Supported Decision-Making New York: Evaluation Report of an Intentional Pilot

“This is not just signing a piece of paper. It's about a real transformation, that we have now seen over and over, in which people with IDD become real agents of their own lives.” SDMNY staff

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Executive Summary

In 2015, the New York State Developmental Disabilities Planning Council (DDPC) issued a Request for Proposals for a five-year Supported Decision-Making Pilot Grant. The purpose of the project was to develop and distribute educational materials and to pilot supported decision-making with people with intellectual and developmental disabilities (IDD) in locations throughout New York State. DDPC expected the grantee to work closely with the state's Protection and Advocacy agency, Disability Rights New York (DRNY), to perform the work. Narratives and data from this supported decision-making initiative would inform reforms to state law to advance the use of supported decision-making as an alternative to guardianship.

"Supported Decision-Making New York" (SDMNY), a consortium of collaborating institutions, was awarded the grant. Hunter College/CUNY serves as the lead agency for the consortium, which also includes the New York Alliance for Inclusion and Innovation (formerly the New York State Association of Community and Residential Providers, or NYSACRA), and The Arc Westchester.

SDMNY partners developed educational information about supported decision-making (SDM) and have presented to a wide variety of stakeholders. By the end of the third year of the grant, the partners had conducted over 90 awareness and outreach sessions utilizing an array of platforms, from in-person presentations to podcasts to webinars. SDMNY partners also designed a facilitation model offering SDM to two groups of people with IDD: the **Diversion** pilot offers SDM to divert those at risk of guardianship away from guardianship whereas the **Restoration** pilot offers SDM to those with guardianship orders with the aim to restore their decision-making rights by terminating the guardianships. The DDPC grant requires SDMNY recruit a minimum of 90 persons in the Diversion pilot and a minimum of 45 persons in the Restoration pilot.

Diversion and Restoration SDM pilot sites have been established in five geographic locations around the state, first in New York City, then in Westchester County, followed by the greater Rochester area, Long Island, and the Capitol region. By the end of the third year of the grant, 79 people with IDD had enrolled in an SDMNY pilot; 8 had completed the facilitated SDMNY process and held executed SDM Agreements with supporters.

During the third year of the grant, Hunter/CUNY subcontracted with an independent consultant to conduct the one-year focused process evaluation reported here, related to SDMNY Restoration and Diversion pilot activity. This evaluation was not a comprehensive evaluation of SDMNY activities to date. Instead, it was an inquiry into selected pilot activity with regard to four research areas:

- What concerns or advice led family members of people with IDD to consider or to become a guardian?
- What influenced family member and guardian adoption of SDMNY?
- Has the SDMNY process in this pilot addressed or reduced concerns that led family members to become or to consider becoming a guardian?
- Has participating in the SDMNY pilot affected or changed the individual with IDD?

This evaluation also provided key Hunter/CUNY staff an opportunity to reflect on their experiences to date and identify challenges and recommendations useful to sustain and broaden SDMNY adoption after grant funding concludes.

In addition to interviews and surveys conducted for the purpose of this evaluation, the evaluator also reviewed background papers, SDM pilot evaluation reports in the U.S. and around the world, and other publicly available materials.

Evaluation Findings

A selection of evaluation findings follows.

Model

- The SDMNY model utilizes trained volunteer facilitators who develop a relationship with the person with IDD and assist with creating a Supported Decision-Making Agreement. Recruitment of volunteer facilitators has been challenging. Initial attempts to utilize social work students posed problematic as the timing of SDM facilitation meetings did not sufficiently align with clinical practice requirements. Facilitator recruitment through provider agency personnel was attempted but deterred due to the absence of an available funding stream for facilitation activities. SDMNY staff continue to explore renewable sources of volunteer facilitator pools with academic professional programs—including occupational therapy assistants and graduate students in special education—as well as court-affiliated mediators.
- Developing a Supported Decision-Making Agreement using the SDMNY facilitation process takes at least twice as long as originally planned. The three-stage facilitation process was designed to occur over 6 to 9 months. Completed and signed agreements have taken a year to 18 months.

- Mentors provide oversight of, and assistance to, facilitators, and quality review of Supported Decision-Making Agreements. SDMNY began with staff serving as mentors. With geographic expansion and the growing number of facilitators, the need for paid mentors has become apparent. Additional development is needed to secure and expand a paid professional mentor pool.
- SDMNY staff reflected that people with IDD could have been more consistently involved as full partners—from the establishment of the pilot, to research, training, recruitment, and planning expansion and system change strategies.
- SDMNY has established important initial safeguards. For long-term SDM sustainability, additional safeguards are needed related to the use of Supported Decision-Making Agreements—including reporting and examination of complaints and concerns (e.g., undue influence by a facilitator, mentor, or supporter, or a third party not honoring a decision), and for reporting and investigating possible abuse, neglect, or financial exploitation.

Outreach and Recruitment of People with IDD

- Recruiting people with IDD to engage in SDMNY takes more time and effort than expected, particularly for those under guardianship orders. Significant challenges to recruitment are a lack of legal standing for SDM and a widely held belief that guardianship is necessary in order for family members to be involved in decisions, particularly in a crisis or urgent situation.
- Recruitment was most successful when SDMNY staff developed a relationship with an organization (a school) over time and engaged in ongoing conversations with school personnel, both administrators and teachers, in order that all school staff, not just transition coordinators, understood the potential benefits of SDM for persons with IDD.

Pressures Toward Guardianship

- Guardianship is not well understood. Most guardians and potential guardians (60%) reported awareness of but not a clear understanding of the specific loss of rights that accompanies guardianship in New York.
- Family members, both guardians and potential guardians, are advised that guardianship is necessary, most persuasively from other parents with children with disabilities, from schools, and from health care providers.
- Many family members are not fully cognizant that alternatives to guardianship exist; as a result, they are unable to make informed decisions about guardianship or alternatives.

Family Members Are Interested in SDMNY Values

- Family members participated in SDMNY because supported decision-making aligns with their values and expectations of how to treat their adult family members with IDD:

respecting their voice, encouraging them to advocate for themselves, and supporting them to have more control over their own lives.

- Family members found SDMNY information sessions very impactful. In particular, they found the following information persuasive: limits of guardianship, removal of rights, evolution of best practices to SDM, and how deeply it matters to allow people to experience risk-taking and decision-making in their own lives.
- Legal recognition of SDM would increase guardian and potential guardian confidence in SDM viability, providing them assurances that decision-makers' rights would be protected in the future, that third parties would accept decisions made using SDM, and that SDM will continue even after parents and other family members become unavailable or pass away.

SDMNY Early Impacts

- Facilitators who participated in this evaluation reported that the SDMNY training and experience changed their perspective and removed some stereotypes about people with IDD.
- For most potential guardian family members, participating in SDMNY reduced concerns that may have led to guardianship petitions. For guardian family members, participating in SDMNY has yet to reduce the concerns that led them to petition for guardianship.
- Positive impacts reported for people with IDD participating at this early stage of SDMNY engagement included increased self-advocacy, greater self-confidence, a wider array of experiences and trying new things, reduced anxiety, and greater happiness.

Introduction

At its core, supported decision-making (SDM) is the normal human activity of consulting other people and sources to inform a decision. In the context of disability rights, there are numerous descriptions of SDM. The National Council on Disability—an independent federal agency that advises the president, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities—uses the following description:¹

There is no singular definition or model, but this generally means an individual choosing one or more people to assist that person in understanding the nature and consequences of potential personal and financial decisions, supporting the individual in making their own decisions, and then communicating decisions as needed. It generally occurs when people with disabilities use friends, family members and professionals to help them understand the everyday situations they face and choices they must make, allowing them to make their own decisions without the need for a substitute decision maker such as a guardian. This process works in the same way that most adults make daily decisions – by seeking advice, input and information from trusted knowledgeable others.

SDM is also derived from an international human rights treaty, the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD asserts that people with disabilities share legal capacity on the same basis as people without disabilities—that is, they have the right to make their own decisions and have those decisions legally recognized. Article 12 of the treaty affirms the equal recognition before the law and legal capacity of persons with disabilities. Countries ratifying the UNCRPD commit to “...provide access by persons with disabilities to the support they may require in exercising their legal capacity.”² SDM is recognized as a mechanism for operationalizing equal legal capacity.

Nearly every country has ratified the UNCRPD.³ The United States, North Korea, and Sudan are among those countries that have yet to do so. Former President Barack Obama signed the UNCRPD in 2009. In the U.S., however, a two-thirds majority Senate vote is also required for ratification of an international treaty. The UNCRPD has made it to the Senate floor, but the majority vote has yet to be achieved.

Even so, there is much interest and progress underway to advance SDM here in the U.S. SDM is emerging as self-direction, person-centered planning, and service choices that include integrated, non-disability options are becoming the norm. And SDM is advancing quickly in the U.S. At the time SDMNY launched, just two states (Texas and Delaware) had revised their guardianship law to recognize SDM Agreements (SDMAs) and advance SDM.

Now eight states and the District of Columbia have passed legislation recognizing SDM agreements: Texas, Delaware, Wisconsin, Alaska, North Dakota, Indiana, Nevada, and Rhode Island.⁴

Prevalence and Outcomes of Guardianship for Adults with IDD

In the U.S., guardianship is a legal process. A state court appoints a guardian, a substitute decision-maker, when a judge determines a person lacks capacity to make important decisions regarding his or her own life or property. A guardianship order removes a person's right to decision-making about her or his own life, including decisions such as where to live, whether to work, whether to have an intimate relationship, what medical care to receive or refuse, and how to spend money. Guardianship can also, depending on the state law, remove a person's right to vote, to marry, to drive a car, and other forms of engagement in community life. Young adults with IDD are particularly at risk of guardianship and losing their legal right to make decisions about their lives.

The use of guardianship in this country has been promoted and adopted as a protective measure, primarily for older adults with dementias and for people with IDD, to reduce perceived or experienced risk or vulnerability. But best practices evolve and are changing to affirm rights. People with disabilities have been demanding their full human and legal rights. Civil and human rights protection for people with disabilities is steadily gaining legal footholds and social acceptance. The UNCRPD and SDM are real drivers for change here in the U.S. and around the world.

While a dearth of data on guardianship means exact numbers are unknown, the number of people under guardianship is still on the rise in the U.S. Since 1995, the estimated number of older adults and adults with IDD under guardianship in the U.S. has tripled, from 500,000 to 1.5 million.⁵ And according to the National Council on Disability, actual guardianships may be much higher.⁶ Since the late 1990s, the National Core Indicators™ (NCI) has been collecting data on guardianship rates among adults with IDD who are receiving publicly funded services. While the rate of people who have IDD across the country is the same, the rate of guardianship for adults with IDD receiving publicly funded services varies widely by state. Data from the most recent NCI™ dataset (2017-2018) found that adults with IDD reported to have full or partial guardianships ranged from 5.5% in one state to 89% in another.⁷ Such variation indicates that something other than the personal characteristics of adults with IDD influences guardianship rates within state service systems.

Guardianship is correlated with negative impacts for people with disabilities beyond a loss of rights. Adults with IDD under guardianship have different life experiences than those not under guardianship. A new National Core Indicators™ Data Brief, *What Do NCI Data Reveal*

About the Guardianship Status of People With IDD?, examines the data from a 2016-2017 NCI survey of 25,671 adults with IDD who are receiving publicly funded services and compares the lives of those who are under guardianship with those not under guardianship.⁸ According to the report, those not under guardianship were more likely to:

- Be employed in a community-based job
- Live in their own home or apartment (and less likely to live in a group residence)
- Be involved in making decisions about their lives
- Be included in their communities
- Receive preventative health care screenings, if female (mammograms, Pap test)

In addition, guardianship can place people at risk of victimization. Although guardianship is presumed to provide protections, there are some cases where guardians (both family member and professional guardians) take advantage of their authority and victimize their wards. The extent to which people with IDD and older adults are victimized by guardians is not known as our government has not collected this information in a systematic way. The Government Accountability Office conducted an examination into the extent of abuse by guardians for older adults and, in its 2016 report, confirmed abuse and financial exploitation by guardians occurs; and in the same report, the GAO reiterated the dearth of national data.⁹ Efforts are underway to collect accurate national data on the exploitation and abuse of older adults and adults with disabilities through state Adult Protective Services.¹⁰ Information on perpetrators including guardians will be available through the National Adult Maltreatment Reporting System which began collecting data in 2016.

Paradigm Shift Underway: Recognizing SDM and Renewed Guardianship Reforms

As previously mentioned, SDM is advancing quickly in the U.S., and eight states have passed legislation recognizing SDM Agreements (SDMAs). Some state statutes require the use of a standard form for SDMAs whereas others do not. And while statutory requirements vary across jurisdictions, SDMAs generally include statements that a person is voluntarily adopting SDM and identify areas where decision support is desired, who provides the support, and how support is to be delivered. SDMAs are meant to be living documents that extend indefinitely into the future and can be modified or terminated at the decision of the person with a disability.

Alaska has a novel approach to SDM. The state's new statute offers SDM to all citizens, those without and with disabilities, as well as people under guardianship. If a part of the SDMA has to do with decisions under the guardian or conservator's domain, then the guardian must consent and sign the agreement acknowledging others are involved.¹¹

The Uniform Law Commission, a national group of lawyers appointed by their state governments who provide states with nonpartisan, uniform draft legislation in areas of

state law, has recommended major changes to guardianship law at several points, beginning in 1969.¹² Over time, states have adopted important recommended procedural provisions, including a right to notice, to object to the guardian and guardianship, and preference for limited, tailored guardianship over plenary guardianships. In 2017, the Uniform Law Commission approved the *Uniform Guardianship, Conservatorship and Other Protective Arrangements Act* (UGCOPAA) that presents SDM as a less restrictive alternative that must be considered before guardianship can be imposed.

The American Bar Association (ABA) is also a proponent of attempting SDM before guardianship. In 2017, the ABA adopted Resolution 113 urging state, territorial, and tribal legislatures to amend guardianship statutes to require SDM be identified and fully considered as a less restrictive alternative before guardianship is imposed. This resolution also urges judges to consider decision-making supports, including SDM, that would meet the individual's needs as grounds for termination of a guardianship and restoration of rights.¹³ Prior to passage of Resolution 113, the ABA published guidance for attorneys, in its *PRACTICAL Tool for Lawyers: Steps in Supported Decision-Making*, that also proposes consideration of less restrictive options, including SDM, before proceeding with a guardianship petition.¹⁴

Other professional associations have published policy and practice recommendations favoring SDM. In 2016, the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc published a joint policy statement in support of guardianship reform and the importance of individual autonomy for people with IDD, *Autonomy, Decision-Making Supports, and Guardianship*.¹⁵ An excerpt from that statement reads:

The personal autonomy, liberty, freedom, and dignity of each individual with IDD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with IDD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

The federal government is also promoting SDM. In 2014, the Administration for Community Living, Department of Health and Human Services, funded a national technical assistance center to research and advance SDM for older adults and people with IDD. The National Resource Center on Supported Decision-Making has been collecting and sharing stories of those using SDM and has funded 18 SDM projects around the country to advance the SDM knowledge base and encourage states to recognize SDM in many forms—from an alternative to guardianship to reducing disability discrimination in organ transplantations. For more information about the Center visit: <http://supporteddecisionmaking.org>.

The U.S. National Council on Disability 2018 report, *Beyond Guardianship: Towards Alternatives that Promote Greater Self-Determination of People with Disabilities*, presents the civil rights implications of guardianship and alternatives and recommends expansion of SDM at state and local levels.¹⁶

Pilot programs (in this country and around the world) are contributing to the advancement of SDM. These pilots are demonstrating the positive impacts of assisting people to retain their rights and receive support with decision-making. Evaluations of pilots that examined impact to date have found SDM to enhance self-esteem, self-confidence, and decision-making skills of SDM adopters. SDM pilots have demonstrated that SDM is a viable alternative to guardianship. Bulgaria's SDM pilot even demonstrated that service costs were lower for those using SDM, including reduced hospitalizations and reduced social welfare costs due to an increase in competitive employment. As retired Surrogate Judge Kristin Booth Glen stated at the 2019 National Supported Decision-Making Symposium, "SDM pilots around the world demonstrate that SDM is a process that changes learned helplessness to people becoming agents of their own lives, and repositions those around them to stop being fixers and, instead, to become true supporters."¹⁷

Supported Decision-Making in New York

In New York, the guardianship law for people with IDD (Surrogate's Court Procedure Act Article 17-A) is separate from and provides less due process protections than the general adult guardianship statute (Mental Hygiene Law Article 81). There is no requirement for a hearing, and no requirement for specific evidence about a person's capacities or need for support (i.e., a functional assessment). Instead, the legal criterion is simply a diagnosis of intellectual or developmental disability, without examination of how a person operates in the world or evidence about supports in place or that could be accessed related to areas of vulnerability, and the judge's determination that guardianship would be in the person's "best interest."

This evaluation found that in New York, schools, health and behavioral health care providers, and other parents with children with IDD tend to guide families toward guardianship. The path to guardianship is compelling, as according to the most recent National Core Indicators™ (NCI) data, 41% of adults with IDD receiving publicly funded services in New York have guardians and most of these guardians (82%) are family members.¹⁸ As NCI does not capture information about adults with IDD who are not receiving publicly funded services, data about those with guardians is likely underreported.

The use of SDM in New York has the potential to make a significant difference in reducing dependence on guardianship and increasing the quality of life of adults with IDD.

Recognizing this, in 2015, the New York State Developmental Disabilities Planning Council (DDPC) awarded a five-year grant to Supported Decision-Making New York (SDMNY), a

consortium of collaborating institutions, to develop and distribute educational materials and to pilot SDM for people with IDD throughout New York State. Narratives and data from the SDMNY educational and SDM pilot activities are intended to inform any law reform initiatives to advance the use of SDM as an alternative to guardianship.

SDMNY Partners

The SDMNY partners are Hunter College/CUNY, the New York Alliance for Inclusion and Innovation, and the Arc Westchester. Disability Rights New York (DRNY), the state Protection and Advocacy agency, serves as the legal resource. More information about this partnership can be found on the SDMNY webpage: <https://sdmny.org/who-are-we>.

In addition to providing information about SDM to a wide variety of stakeholders, SDMNY partners designed pilots offering SDM to two groups of people with IDD: The SDMNY Diversion pilot seeks to divert those at risk of guardianship whereas the Restoration pilot aims to restore decision-making rights by terminating guardianships. Grant deliverables require that SDMNY recruit at least 90 persons with IDD for the Diversion pilot and at least 45 persons under guardianship for the Restoration pilot.

Hunter/CUNY is the direct contract grantee, charged with overall administration of the project and the grant funds through the Research Foundation of CUNY. Hunter/CUNY took the lead in developing the three-phase SDM facilitation model utilized in the pilots and operates the SDMNY pilot project site in New York City. The Arc Westchester established the first site expansion into Westchester County, and, in Project Year 3, the New York Alliance for Inclusion and Innovation began overseeing expansion to three additional sites—in Long Island, Rochester, and the Albany/Capitol region.

Independent Evaluation

DDPC contracted with an independent evaluator to begin work in SDMNY's fourth year, with reports due after the end of the grant. However, Hunter/CUNY staff wanted evaluation information that could guide project activity in Years 4 and 5 and subcontracted with another independent evaluator in Year 3 to conduct a one-year targeted process evaluation. This focused evaluation gathered information from family members of individuals with IDD primarily involved in the SDMNY New York City site to explore four research questions:

1. What concerns or advice led you to consider guardianship, or to become a guardian?
2. What led you to become involved in Supported Decision-Making New York "SDMNY"?
3. In what ways has the SDMNY process in this pilot addressed or reduced concerns that led you to consider guardianship or to become a guardian?
4. From your perspective, how has participating in the SDMNY pilot affected or changed the individual with IDD?

Approach

SDMNY staff anticipated the evaluator would conduct telephone interviews with 30 to 35 family members from the Diversion and Restoration pilots. This evaluation report refers to family members involved in the Diversion pilot as “potential guardians” and family members involved in the Restoration pilot as “guardians.”

Additionally, this evaluation report refers to SDMNY Diversion and Restoration pilots as one pilot (as “SDMNY”) because decision-makers across both pilots use basically the same facilitated process and agreement template. Presentation of the family member evaluation data, however, retain their affiliated pilot distinction to examine areas of commonality and divergence.

The scope of this evaluation was expanded in February 2019 to include the experience of key Hunter/CUNY staff and those serving in the role of “Facilitators.” This information will serve to document specific areas of SDMNY development, to inform and guide next steps, and to compare SDMNY with other SDM pilots. Online surveys were conducted to collect key SDMNY staff reflections (from the Project Director, Senior Project Coordinator, NYC Site Coordinator, and Faculty Associate) and reflections from facilitators. Questions for staff covered the development of the SDMNY model, outreach and recruitment, challenges and strategies, and thoughts for sustaining SDMNY initiatives after grant funding ends. (See Attachment D for the SDMNY Key Staff Online Survey.) Given that the role of facilitator is a volunteer position, the facilitator survey was very short and focused on facilitator impressions regarding training and perceived impacts of SDMNY. (See Attachment E for the Facilitator Online Survey.)

For more information in general on the approach and methodology for this evaluation, please refer to Attachment A: Evaluation Background, Methods & Approach.

Limitations of the Evaluation

This evaluation was both time limited and limited in scope. It does not include the experiences of people with IDD directly—experiences that may provide additional evidence of the importance and life-changing nature of having one’s decision-making rights upheld. Nor does this evaluation include the perspective of other SDMNY partners or Advisory Council members. This evaluation also does not examine the facilitation process, the types of decisions made using SDMNY, satisfaction with decisions, or third-party acceptance of decisions.

SDMNY Staffing & Roles

SDMNY staff for the New York City (NYC) site are affiliated with Hunter/CUNY and include the Project Director, Senior Project Coordinator, NYC Site Coordinator, Faculty Associate, and Project Assistant. The DDPC grant requires a matching resource contribution from grantees. In 2017, the Project Director published an article describing SDMNY's development, noting the need for additional staff support to supplement grant-funded positions:¹⁹

SDMNY's core staff was painfully small, considering the project's ambitious goals and the "deliverables" required under the grant. Housed at the Silberman School of Social Work at Hunter College in East Harlem, the staff consisted of a project director whose salary was contributed by CUNY, a project coordinator, and a half-time office assistant. As it became clear that the staff was inadequate to fulfill the grant's several missions, Hunter College generously added to the team by providing two years of funding for a full-time coordinator of facilitation and education, a position essential to the project's success.²⁰

SDMNY Core Staff

Project Director

The Project Director notes that an important role she plays is to remain focused on, and bring the team back to, the "big picture" as there are many competing demands on staff every day. The Project Director oversees all SDMNY initiatives which includes a myriad of activities. These include but are not limited to:

- Review reports prepared for grant funder
- Serve as Principal Investigator
- Liaison to Hunter and CUNY university system
- Raise funds for project expenses not covered by the grant (e.g., NYC Site Coordinator position; small individual external contracts, etc.)
- Write articles for publications (law review, etc.)
- Present at professional conferences and symposia
- Develop and review content for SDMNY website
- Participate in SDMNY outreach and training presentations

Sixty percent of the Project Director's time (salary and fringe) are provided by CUNY to meet the grant requirement for matching funds.

Senior Project Coordinator

The Senior Project Coordinator is a full-time, 100% grant-funded position with these responsibilities:

- Coordinate implementation of grant activities and ensure quality
- Periodic reports to funder and tracking progress toward project goals
- Recruit and hire paid project staff and subcontractors
- Budget management including processing invoices and reimbursements
- Plan and carry out strategic initiatives
- Serve as a facilitator for the NYC site
- Develop training and informational materials
- Train and mentor facilitators, primarily at the NYC site, with supervisory responsibilities over the other sites
- Manage the SDMNY website: <https://sdmny.org/>
- Participate in SDMNY outreach presentations
- Liaison with the independent evaluator

NYC Site Coordinator

The NYC Site Coordinator is a full-time position whose salary is contributed by Hunter College (through the Hunter College Foundation) to meet the grant requirement for matching funds. (From October 2018 through March 2019, however, this position was grant funded.) The NYC Site Coordinator's responsibilities include:

- Co-create training materials for facilitators
- Conduct facilitator trainings throughout the state
- Coordinate recruitment of prospective facilitators, mentors, and collaborating organizations
- Participate in SDMNY presentations to prospective expansion site facilitators, mentors, and collaborators
- Collect satisfaction and demographic data from participants as required by funder
- Pair decision-makers with facilitators and facilitators with mentors

Faculty Associate

The Faculty Associate served an important role in writing the grant proposal, designing the SDMNY model, and currently recruits graduate students as facilitators. Currently the Faculty Associate also serves as a mentor for facilitators. This position is grant funded for 17% of faculty time.

Project Assistant

The Project Assistant is a grant funded, part-time (57% of full time) administrative position that supports the SDMNY team by:

- Assisting the Project Coordinator and Site Coordinator with facilitator trainings
- Social media updates (Facebook and Twitter)
- SDMNY information and outreach session demographic and satisfaction data collection
- General administrative and office management tasks as requested

Recommendations

SDMNY staff offer the following recommendations to enhance the contributions from staff.

SDMNY Recommendations: Staff Resource Considerations

- Staffing plans frequently change due to turnover and changes in project activity. Where additional staffing resources are necessary, seek additional resources as soon as possible.
- Consider staff technological capability and time for website design, construction, maintenance and updating.

SDMA Facilitators and Mentors

Volunteer Facilitators

The SDMNY model uses trained volunteers called “facilitators” to assist decision-makers to develop SDMA that identify trusted people to provide support and map out specific areas for support, the kinds of support desired, and the methods for providing support. Using volunteer facilitators was important to the design of a sustainable model.

Some SDM models have used paid staff to assist people with disabilities to craft an SDMA. For example, in two Australian SDM pilots, paid independent professionals guided the development of SDMA and ensured supporters were able to meet the support requirements of the decision-maker and were open to coaching.²¹

Mentors

Facilitators are assigned, and have ready access to, persons experienced in the facilitation model called mentors. SDMNY staff report that mentor support and supervision provide skill development and confidence for the facilitator, and a degree of quality control for pilot operations.

Mentors meet with their designated facilitators upon a facilitator's assignment with a decision-maker, and at least monthly thereafter, typically around a facilitator's meeting with a decision-maker. Meetings are generally by phone. Mentors are also available for coaching and problem-solving as needed. Mentors review and approve SDMA's prior to signature by parties.

For the first two years of active SDMNY facilitation, paid staff served as mentors. But as the number of decision-makers and facilitators increased, mentoring facilitators became too great of a time demand. So in Year 3, SDMNY began supplementing the mentor pool with modestly paid mentors drawn from facilitators with successful facilitation experience.

Evaluation findings related to Volunteer Facilitators and Mentors are found in the next section, "SDMNY Pilot Model Development."

Advisory Council

The use of Advisory Councils to guide SDM initiatives is a common and useful practice. DDPC's grant required an Advisory Council with representation from a variety of stakeholders: people with disabilities, parent and sibling groups, special education system, the state Protection and Advocacy agency, attorneys, and members of the court system. Not specified were the number of representatives or how they were to be utilized. SDMNY's Advisory Council has 54 members from diverse stakeholder groups (a complete list is shown on the SDMNY website at: <https://sdmny.org/who-are-we/>). Advisors met in person for a one-day conference to kick off SDMNY in March 2017 and will meet in person again at the conclusion of the five-year grant. Interim communication is at least quarterly and occurs via teleconference.

This evaluation explored with key pilot staff their assessment of Advisory Council guidance and contributions. Pilot staff report that they value and rely on Advisors, both individually and collectively, for guidance and advice, and touch base frequently for feedback. Advisors also contribute by extending SDMNY reach, spreading the word and conducting outreach into different communities throughout the state.

Asked what would strengthen the role or impact of this Council, pilot staff mentioned funding to offer more frequent in-person meetings. The Project Director, who served on the Advisory Council with CPR-Nonotuck's SDM pilot, opined that the annual in-person Council meetings for that pilot were "incredibly valuable," and that an annual in-person meeting with the SDMNY Advisory Council (in addition to periodic teleconferences) would be more constructive than relying only on teleconference engagement.

Recommendations

SDMNY staff offer the following recommendations to enhance the contributions from the Advisory Council.

SDMNY Recommendations: Advisory Council

- Fund an annual in-person meeting with Advisory Council.
- Create an online discussion forum organized by topics on the SDMNY intranet portal for Advisors to engage as issues arise, as well as over time.
- Share quarterly project narrative reports submitted to the funder with Advisors to convey progress in more detail.
- Develop small, subject matter work groups to utilize Advisor expertise more effectively. Work groups would report back to the full Advisory Council.

SDMNY Pilot Model Development

SDMNY was designed by a planning group that reviewed SDM experiences in the United States and other countries—specifically Bulgaria, the Czech Republic, Kenya, Australia, and Israel.²² Significant SDMNY model design elements are noted in Project Director Kristin Booth Glen’s 2017 law review article, including:²³

- The person with IDD is at the center of the process, even if under guardianship. The term “decision-maker” is used to refer to a person with IDD, reinforcing the person’s central role.
- The facilitator works with the decision-maker and the decision-maker’s chosen supporters to create a written agreement, the Supported Decision-making Agreement (SDMA). The SDMA reflects the understanding between decision-maker and supporter(s) of the process they will utilize going forward.
- Decision-makers always have the right to remove or add supporters, as well as change or cancel the agreement.
- The SDMNY model and facilitation process should be replicable and sustainable on a state-wide basis. The facilitation process will need to be paid for through existing or repurposed sources or have minimal or no cost.

Two pilot program experiences were particularly useful to the development of the SDMNY model. One was an early SDM pilot in the U.S., undertaken by the Center for Public Representation (CPR) and Nonotuck Resource Associates in Western Massachusetts; the other, an early Australian SDM pilot spearheaded by the Office of the Public Advocate in South Australia. SDMNY planning team members spent considerable time communicating with developers of these pilots.ⁱ Table 1 is a crosswalk of key structural components across the three SDM pilots: SDMNY, CPR-Nonotuck, and the South Australian Office of the Public Advocate.

ⁱ The first Australian pilot was substantially modified for subsequent Australian pilots. Significant was refinement of the facilitated process for assisting an individual with disability to consider and establish decision support. This crosswalk is not an examination of the facilitation processes used to develop an SDMA.

Table 1. Structural Elements of SDM Models: SDMNY, CPR-Nonotuck, South Australia

Element	SDMNY	CPR-Nonotuck	South Australia
Funding	New York State Developmental Disabilities Planning Council (DDPC) competitive grant award	Primary funding contributed by partner agencies with evaluation funding support from Open Society Foundations	M.S. McLeod Benevolent Fund and Office of the Public Advocate
Timeframe	5 years (2016-2021)	2 years for initial pilot (2015-16); expansion ongoing	Almost 2 years, Dec. 2010 to Oct. 2012
Independent Evaluation	Focused independent 1-year evaluation of NYC site (report 2019). Second, project-wide evaluation funded by DDPC for years 4-5 and one subsequent year.	Independent 2-year evaluation (reports in 2015 and 2016)	Independent evaluation aligned with project timeframe (report 2012)
Advisory Council	Yes, includes individuals with IDD	Yes, included individuals with IDD	Yes, included individuals with IDD
Recruiting Individuals with IDD	Initial outreach to special education schools, self-advocacy organizations, provider agencies. Open to all individuals with IDD expressing interest.	Adults served by provider agency (Nonotuck) with cooperative social networks including guardians and family members interested in trying SDM.	Outreach via information sessions to service providers at work sites. Outreach to guardians via public guardian office. Open to people with IDD, acquired brain injury, or neurological disease.
Person with Disability Legal Status	At end of Year 3: Without guardian = 58 With guardian = 21 (1 guardianship discharged before person enrolled in SDMNY)	Without guardian = 8 With guardian = 1 (1 guardianship discharged during pilot)	Without guardian = 24 With guardian = 2 (1 guardianship discharged during pilot)
SDM Adopters “Decision-makers” Info	79 adults at end of Year 3 with primary diagnoses IDD and autism. (10 decision-makers withdrew by end of Year 3.)	9 adults with primary diagnosis IDD, age range 24-79, most with co-occurring behavioral health conditions including dementias	26 adults, age range 18 to between 70-79, with acquired brain injury, IDD, autism. Excluded those with primary diagnosis of dementia or behavioral health, those in significant conflict with friends or family, those experiencing abuse or neglect.

Element	SDMNY	CPR-Nonotuck	South Australia
Decision Supporters	<ul style="list-style-type: none"> Identified by person with disability Voluntary role Family members, guardians, staff, neighbors, friends 	<ul style="list-style-type: none"> Identified by person with disability Voluntary role 2-10 supporters including family members and guardians, as well as current and former paid staff who are also friends 	<ul style="list-style-type: none"> Identified by person with disability Voluntary role Family members or friends with 1 exception (project coordinator served as supporter as social network depleted) Supporter criteria: expected to be well informed about a participant's goals and commit time needed for support role and assist participant to make a decision known.
SDMA Development Guided by	Trained volunteer and paid staff guide decision-maker and supporters through SDMA development	Paid pilot staff (CPR attorneys with provider care managers) partnered to guide decision-maker and supporters through SDMA development	Paid pilot staff guided decision-maker and supporters through SDMA development
SDMA Legal Status	<ul style="list-style-type: none"> No legal recognition in New York Notarized when signed by individual, facilitator, and supporters <p>At decision-maker's election, health care proxies have also been signed.</p>	<ul style="list-style-type: none"> No legal recognition in Massachusetts Notarized when signed by individuals and their supporters Other legal documents often notarized as well such as Power of Attorney, Health Care Proxy 	<ul style="list-style-type: none"> No legal recognition in South Australia, informal agreement SDM decisions limited to where to live, lifestyle and health. Excludes finances and asset decisions.
Ongoing SDM Monitoring & Complaint Protocol	<ul style="list-style-type: none"> DRNY provides free legal representation for rights restoration. During grant period, Project Coordinator addresses concerns or complaints with developing an SDM agreement. Procedures to address complaints or concerns re: SDMA use are not yet in place but planned for year 4. 	<ul style="list-style-type: none"> CPR free legal representation for rights restoration as well as SDM-related complaints. Nonotuck care managers provide oversight of SDM monthly monitoring. During initial pilot, monitoring was formal, now informal as per service provider case management. 	<ul style="list-style-type: none"> SDMAs lapsed at project end, Oct. 31, 2012.

When developing SDMNY, a foundational decision was whether SDMNY would be housed in an existing provider agency or be a freestanding entity that could be incorporated into different kinds of settings. Key SDMNY staff surveyed for this evaluation expressed concern that if housed within provider agencies, SDM could become diluted—that is, with lip service to voice and choice but bereft of the true experience of legal personhood. Thus, SDMNY’s facilitated SDM process was designed as separate from, but available to, service providers.

Facilitated Development of SDM Agreements

Key pilot staff consider SDMNY’s structured facilitation process to develop an SDMA distinct from other SDM endeavors in the U.S. because SDMNY’s process focuses on decision-making as an ongoing process, and not just on completing the SDMA:

“I think it's because we are focused on the PROCESS by which the decision-maker makes decisions and uses support. We see ourselves not as getting an agreement signed, but as creating a lasting, viable process that the decision-maker and her/his supporters, who almost certainly will change over time, can use throughout her/his life.” –SDMNY staff

SDMNY’s facilitation model identifies three stages of development. The following excerpt from the SDMA template describes the activity within each stage. (The full SDMA template is available at <https://sdmny.org/wp-content/uploads/2019/08/SDMA-draft-3.5.pdf>.)

Phase 1: The facilitator works with decision-maker to learn about how s/he communicates, makes decisions, what kinds of decisions are likely to arise in the long and short term, and who are the important people in the decision-maker’s life from whom s/he may choose trusted supporters.

Phase 2: The facilitator works with the supporters the decision-maker has chosen, educating them about SDM, and helping them “reposition” from people who make decisions for the decision-maker to supporting her or him in making her or his own decisions, including consideration of the “dignity of risk.”

Phase 3: The facilitator works with the decision-maker and her/his chosen supporters to negotiate the SDMA, to ensure that all parties understand their roles, obligations and responsibilities; prepares a draft of the SDMA that all parties review and may alter; and oversees the signing of a final version.

Setting the Stage for an Evolving Decision-Maker

A distinctive SDMNY design component is the expectation that facilitators begin working one-on-one with decision-makers, free from the influence of others. This provides decision-

makers an opportunity to share their stories free of input from others. It highlights for the decision-maker, and for others, that the decision-maker is the locus of control for SDM meetings and the resulting agreement.

Several family members interviewed for this evaluation suggested that more information at the outset of the facilitation process about the first phase of facilitation would be helpful. The following statements from family members represent these sentiments.

“I’m not sure what the process is, how it works. Not sure what they are talking about when they meet. What are they really trying to do? What is the process? She [the facilitator] just called me and asked for [name’s] number. I know they want him to make his own decisions. I don’t know what they are doing, but I would like to know what all this process is and how it is going to help him.” –Potential guardian

“Well, I’m still learning about it. Only went to one session. A written agreement comes, right?” –Potential guardian

“I think the family could be brought in a little earlier, brought in some of their concerns. I could have let them know her go-to is to say, ‘I forgot.’ To involve the family a little earlier in the process to discuss their concerns with the person and their decision-making capabilities. I understand the one-on-one. But have family voice concerns about decision capabilities before going forward. People believe in it [SDMNY] and think it would be good.” –Guardian

“He goes to so many different activities, appointments, it’s getting to be a little too much with all the activity. He feels he is able. I don’t know because he is talking to people and they may be agreeing with him but not know the state of his mental capacity. He is a young man who agrees with a lot of things. They are telling him he can do certain things on his own but when it comes to it, he is not as able. He has someone coming to teach him how to cook but that is not happening.”
–Potential guardian

For Consideration – Initiating meetings between facilitators and people with IDD without others does place the individual at the center of the process. It also has raised anxiety for some family members. It may be useful to explore if guardians and potential guardians who attend an SDMNY information session and learn about the process experience reduced anxiety or concern compared to those who first learn about SDMNY by receiving a packet of materials from the decision-maker.

SDM Agreement Design

Supported Decision-Making Agreements (SDMAs) are documents that describe and formalize the SDM process to which the parties have agreed. SDMNY developed their SDMA template after comparing more than a dozen available formats. Planners felt it was important to craft a template where:

- Decision-making areas for support were open, not prepopulated with common decision areas of support (for example, health care decisions).
- Decision-makers could prescribe the kinds of support from different supporters (for example, gathering information, explaining information, communicating decision to a third party).

On the advice of DRNY, the template was designed to resemble the New York State statutory Power of Attorney form to appear more familiar to courts and judges.

After several revisions, a working draft was presented for feedback and comments to a focus group of self-advocates from the Self-Advocacy Association of New York State (SANYS) and shared with Advisory Council members with legal experience. A significant change to the template suggested by self-advocates was to enlarge the font size identifying the decision-maker's name on the first page to powerfully communicate whose SDMA it is. A revised draft incorporating feedback was then presented to facilitator training participants and has remained the template to date. SDMNY participants in both the Diversion and Restoration groups utilize the same SDMA template.

The final SDMA template identifies the person with IDD as the decision-maker and sets out the rights and responsibilities of the decision-maker and supporters. Explicit is that the decision-maker is responsible for his/her decisions and is free to amend or end the agreement at any time. The template provides four areas for specifying individualized decision support, which SDMNY staff refer to as the "Big Four":

1. **Which** areas a decision-maker wants decision support in (i.e., financial matters, health care, living arrangements, etc.)
2. **Who** is chosen to provide that support (trusted persons in the decision-maker's life)
3. **What** kinds of support (gathering information, helping to weigh alternatives or possible consequences, communicating decisions to others, etc.);
4. **How** support will be provided (face-to-face conversation with individual supporters for individual areas, group meetings, text, telephone, Skype, etc.).

The SDMA template includes other administrative information including how to make changes to decision support, to supporters, and how to revoke the agreement.

Comparison of SDMA Templates

A number of SDMA templates are in use in the U.S. These have been developed by advocacy organizations, as per SDM pilots, and in some states that have modified law to incorporate SDM. Table 2 below shows a comparison of SDMA templates (two from pilots, including the Center for Public Representation (CPR) and Nonotuck pilot mentioned previously, and one from state law) by key domains.

Table 2. Comparison of SDM Agreement Template Design and Development

Domain	SDMNY Pilot Form	CPR Pilot Form	Alaska Statute H.B.336
Assistance with SDMA development	Trained volunteer meets solely with person with IDD (decision-maker) to facilitate SDMA development at the beginning; later brings in supporters	Paid staff (attorney & care manager) facilitate SDMA development with person with IDD and anyone else the person chooses to participate	Options for development: <ul style="list-style-type: none"> • Self-guided without professional assistance • If person has a disability, some service provider and legal service agencies will help • If eligible for low-income legal services, Legal Services Corporation will help • Lawyers can be hired privately
Supporter	Provides for multiple supporters. No supporter inclusion or exclusion criteria. Each supporter signs declaration to provide the assistance described, to not exert undue influence, and to avoid conflicts of interest.	Provides for multiple supporters. No supporter inclusion or exclusion criteria. Each supporter signs declaration that it is their job to honor and present the person's expressed wishes.	Provides for multiple supporters. Inclusion criteria: should clearly understand and communicate with person to be supported. Each supporter signs declaration to provide the assistance described. Supporter exclusions: <ul style="list-style-type: none"> • Person with court order prohibiting contact • Person paid to provide a single service cannot be a supporter for choices re that service (unless a family member) • Person you work for or who works for you (unless a family member)

Domain	SDMNY Pilot Form	CPR Pilot Form	Alaska Statute H.B.336
Areas for Decision Support	Person with IDD identifies areas for decision support. SDMA form does not include decision area prompts.	Form prompts areas for decision support and allows for identifying other kinds of decisions. Person with IDD identifies which supporter provides assistance by decision type.	Form in statute but use of a substantially similar format is accepted. Statutory form prompts areas for decision assistance. Includes prompt to exclude any supporter from helping with decisions the person notes. Allows people under guardianship to use SDM; for decisions designated to the guardian, guardian consent is required. Includes worksheet with ideas (e.g., staying safe, education) plus write-in areas.
Method of Decision Assistance	Prompts method of decision assistance. Prompts noting areas where decision assistance is not wanted.	Prompts method of decision assistance. Prompts person with IDD to inform supporter how he/she expresses preferences in each decision area. Indicates if supporters act jointly or successively within each decision area. Allows excluding any supporter from helping with specified decisions.	Prompts method of decision assistance and frequency.
Routine oversight of SDMA	Oversight by Mentor during development. Planning underway for complaint and concern reporting and review to be in place during Year 4 and post-pilots.	Monthly visits by Care Manager. During initial pilot, monthly meetings between partner agencies.	For financial decisions, Decider must choose a Monitor, a non-supporter to ensure supporter(s) are honest and use good judgment.
Complaints	During SDMA development complaints are directed to Project Coordinator. After SDMA signing ceremony, no complaint entity or process in place. To be developed Year 4.	Until state passes law with complaint procedures, CPR offers pilot participants free legal resources to address SDM-related complaints. Other complaints follow provider and state agency policy. Abuse, etc. is reported to state agency.	Relies on complaint procedures already in place for reporting abuse, neglect, exploitation such as mandated reporting for vulnerable populations and court oversight of guardianships.
Notarized Signatures	Yes	Yes	Yes

Domain	SDMNY Pilot Form	CPR Pilot Form	Alaska Statute H.B.336
Changes/Revocation	Changes expected. SDMA attachments provide format for decision-maker to revoke or make changes. Revised SDMA is notarized.	Changes expected. By statement or expression of preference of person with IDD at any time. Revised SDMA is notarized.	Changes expected. Revised using same format with supporter attestation and notarized.
Expiration	Active until decision-maker revokes.	Active until person with IDD revokes.	May include an end date. If no end date, active until the Decider revokes. Expires if guardian or conservator is ordered.
Liability of Third Parties	Not yet established. SDMA is not yet legally recognized.	Not yet established. SDMA is not yet legally recognized.	Third parties are not legally liable when acting in good faith on the SDMA.

Creating an SDMA Takes Time

SDMNY's three-stage facilitated SDMA process was designed to occur over 6 to 9 months with an expectation of monthly in-person meetings, lasting no more than an hour, between facilitators and decision-makers. However, facilitating development of an SDMA has taken much longer, typically over a year and often up to 18 months.

“Initially, the facilitation process was anticipated to last 6 to 9 months, in part so that the process could be completed within the span of two semesters. Over time, the facilitation process generally seems to require at least 12, and often up to 18 months of once-a-month meetings. Generally, phase 1 seems to last 5 to 7 months, phase 2 lasts 3 to 4 months, and phase 3 lasts another 4 to 6 months.”
 –SDMNY staff

Delays occur when there are not trained facilitators to match with a decision-maker, or when facilitators cease their volunteer commitment before completion of an SDMA. In addition, meetings rarely occur monthly, and both facilitators as well as decision-makers initiate postponements. One- to three-month gaps in meetings were noted by pilot staff as “not uncommon.”

Although in-person facilitation meetings are the expectation, pilot staff report that “more often than not, phase 2 meetings do not occur in person but over the phone.” And phase 3 meetings “frequently” occur via videoconference due to the logistical challenges of finding meeting times and dates that accommodate all attendees (supporters, the facilitator, and the decision-maker). Once an SDMA is prepared, a signing ceremony is scheduled, which adds another month or two to the process.

SDMA Signing Ceremony

Signing ceremonies are the final stage of creating an SDMA and are important occasions, providing meaning and significance to the achievement of a negotiated support agreement. Decision-makers, their supporter(s) and the facilitator meet to sign and have the agreement notarized. For an original SDMA or a modification, the signing parties are the decision-maker, facilitator, supporter(s), as well as a Notary Public.

Signing ceremonies are personalized. The facilitator may share a few words of congratulations, followed by remarks from the decision-maker and/or a supporter. It is up to the decision-maker to determine who, if anyone, speaks. Next, the facilitator goes through the “Notice to Decision-maker” section of the SDMA, and the decision-maker checks off his/her rights and responsibilities with regard to the agreement. If satisfied with the provisions, the decision-maker signs the agreement, followed by the supporter(s). Signatures are notarized. Supporters unable to attend in person may send digital signatures in advance of the event, which are incorporated into the agreement but are not notarized. The decision-maker keeps the original document and copies for each supporter are made at the time of the ceremony. Everyone receives a folder with FAQs regarding the agreement and a congratulatory letter from the SDMNY Project Director. Health care proxies have also been executed as part of the SDMA signing ceremony.

Most decision-makers have chosen to have group ceremonies located at an organization (i.e., a school or a self-advocacy group). For group ceremonies, SDMNY staff may invite a guest speaker. Past speakers have been a school principal and the Commissioner for the Mayor’s Office for People with Disabilities. Refreshments are served so that the attendees can mingle after. One decision-maker, who preferred a private ceremony, requested his ceremony attendees wear green and that key lime pie be served.

Signing ceremonies affirm decision-maker and supporter courage and their important role in advancing human rights. At the first signing ceremony on September 25, 2018, Kristin Booth Glen, SDMNY Project Director and Former Surrogate Judge of Manhattan, addressed decision-makers in this way:

By signing your agreement, you are letting others know that you are capable of making decisions with support. Your agreement will serve as a guide for you and your supporters as you navigate life’s many challenges... By being a part of SDMNY’s pilot project, you and your supporters are pioneers in demonstrating how SDM can work as a better alternative to guardianship. And, as well, you are part of a worldwide movement that honors and respects the rights of persons with intellectual disabilities to make decisions like anyone else. That deserves our thanks at SDMNY, and our deepest congratulations.

Additional signing event information and photos are posted on the SDMNY website: <https://sdmny.org/news/>.

Modifying or Revoking an SDMA

Modifying the SDMA is considered a normal, expected future event as decision-maker capabilities change, as decision-support areas alter based on life experience, supporter commitment changes, or as a decision-maker changes his or her mind regarding a supporter. Facilitators are expected to convey this to decision-makers. The SDMA template provides a mechanism for the decision-maker to initiate modification. Attachment C to the SDMA provides for a decision-maker to revoke the agreement, while Attachment D is for making changes. Both revocations and modifications require two witnesses, their signatures, as well as a Notary Public signature that the decision-maker authorized the changes.

At this stage, SDMNY focus is on recruiting decision-makers and facilitating their completion of an SDMA. Having the instruction on how to make a change to an SDMA is an important step in laying the foundation for a living, flexible document. But actually making changes and checking on how an SDMA is working in real life are also important for SDM sustainability and retaining trust of SDMNY participants. One of the potential guardians interviewed for this evaluation shared his concerns as to whether someone would check in and assist his son to make changes after grant funding ends:

“Big concern of mine is the way it’s set up now, there is a neat plan and it looks good on paper, but as his plans and goals shift and change, how does that support change? Who will help him with that? How will [name] know ‘I need to modify this’? When the pilot funding is not in place, who will be monitoring? We think there should be another layer to check that his plan is working for him. Now it’s a very specific plan, but is not specific in making changes to plan such as who will take over [facilitator’s name] role when she is not there any longer? To transition supporters and roles, who is there to help him change this document?” –Potential guardian

Evaluation Findings: SDMA Facilitation Process

- Completing an SDMA using the SDMNY facilitation process typically takes twice as long or longer than expected, from a year up to 18 months.
- Although in-person meetings between a facilitator and decision-maker were the expectation, meetings in later stages often occur by phone or video conference.
- For SDM sustainability, identify a responsible entity to check on how SDMA’s are functioning for decision-makers and supporters and identify a responsible entity to assist decision-makers with SDMA changes after grant funding ends.

For Consideration - Pilot staff may find it useful to explore whether facilitator retention is impacted by:

- Holding facilitation meetings more often than once a month, reducing time to complete an SDMA and the volunteer commitment.
- Explicitly advising potential facilitators on how long the facilitation process can take.
- Having back-up facilitator plans in place for each decision-maker so that substituting a new facilitator does not lead to delays in SDMA completion.
- Where logistics complicate in-person meetings, it may be useful to explore the extent to which virtual meetings meet expectations and serve both SDMNY's and the decision-maker's goals.

SDMNY Roles: Decision-Maker, Facilitator, Mentor, Supporter

Decision-Maker Role

Adopting the term “decision-maker” to refer to an individual with IDD engaged in SDMNY was important to key staff. The term decision-maker sets the stage and expectations, both for the individual with IDD as well as supporters and third parties. Decision-makers drive the process. They voluntarily adopt SDM, identify areas where decision support is welcome, identify and invite supporter involvement, and advise supporters how to provide decision support.

Facilitator Role

Facilitators are trained volunteers who assist decision-makers to develop SDMA's. Facilitators assist decision-makers to consider what kinds of decisions they may want help with making, who they want decision assistance support from, what kinds of support they want, and how support should be provided. Facilitators also assist decision-makers to reach out to potential supporters and negotiate the terms of their SDMA with supporters. The NYC Site Coordinator matches facilitators with decision-makers with matching largely determined by geography.

SDMNY staff consider the work that facilitators undertake as powerful and empowering:

“On a more profound level, the facilitators act as Virgilian guides for decision-makers navigating vexing issues surrounding their decision-making futures. Some of the questions that facilitators help decision-makers address are difficult and anxiety-inducing, for example, who a decision-maker might want to support her when a loved one passes away? In this way, facilitators are agents of self-discovery,

empowerment, and relational transformation that may affect the decision-makers beyond what is reduced to writing in their SDMAAs.” –SDMNY staff

“At the same time that the ‘end’ of the facilitation is the SDMA, facilitating the development of the process, by which the decision-maker will use support throughout her/his life, is equally important, as is helping the decision-maker to see her/himself as a decision-maker, and to empower her/him to be an agent in her/his own life.” –SDMNY staff

Facilitator Qualifications

The SDMNY model purports no required facilitator qualifications (such as education degree, language fluency, experience with individuals with IDD, knowledge of developmental disabilities system, etc.). Facilitators do not know individuals with whom they are matched and thus spend time developing their relationship while facilitating progress toward an SDMA. When recruiting facilitators, what matters to key staff is:

- Belief in the value of people with IDD making decisions about their own lives
- Respect for the SDMNY process and completion of the 2-day SDMNY facilitator training
- Computer skills sufficient for reporting and communicating with SDMNY staff

Effective Facilitator Characteristics

Asked what characteristics or traits are found in the most effective facilitators, all surveyed SDMNY staff noted commitment to a person’s right to make her/his own choices, SDM, and the SDMNY facilitation model. Other important characteristics mentioned were:

- Good listener
- Flexibility and diligence
- Patience with process
- Being comfortable with potential conflicts that may arise with supporters
- Ability to put other roles aside to focus on SDM facilitation
- Have an open mind (one staff added: an open heart as well)
- Enthusiasm and personal satisfaction for the work

An insight from one staff was that the most effective facilitators are those who see themselves as benefiting from the experience:

“Facilitators who believe they are benefiting from the facilitation process and their interactions with decision-makers seem to be the ones who remain the most engaged and committed throughout the process.”

Facilitator Recruitment: Unexpected Bumps in the Road

From the outset, the plan was to create a sustainable, low-cost facilitator model for eventual expansion. Toward this goal, SDMNY staff explored securing volunteer facilitators from various organizations. The predominant effort has been directed toward students in professional programs, but recruitment efforts have also included volunteer organizations, provider agency staff, and trained volunteer mediators from court-affiliated Community Dispute Resolution Centers (CRDC).

Facilitator recruitment began with graduate professional university students. Between CUNY and the State University of New York (SUNY), there are campuses in every county in New York State. The influx of new students was viewed as a potential sustainable source of facilitators.

Students pursuing their Master of Social Work (MSW) degrees, whose code of ethics embraces client self-determination, were first explored. The SDMNY NYC site is located in the building that houses the Silberman School of Social Work at Hunter College. SDMNY staff anticipated that MSW students would use work as facilitators to meet part of their clinical practice requirements. SDMNY staff also anticipated that MSW graduates would find the experience so rewarding that they would continue as volunteers after graduation. This effort was initially less successful than planned because the timing of facilitation meetings was not compatible with the routine hours and supervision required for MSW credentialing. Even so, some MSW students were recruited to volunteer as facilitators outside of their clinical practice requirements.

Next, staff tried recruiting Bachelor of Social Work (BSW) students as clinical practice requirements are more flexible. Staff collaboration with BSW faculty and administration has been time-consuming but is expected to result in a structure for BSW facilitators that can be replicated in BSW programs across the state.

A promising collaboration is underway with the Occupational Therapy Assistant (OTA) program at LaGuardia Community College (part of the CUNY system). As with social work ethics, SDM philosophy aligns well with occupational therapy values to identify ways to enhance client autonomy. SDMNY staff report that OTA facilitators have demonstrated great interest, commitment, diversity, and high energy. At this stage, however, there is much work to be done to formalize the administrative structure.

Facilitator recruitment was also explored with service provider agencies but was less successful than anticipated. SDMNY staff report a significant deterrent for providers is the lack of clarity regarding billing for the time that staff engage in facilitation as a reimbursable service under the Medicaid Home and Community-Based Services waiver program. Even so, some SDMNY facilitators are employed by service providers. The SDMNY Project Director noted that The Arc Westchester, an SDMNY partner organization that

received grant funding, allows staff to use work hours to engage in facilitation activities. And some provider staff have volunteered on their own time. However, with the complications of reimbursable time and a workforce shortage of direct support professionals, SDMNY staff turned to other potential facilitator pools.

Outreach was made to volunteers with Re-Serve, an organization that places retired professionals and others with nonprofit organizations. Several Re-Serve members took the facilitator training but only one followed through to become a facilitator. More recently, facilitators were recruited from the volunteer mediator program at the CDRCs, affiliated with the New York State court system's Office of Court Innovation.

In addition to continuing to develop facilitator opportunities with social work and OTA college students, future facilitator recruitment plans include exploring graduate students in special education as well as non-professional volunteers connected to other community organizations (churches and other faith-based entities, union retirees, civic groups, etc.). And, as in the Bulgarian SDM pilot, SDMNY is exploring the idea of using parents and others who have experienced the transformation of SDM in their own families as volunteer facilitators for non-related individuals.

What Attracts Facilitators to SDMNY

Each of the four facilitators participating in the evaluation survey reported being drawn to this volunteer relationship for a different reason: to assist individuals with varied abilities to be as independent as possible; to comprehend their rights; to support making decisions; and to establish an alternative to guardianship.

Facilitator Training Evolution

SDMNY staff describe a very thorough training development process that entailed numerous brainstorming sessions, examining other pilot models (including Bulgaria, Israel, CPR-Nonotuck), and hosting Cher Nicholson to present for four days on the facilitation method she refined from experience with Australian SDM pilots and consulting with SDM initiatives around the world.²⁴

Though much up-front work was done to develop the training, SDMNY staff have continuously modified it based on actual experience and feedback from training participants and others. Facilitator trainings are in English and are multi-modal, utilizing in-person presentations, written materials, role-playing, and video instruction. Major modifications have included:

- Expanding the training from one day to two consecutive six-hour days
- Establishing goals and objectives for each phase of facilitation
- Stressing the aim of facilitation before discussion of facilitator skills
- Consolidating into one module the skills and strategies involved in facilitation

- Adding a module on the SDMA design and creation
- Adding emphasis on dignity of risk
- Adding video simulations, one for each of the three facilitation phases, in collaboration with Outside Voices, a theater group of people with IDD

Over time, SDMNY staff gained insight that the original training videos and in-person role play simulations inadvertently conveyed supporting a decision-maker to reach a goal rather than supporting the decision-making process.

“For example with decision support around money, the video and the in-person simulations frequently ended up with helping a decision-maker open a bank account or learn to budget rather than how to make decisions, and use support to do so, about finances.” –SDMNY staff

“Trainings now stress that facilitators are not decision supporters; their role is to assist decision-makers to make decisions with the kinds of support they desire. Training now directs the facilitator to reflect on the decision-making processes rather than engage in directly supporting decision-makers to make decisions about their lives” –SDMNY staff

SDMNY staff remark on how challenging it is to be a facilitator and not someone who makes things happen or fixes problems:

“How hard it is to get everyone involved (staff, facilitators, etc.) to move from thinking about facilitating decision-makers to reach their goals to facilitating how they make a decision. We are all basically problem solvers, and it is really hard to get off this, as witnessed by our training videos, and even the revised facilitators' manual, which still has instances of focus on goals rather than the decisions necessary to attempt/reach them. It comes up in the facilitator training all the time.”

“Be clear, from the beginning, internally and in training, etc., that we are not, nor can we facilitate decision-makers to reach goals or accomplish things they want to do (open a bank account, find an apartment, get better services, etc.) and that we are solely engaged in facilitation (with trusted supporters) of DECISIONs!”

As there was initially neither money nor time to remake the videos, trainers critiqued videos and simulations probing whether a facilitator over-stepped her/his role. SDMNY staff anticipate the next iteration of the training manual and videos will clarify and reinforce the distinction between creating the process for the decision-maker to utilize decision support and making a decision to achieve a goal.

Facilitator Perspective on Training

Each of the facilitators surveyed for this evaluation stated that they found the training useful. One described it as “intensive and thought-provoking.” Another stated it was “...providing a road map process for guiding and assisting the decision-maker through the SDMA process.” For one facilitator, training was transformative:

“I did not realize that it would change my perspective on how to approach working with adults in general with different abilities. The training allowed me to reflect on how we structure and execute programming here, and how SDMNY/empowering our individuals towards independence can be interwoven through all of the work that we do.”

To enhance the training, facilitators suggested including real case scenarios that convey the experiences of facilitators and decision-makers, issues or problems, and how these were addressed or resolved. SDMNY staff note that with the increasing number of decision-makers with SDMA, case scenarios now reflect lived experiences.

Facilitator Issues and How Pilot Staff Addressed

Facilitator continuity and attrition have been the significant challenges for the SDMNY pilot. Utilizing volunteer facilitators, and particularly students, entails attrition after graduation, downtime between semesters, and during semesters, students finding time for SDMNY amid competing priorities. When facilitators have not been able to continue the SDMNY process to its completion (e.g., through the signing ceremony), either the assigned mentor or Site Coordinator has stepped in, or the mentor secured another facilitator.

An unexpected challenge that SDMNY staff worked through was that not all facilitators who completed a training subsequently agreed to volunteer their time. Some people participated in the training only because they were interested in learning about SDM. To address this, staff initiated a signed commitment form which specifies the time commitment expected of those who complete a facilitator training to complete an SDMA (3 to 4 hours per month for 12 months). Since instituting this commitment form, facilitator uptake has increased.

Another challenge was timing a facilitator’s training to align with being matched to an available decision-maker. When lag time occurred between training and a decision-maker assignment, the impact of training diminished, and facilitator availability reduced. To retain commitment of a trained facilitator, staff realized it was preferable to have decision-makers wait to be assigned a facilitator rather than have trained facilitators wait for months for a decision-maker assignment.

Evaluation Findings: Facilitator

- Facilitator recruitment and attrition have been significant challenges to establishing a sustainable volunteer pool. Given recruitment strategies and organizational hurdles cleared to utilize professional students and other potential volunteer pools, going forward, SDMNY staff are confident that using volunteer facilitators is viable and sustainable.
- Facilitator training has evolved with substantial changes. A fundamental change was stressing the distinction between helping a decision-maker develop his/her support for decision-making rather than support in achieving a goal.
- Facilitators found the training useful. For some, the training altered their personal values and beliefs about people with disabilities and deepened their understanding that all people want to make decisions about their lives.

Mentor Role

From the outset the mentor role was devised to provide guidance as well as technical and emotional support to facilitators. Mentors and facilitators typically check-in via a monthly phone call after the facilitator and decision-maker meet. Mentors review facilitators' draft SDMAs, which are also reviewed by the Project Director and Senior Project Coordinator. Thus mentors, as monitors of the SDMA process and development, serve an important oversight role.

"Mentors are a crucial source of guidance and both technical and moral support. They also serve as backup facilitators if, for whatever reason, a facilitator becomes unavailable. Increasingly, the project has come to view them as an important mechanism for quality control in the future, in order to preserve the integrity of the three-phase facilitation process developed by SDMNY beyond the grant period."
–SDMNY staff

In response to the increasing number of decision-makers with completed SDMAs, the mentor role has expanded. SDMNY staff initiated SDMA user focus groups facilitated by mentors. Decision-makers have the opportunity to meet in person once a month to review the content of SDMAs, share experiences, practice problem-solving and provide mutual support.

Mentor Qualifications

The NYC Site Coordinator matches mentors with facilitators; each mentor oversees multiple facilitators. Mentor qualifications are twofold: first, completion of the SDMNY facilitator training, and second, successful facilitation experience with at least one decision-maker through the creation of an SDMA. Queried about which characteristics are present in the most effective mentors, SDMNY staff specified effective mentors are those who:

- Value facilitators as change-makers in the lives of decision-makers
- Impart to volunteer facilitators their important role and retain volunteers
- Possess strong listening, and probing skills, as well as skill running meetings
- Are flexible and available to facilitators, willing to give additional time and energy to help facilitators navigate challenges

Beyond the facilitator training and expectation to have guided at least one decision-maker through completion of an SDMA, there currently is no additional training specific for mentors. Developing a training and resource manual for mentors is planned for Year 4.

“Throughout the project it has become ever more compelling how important the mentor is to the success and integrity of the process. I’ve insisted, often with a lot of pushback, that as we have expansion sites, there should be at least one person who has already done at least one facilitation and is otherwise appropriate to mentor the facilitators at that site.” –SDMNY staff

Paid v. Volunteer Mentors

The SDMNY design plan to recruit volunteer mentors from experienced facilitator volunteers was not realized. Thus far mentors have been drawn almost entirely from paid pilot staff. One explanation put forward by pilot staff is the length of the facilitation process:

“There was an expectation among SDMNY partners that strong facilitators would later go on to serve as mentors, but the length of many facilitation processes has delayed the anticipated development of mentors for both the NYC site and expansion sites in Westchester, Rochester, Albany, and Long Island.”

As SDMNY expands, additional mentor positions for facilitator supervision and support and SDMA quality oversight need to be established. Three of the four SDMNY staff serve as mentors in the NYC area and co-mentor at SDMNY expansion sites. As staff explain, planning is underway to expand the mentor pool, but funding is not yet in place for additional mentor positions:

“It became increasingly clear the significant role that mentors play in ensuring quality control and model fidelity, especially as the New York City pilot program site grew. To promote post-project sustainability, we considered it advisable that high-quality mentoring be available and that mentoring experience not be the exclusive purview of the grant’s core staff. Therefore, we plan to contract in Y4 two outside part-time mentors to provide mentoring to our growing corps of facilitators.”

“Increasingly I think, as the role and importance of mentors grows, and as the need for mentors to serve a significant number of facilitators becomes clear for administrative and quality control reasons, there will need to be a funding source for these crucial participants as, by and large, volunteers are unlikely to be willing or able to take on the workload that mentors will need to undertake to make the work successful.”

To sustain and support mentors into the future, staff envision establishing facilitator and mentor learning communities.

“I think it is important to cultivate and nourish a dedicated professional community of facilitators and mentors who take pride in their role in increasing decision-makers’ autonomy. I believe that facilitators and mentors must feel not only committed to this cause but also, they must have a way to support, sustain, and learn from each other’s endeavors in their own lines of work. Especially because I view current facilitators and mentors as crucial future resource persons for decision-makers who may seek to modify their SDMA’s or to reeducate their supporters about their decision-making preferences, they need to be invested in the cause itself so that today’s decision-makers will have persons to go to when they face challenges in getting recognition of their SDMA’s from third parties or holding their supporters accountable.”

Evaluation Findings: Mentor

- Several factors have contributed to the need for additional mentors: the time investment to develop SDMA’s, SDMA’s geographic expansion, and utilizing SDMA’s staff solely as mentors to support facilitators.
- The mentor position entails supervisory and quality monitoring responsibilities and should be a paid position. With expansion of SDMA’s, additional development efforts are needed to secure funds for, and expand the paid mentor pool.

SDMA’s Recommendation: Mentor and Facilitator Mutual Support

- To sustain mentors and facilitators, establish and support professional networking forums (such as a learning community) for mutual support, problem-solving, and sharing resources and ideas.

Supporter

In Phase 1 of the facilitation process, decision-makers identified family members—usually parents, but also grandparents, siblings, friends, and paid service provider staff—as supporters. During Phase 2 meetings, supporters meet with the facilitator and decision-maker to learn about SDMA’s and their role as defined by the decision-maker’s preferences.

This is a negotiated voluntary undertaking with supporters free to offer the requested support, negotiate the delivery of support, as well as decline to participate. The SDMNY model does not require supporters commit to a term of service.

Supporters who sign SDMA's pledge to provide support as described in the agreement, to refrain from acting as a substitute decision-maker, to avoid conflicts of interest and not to exert undue influence. After signing the SDMA and pledging their assistance, no additional training or coaching is planned for supporters.

In the first Australian SDM pilot undertaken by the Office of the Public Advocate, proposed supporters were expected to meet two expectations:²⁵

- Be well informed about the participants' goals
- Affirm they would offer the time needed to undertake the support role and assist participants to make their decision known.

Evaluation recommendations for the CPR-Nonotuck SDM pilot included providing supporters opportunities to share their experiences with other supporters.²⁶ SDMNY supporters may welcome the opportunity to participate in a learning community of other supporters to learn about issues and complicated situations and strategies undertaken. Sharing experiences may also increase supporter confidence in SDM as a sustainable alternative to guardianship.

The extent to which decision-makers are utilizing friends and other non-relatives as supporters was not examined in this evaluation. SDMNY staff opined that the SDMNY model has thus far only been accessible to those with natural support networks. Extending the supporter role beyond relatives, particularly parents, would:

- Allow aging relatives to pass on or "retire" from their role as supporters with less anxiety;
- Broaden access to SDM for people who may not have involved family or who are socially isolated; and
- Reduce vulnerability to abuse, neglect and exploitation by having wider social networks.

"I don't believe that as currently designed, the SDMNY facilitation process can have a major impact on the lives of persons with IDD without preexisting natural support networks. To address this limitation I would personally recommend that, just as we have secured OPWDD's approval for decision-makers to use self-direction funds to finance facilitation services to develop SDMA's, we should also work towards finding ways for future decision-makers without natural supports to use either self-direction or traditional funding streams to hire (and fire) persons specifically tasked with providing decision-making support. Especially since many prospective

decision-makers without natural supporters reside in restrictive or under-inclusive settings, I believe that they should have opportunities to hire peers (i.e., self-advocates) as supporters. This possibility would enable them to have regular contact and form meaningful relationships with experienced self-advocates who could not only support their decision-making but also foster their empowerment. In this way, SDM might become a vehicle for enhancing the interconnectedness and autonomy of both persons with IDD.” –SDMNY staff

SDMNY Recommendations

Find ways to offer SDM to decision-makers who do not have trusted people in their lives available to take on the role of supporters. Test using self-direction or other funding streams to finance paying for decision-making support, particularly other people with IDD (e.g., self-advocates) as supporters.

SDMNY Pilot Safeguards

Abuse, neglect and financial exploitation are a widespread problem for people with disabilities. A 2012 national survey by the Disability Abuse Project found that more than 70% of people with disabilities have been victims of abuse.²⁷ The CPR-Nonotuck SDM pilot evaluation examined whether use of SDM instead of guardianship had increased decision-maker vulnerability to abuse, neglect, or exploitation. Evaluation respondents (including decision supporters, family members, and provider case managers) viewed SDM as reducing risk and vulnerability, especially where multiple decision supporters were utilized.²⁸

Stressing Best Practices Through Outreach

SDMNY outreach and educational sessions are, according to staff, an avenue for discussing concerns regarding potential abuse, neglect, and financial exploitation. During information sessions, the Project Director, a retired judge who reviewed guardianship petitions while on the bench, asks audience members if guardianship truly protects individuals from exploitative experiences. Then she notes, *“the incredible persistence of the belief, with no empirical evidence, that only guardianship protects,”* and shares information on the abuse, neglect, and financial exploitation of people with disabilities, including those under guardianship. Audience members are advised that court oversight of guardianships, which many believe protects the person under guardianship, is minimal if not nonexistent.

During information sessions, the Project Director places guardianship in historical context, as the most recent form of protective intervention after institutionalization was rejected as the professionally recommended form of protection for people with IDD. She describes the

evolution of best practice thinking which now embraces legal personhood and full citizenship of people with disabilities.

“People have found the historical information especially useful and compelling, especially as it allows us to not blame anyone who thought about, or actually did guardianship. It was the only alternative they were given to protect their kids or loved ones. It’s also great now to have supporters and parents who have been through the SDMNY process give their heartfelt testimonials.” –SDMNY staff

SDMNY information and outreach sessions also stress the dignity of risk as a critical dimension of SDM and an important human experience. Presenters advise that decision-making is a skill, and that practice leads to increased skill, as does having input from others to help inform decisions.

“Rather than focus on proving that SDM makes decision-makers less vulnerable to certain risks, SDMNY has endeavored to convince those it has reached that SDM makes decision-makers better equipped to face and avoid those inevitable risks.” –SDMNY staff

Important to SDMNY viability is instructing audience members to anticipate decisions they do not agree with:

“SDMNY in various ways encourages those it reaches to embrace the “dignity of risk.” It helps reduce the likelihood that program participants become disillusioned with the facilitation process.” –SDMNY staff

SDMNY sessions educate the public to consider SDM as a means for individuals with IDD to be empowered to make decisions and steer their life paths, and to cultivate relationships that will make them less vulnerable to abuse, neglect, and exploitation.

SDMNY Facilitation Process as Safeguard

SDMNY staff consider the SDMA facilitation process and the SDMA to provide foundational safeguards. People with IDD and supporters learn to speak up should abuse, neglect, exploitation occur, be threatened, or suspected. In this and other SDM pilots, people with IDD who learn about their human rights, receive coaching on speaking up, and experience their decisions respected by others, have experienced greater self-advocacy and speaking up. (This evaluation provides evidence of positive impacts in the section entitled “SDMNY Impact”).

Supporters as Safeguard

SDMNY information sessions convey that a risk factor for being taken advantage of is social isolation and that reliance on fewer people puts people with IDD at higher risk for abuse, etc.

Safeguards for Supporters

In terms of safeguards for supporters, the SDMA template informs the decision-maker that she has responsibility for decisions. Should a third party accept an SDMA decision and something untoward result, supporters should be free of any liability. However, in the absence of statutory guidance, potential liability remains uncertain.

Another SDMNY initiative planned for Year 4 is the creation of online forums for decision-makers, and separately, for supporters, to assist one another by sharing experiences, resources, and problem solving.

Concerns, Complaints, Disputes Among or Between Supporters and/or the Decision-maker. During this pilot stage, SDMNY-related dispute resolution is through the Senior Project Coordinator. Decision-makers and supporters are given the Senior Project Coordinator's telephone and email for raising concerns about the facilitation process. For concerns or problems after SDMAs are signed, there is not yet an established complaint resolution process or responsible entity, though planning is underway to establish these resources. To date, SDMNY staff are not aware of any issues or problems after an SDMA has been signed.

To compare, in Alaska, concerns and complaints related to SDM are directed to the adult protective services agency. For the South Australia pilot, all participants in the pilot were given information about the Office of the Public Advocate's Complaint Policy. In the CPR-Nonotuck SDM pilot in Massachusetts, those who adopted SDM were advised that they would be able to utilize the legal services of CPR to resolve SDM-related legal problems. For non-legal problems that did not rise to the level of suspected abuse, neglect, or exploitation, SDM complaints were to be worked out by the care manager, individual with IDD, supporters, and service providers. Abuse and neglect concerns were to be reported to a state agency, the Disabled Persons Protection Commission.

Additional Safeguards Planned

Professor Rebekah Diller, of the Benjamin N. Cardozo School of Law, presented at the 2019 National SDM Symposium hosted by the National Resource Center on Supported Decision-Making. Her remarks primarily addressed consideration of SDM for older adults and included a list of protective components built into various statutes and pilots.²⁹ These included:

- Voluntariness

- Eliminating conflicts of interest
- Accountability
- More than one supporter
- Monitors of the SDM arrangement
- Facilitators for developing an SDM agreement
- Education and training of SDM participants
- Responsibilities and fiduciary duties of supporters
- Recordkeeping
- Reporting and administrative oversight

SDMNY staff are cognizant that while some safeguards identified by Professor Diller are in place (i.e., voluntariness, facilitated SDMA development, education of SDM participants, etc.), more structure is needed to fully operationalize appropriate protections and buttress permanency and sustainable safeguards into the future.

“If and when there is legislation, it should include a provision similar to that in the SDMA laws of states that have passed them, that third parties who have reasonable cause to believe that the agreements are being misused or there is abuse, neglect or undue influence can and should report it to the appropriate adult protection agency. In terms of safeguards for the supporters, the SDMA provides that the decision-maker takes responsibility for her/his decisions, so if a third party accepts the agreement, and things go South, the supporters should be free of any liability.”

SDMNY is creating a mediation protocol for resolving conflicts between decision-makers, supporters and/or third parties in collaboration with the Mediation Clinic at CUNY Law School during the fourth year of the grant. For dispute resolution after the grant ends, staff report that SDMNY is forging a partnership with the state’s court-affiliated but independent CRDCs. These Centers exist in every county and provide trained volunteers for dispute resolution and conflict coaching. SDMNY staff envision that challenges related to SDM will be handled by CRDC volunteers who will receive additional training on SDM.

Evaluation Finding: Safeguards

- SDMNY has established important initial safeguards. For long-term SDM sustainability, additional safeguards are needed related to use of SDMAs including reporting and examination of complaints and concerns (e.g., undue influence by a facilitator, mentor, or supporter, or a third party not honoring a decision), and for reporting and investigating possible abuse, neglect, or financial exploitation.

SDMNY Outreach & Decision-Maker Recruitment

To recruit people with IDD, SDMNY initially planned outreach to students transitioning out of special education programs in NYC schools as well as to service providers, and referrals from Disability Rights New York (DRNY), the state Protection and Advocacy agency.

As mentioned, the five-year grant requires SDMNY to recruit at least 135 people with IDD for its pilot programs. The Diversion pilot aims to avoid guardianship for 90 people, and the Restoration pilot to recruit 45 people under guardianship. Between January 2017 and March 2019, 79 individuals with IDD signed up for one of the SDMNY pilots, 58 in Diversion and 21 in Restoration; however, 10 withdrew after signing up. As of May 2019, 8 decision-makers have fully executed SDMAs (7 Diversion, 1 Restoration). None have yet experienced a restoration of rights, although one decision-maker is represented by DRNY in potentially pursuing that goal, and another decision-maker began the SDMNY facilitation process after his guardianship was discharged.

Surveyed SDMNY staff note that outreach has been directed to a more diverse pool of individuals with IDD than other SDM pilots in the U.S. They report that SDMNY recruitment was aimed at people with more significant impairment, including those who communicate without using words, and to those with diverse ethnic and racial identities, socio-economic backgrounds, and experiences.

“No model to date caters to such a diverse audience, and the challenges and successes of this model will influence the development of models elsewhere.”

“We also go beyond what might be seen as a willingness to confine supported decision-making to the ‘highest functioning’ people with IDD, insisting on the right to legal capacity for all, and working with people with more significant impairment, non-verbal decision-makers, etc.”

Although this evaluation did not examine the personal characteristics of decision-makers, demographic information was requested of guardian and potential guardian evaluation respondents. (See page 43 for information about family member evaluation respondents.)

Staff report it has been more difficult and time consuming to recruit decision-makers than expected:

“It can often take 2-3 months from the time of an info session for recruitment of DMs until sign-ups actually take place. People need time to think about and process the information before agreeing to participate.”

From January 2017 through March 2019, SDMNY held over 40 in-person decision-maker recruitment events for audiences of persons with developmental disabilities, family members, and professionals (e.g., lawyers, educators, and service providers). In-person information sessions reached over 700 attendees. SDMNY staff also conducted education and outreach, including webinars and conference presentations, to educate stakeholder groups about SDM as an alternative to guardianship. Through Year 3 of the grant, SDMNY information and outreach sessions reached over 4,250 people.

SDMNY staff prioritized recruitment activity across three stakeholder groups: prospective decision-makers, family members, and professionals in the IDD community. As necessary as it is to educate the public, resources are limited, and outreach energies need to be strategically planned. One-time sessions, SDMNY staff realized, were, “...next to useless in generating decision-makers.” More success recruiting decision-makers resulted from developing relationships with organizations over time. “Building relationships and trust takes a lot of time but turns out to be really necessary.”

Most successful was building a relationship with the Cooke School, a special education school for youth through age 21. Although here too recruitment was slow and time consuming. SDMNY staff initiated ongoing, continual conversations with school personnel, both administrators and teachers, in order that all school staff, not just transition coordinators, understood the potential benefits of SDM for persons with IDD. Once awareness of SDMY philosophy and its importance for self-determination was conveyed to educators, SDMNY staff held information sessions for parents and, simultaneously, for students. As students enrolled and passed through the facilitation process, word spread, and more parents and students learned about SDMNY and were interested. A helpful strategy to increase recruitment was when a school invited SDMNY to present and, after the presentation, school personnel reached out to encourage attendees to follow up with SDMNY. Where there was personal encouragement, sign-up rates were higher.

Outreach to self-advocacy groups is considered moderately successful by staff, with at least one person signing up per session:

“That has been an important lesson and suggests (gratifyingly) that SDMNY has designed a process and developed a message that is readily understandable by and attractive to self-advocates, our primary stakeholder group.” –SDMNY staff

SDMNY staff report that the presence of people with IDD in the room is helpful when illustrating the utility of SDM:

“Many times, the folks in the room don’t actually understand the concept of decision-making, so opportunities to brainstorm about easy decisions, hard decisions, everyday decisions and creating a conversational dialogue are appealing.”

Staff realize the contributions of people with IDD at information sessions; at the time of writing, however, outreach and recruitment sessions had yet to include a paid self-advocate presenter.

Referrals for those with guardianships have been rare:

“Those referred by the court system in some cases appear to be frustrated with the project, as they have interpreted the project as being a reason for why their 17-A guardianship petition was denied.” –SDMNY staff

Somewhat successful were presentations to lawyers, through the bar association, and to judges, through the Surrogates' Association. Future outreach plans include court clerks who are responsible for processing guardianship applications, as clerks are often an initial source of information about guardianship for potential petitioners.

SDMNY also conducted outreach to service providers throughout NYC. Provider information sessions did spread the word to staff but did not yield SDMNY referrals.

“When we delivered info sessions to agency providers, often the personnel viewed the presentation as professional development, and did not lead to direct results for recruitment of decision-makers.” –SDMNY staff

The 20 family members (potential guardians and guardians) interviewed for this evaluation described how they (or the decision-maker) first learned about SDMNY. Potential guardians reported that school and self-advocacy organizations presentations were the more frequent path to SDMNY enrollment. For guardians, presentations to self-advocacy organizations (i.e., direct presentations to people with IDD) yielded the greater number of signed up decision-makers. Table 3 below displays the outreach events where evaluation-involved family members learned about SDMNY.

Table 3. Decision-Maker Recruitment

Outreach Method	Potential Guardians (Diversion pilot)	Guardians (Restoration pilot)
School presentation	7/15 (47%)	0
Self-advocacy organization presentation	5/15 (33%)	3/5 (60%)
Other presentation venue	2/15 (13%)	1/5 (20%)
Person assisting with guardianship	1/15 (less than 1%)	0/5
Do not remember	0/15	1/5 (20%)

Primary Barriers to Outreach and Recruitment

According to SDMNY staff, the most significant challenges to recruitment are a lack of legal standing for SDM, belief that guardianship is necessary, and a sign-up procedure.

Lack of Legal Standing

SDMNY staff view the absence of legal recognition for SDM and SDMA in New York State as a primary factor that discourages prospective potential guardians and guardians. State agencies such as the Office for People With Developmental Disabilities (OPWDD) and the Department of Education (DOE) also have yet to officially recognize SDMA. Without legislative or policy grounding in New York, a doctor or banker or landlord, etc., could refuse to accept a decision made using SDMA. This is a deep concern to parents.

Without statutory authority SDMNY may not offer enough practical value, as highlighted in this staff quote:

“Although I believe that the facilitation process and SDMA occasion important conversations and yield unique understandings about decision-makers’ relationships with supporters that inhere regardless of the legal weight afforded an SDMA, many service providers and some family members seem primarily concerned with the day-in and day-out of supporting persons with IDD in other more concrete ways, such as obtaining and maintaining benefits and services, whereas investing time and energy in enhancing more abstract aspects of a person’s life, such as autonomy, can take a backseat in their minds.”

Belief That Guardianship Is Necessary

Another significant barrier to SDM adoption that staff identified is the belief that guardianship is necessary, and a wrap-around protective intervention:

“Parents and other potential guardianship petitioners, and guardians themselves, have been told this over and over, by multiple sources, over many years. It’s hard to break through. But as we have a growing number of success stories, and parents and decision-makers who can attest to the process, we are beginning, just beginning, to break through.”

SDMNY staff address these challenges by laying out the need for SDMA legislation and legal standing for the process and the signed agreement. They explain that the experience and successes of SDMNY will be used as evidence to secure legislative recognition. And as mentioned in the prior section, information sessions share the history of various methods society has used to protect people with IDD, including placement in institutions, to guardianship, to SDM. Sessions present examples of guardianship as an imperfect form of

protection, explaining the risks for abuse, neglect and financial exploitation that can and do occur under guardianship, and in some instances, by guardians.

Surveyed SDMNY staff understand that there is more work to do to inform the public about the existence of a robust alternative to guardianship and to engage people with IDD and their families in SDMNY. To sustain SDMNY into the future, SDM must be taught and utilized at various points in school, starting in elementary school and building SDM into transition programs and curriculum. Educators and others need additional information to understand what guardianship entails: a permanent loss of rights and legal personhood, and potentially limiting the development of a person with IDD's sense of self and full community membership.

SDMNY Procedure

The other primary recruitment barrier identified by staff stems from a sign-up process. Following information sessions, interested individuals are not signed up on the spot. Instead, SDMNY staff schedule a one-on-one meeting with each prospective decision-maker, and in many cases, with one of the decision-maker's family members. Staff report that often, "life seems to get in the way" of arranging the follow-up one-on-one meetings. And even after one-on-one meetings occur, there have been significant delays in retrieving the consent forms to complete sign-up.

For Consideration - Consider SDMNY sign-up immediately after an information session. One-on-one meetings to discuss details can still be part of the process and provide an opportunity to withdraw.

Evaluation Findings: Outreach and Decision-Maker Recruitment

- Recruiting people with IDD to SDMNY required more effort and time than anticipated. Referrals for those with guardianships have been rare.
- The most significant challenges to recruitment are a lack of legal standing for SDM, a widely held belief that guardianship is necessary, and the SDMNY sign-up procedure.
- More successful decision-maker recruitment resulted from developing relationships with an organization over time. SDMNY and a special education school formed a successful partnership that utilized these strategies:
 - First, educate and inform school administrators and teachers about SDM.
 - Host separate but contemporaneous information sessions with family members and students.
 - After an information session, school personnel reach out to encourage specific people to follow up with SDMNY.

Guardian & Potential Guardian Experience

Participating in this evaluation was voluntary and open to all family members with an SDMNY-enrolled decision-maker between December 2018 and May 2019. Family members of decision-makers participating in the Diversion pilot are referred to as “potential guardians.” Family members of decision-makers participating in the Restoration pilot are “guardians.” Potential guardians are being diverted away from guardianship through adoption of SDM, and guardians, it is hoped, will find confidence in SDM and be willing to petition the court to relinquish guardianship and restore decision-makers’ rights.

This evaluation explored the opinion and experiences of SDMNY-involved guardians and potential guardians regarding the following research areas:

1. What concerns or advice led you to consider guardianship, or to become a guardian?
2. What led you to become involved in SDMNY?
3. In what ways has the SDMNY process in this pilot addressed or reduced concerns that led you to consider guardianship or to become a guardian?
4. From your perspective, how has participating in this SDMNY pilot affected or changed the individual with IDD?

Evaluation respondents were potential guardians (n=15) and guardians (n=5) of decision-makers involved in SDMNY. Telephone interviews took place from Feb. 1, 2019 through May 5, 2019.

This evaluation presents quotes from potential guardians and current guardians who gave specific consent to use their words in this evaluation report. Many gave permission to use their names as well. For consistency, however, the evaluator chose not to identify respondents by name. Additionally, when respondents mentioned a decision-maker’s name, that identifier has been removed.

Personal Characteristics of Guardians and Potential Guardians

One of the funder’s expectations for SDMNY was that people with IDD adopting SDM would be from various walks of life and demonstrate the use of SDM for those with diverse backgrounds and abilities. While this evaluation did not collect demographic information about decision-makers, guardians and potential guardians were requested to disclose personal demographic information about themselves. Demographic information was voluntary to disclose; all participating guardians and potential guardians were advised of this and provided additional consent to share their personal information for this evaluation report.

Guardians and potential guardians identified predominately as: parents of the decision-maker, White/Caucasian, as non-Hispanic or Latino, English as primary language, and currently living with the decision-maker. Potential guardians were nearly twice as likely to live with a spouse or partner and almost three times more likely to live with both the decision-maker and other children. While more diversity is demonstrated in the potential guardian pool than those serving as guardian, three times more potential guardians than guardians participated in this evaluation. Information collected about the personal characteristics of guardians and potential guardians is displayed in Table 4 below.

Table 4. Personal Characteristics of Guardians and Potential Guardians

Characteristic	Guardians (n=5)	Potential Guardians (n=15)
Age	Range: 33 to 77 years old Average age: 57 years old	Range: 40 to 70 years old Average age: 55 ½ years old
Race	White 100% (n=5)	White 64% (n=9) Black 7% (n=1) Hispanic 14% (n=2) Mixed race 14% (n=2) 1 declined
Ethnicity	Not Hispanic or Latino 100% (n=5)	Not Hispanic or Latino 71% (n=4) Hispanic or Latino 29% (n=10) 1 declined
Primary Language	English 100% (n=5)	English 93% (n=14) Spanish 7% (n=1)
Legal Status/Relationship to Decision-Maker	Guardian 100% (n=5) - Parent n=4 - Sibling n=1	Parent 73% (n=11) Sibling 13% (n=2) Other Relative 13% (n=2)
Lives with Decision-Maker	40% (n=2)	79% (n=11)
Lives with Spouse or Partner	20% (n=1)	71% (n= 10)
Lives with Other Children (excludes Decision-Maker)	20% (n=1)	57% (n=8)
Works Outside the Home	60% (n=3)	60% (n=9)

Pressures to Pursue Guardianship

One of the principal evaluation research areas was to explore the concerns and influences that lead parents and other family members of individuals with IDD to consider guardianship or to become a guardian. While not all family members are persuaded to secure guardianship or to seriously contemplate guardianship, all conveyed that guardianship is presented as the recommended path by multiple sources. Most influential in guiding family members toward guardianship are other parents of children with disabilities, schools, and health care providers.

Guardian's Reasons for Pursuing Guardianship

Guardians stated that they understood it was their responsibility to protect their adult children or relatives once they became legal adults and were advised guardianship was the way to accomplish this. Guardians did not understand there was a choice not to become guardian. Concern about not being able to help make medical or financial decisions steered some family members to secure guardianship. One family member secured guardianship to keep the State out of her family member's decision-making.

"Yes, 10 years ago, when [name] turned 18, it's what people did. When you turn 18 you get guardianship. There was no gray area. No one said, hey [name] might not need a guardian. Now we know differently."

"There was not a viable choice at that time. It was sort of a package, all or nothing. We've tried to look at things and be proactive and this was one more thing to be proactive about. We've had very good support from our service provider, CFS. And this was just one of those things, we were aware of, so that when he was suddenly 18. Probably what drove it was access to medical information. [Name] could not make medical decisions and we didn't want him to be in a situation where he couldn't give consent. And we wanted to have access to his medical information. There was also concern that he wouldn't have made good decisions in some financial decisions."

"I didn't want the State to have control over him. He is a vulnerable person. He doesn't use verbal language and he's someone who, without someone overseeing, would be vulnerable. I am not an immensely trusting person of the State."

Potential Guardians Who Did Not Consider Guardianship

One-third of potential guardians stated they have not considered guardianship (n=5/15, 33%). Their reasons are varied but have in common a theme of not hindering their family member's independence or the learned experience that comes from making one's own mistakes. Below are some of their comments.

"No, we are working so hard to make him independent, to cut off his rights is not right for us. And the other thing is that we are a family of three; we don't have more family. That is why we are working hard to make him as independent as he can be."

"We always were very protective of him. We like him to have his independence. Unless something goes wrong with him, if he can't speak for himself, if he needed one of us to do something for himself, then we allow him. We treat him as if he doesn't have a disability. He can manage his own decisions. If we disagree, we let

him know we disagree; we tell him. We allow him to make mistakes. You learn from mistakes. We let him handle it. He is very stubborn when his mind is made up. We let him learn from his mistakes, because the same thing keeps happening over and over, because he wants his independence. If we mentioned guardianship to him, it would be like we're taking things away from him. In contract (SDMA), whatever decision he makes no one can interfere with it. If he doesn't like it, he'll call me, he'll call one of us."

"I could not accept the thought of him having to ask his guardian for every little thing he wanted or needed, knowing he is capable of making his own decisions. Couldn't swallow thought of him asking for money."

Potential Guardians Who Considered Guardianship

Most potential guardian family members stated they have considered guardianship (10/15 respondents, 67%). They described being influenced by:

- Advice that guardianship ensures involvement in medical care or financial affairs.
- Advice that guardianship is necessary should an emergency or crisis occur.
- Advice from schools, health care providers, and other parents with children with disabilities to secure guardianship when youth with IDD become legal adults at age 18.

Guardianship is only presented as a helpful intervention, a step to adulthood, devoid of negative consequences.

Potential guardians reported the recommendation for guardianship is often framed as necessary to be involved in medical or financial decisions, as well as to be involved in the case of an emergency. They are told scenarios that scare family members. Below are statements by potential guardians illustrating these pressures.

"Because all the people in school system advised that. Some of the doctors like the neurologist also advised us. We initially thought we would do this because of things they made you think about. They say scary things like what if a medical issue comes up and something needs to be done, but she doesn't understand and doesn't want the care. She could jeopardize her health. Or that someone could take advantage of her by selling her a service. The idea was guardianship would protect."

"I knew [name] would need support in making decisions for himself and thought guardianship was the way to go about it. When we had an evaluation done, the GAL was respectful, but she never said we are taking rights away. We were told this is the only way we could help him make decisions. There is misinformation out there about guardianship. One thing you hear is that if you don't have guardianship then

you won't be able to participate in your son's care or life decisions such as in an emergency. If there is an emergency and you aren't guardian, then there is nothing you can do. I'm a nurse. I know that's not the standard of care. I don't think I wouldn't be included. Information about guardianship was attached to very emotional, extreme situations. You hear about your child being preyed upon and taken advantage of if you don't get guardianship. It was like one of the 5 things to do, check the box."

Potential guardian family members report receiving recommendations from multiple sources to secure guardianship: "Everyone saying the same thing: the school, SSI, other parents." As shown in Table 5, pressure from other parents with children with IDD, health care providers, and schools are the primary external sources of influence. Service providers and financial institutions rarely if ever recommended guardianship to these family members.

Table 5. External Sources of Influence Toward Guardianship

Sources of Guardianship Recommendations	Yes Recommended
Other parents with children with IDD & from one's own family	7/15 (47%)
Health care providers	6/15 (40%)
School, teacher, transition coordinators	6/15 (40%)
Disability service providers	0
Banks / financial institutions	1 (less than 1%)

Influence of Other Parents with Children with IDD

Most commonly mentioned was the influence of other parents who have children with IDD. However, their influence is not unidimensional but comes in many forms. The comments of potential guardians below illustrate some of the permutations.

"I have two groups of parents. A group of urban, well-educated parents with children the same age. We have discussed this. Some are doing guardianship for medical care, but of very high functioning young adults. So I was surprised. I was thinking, "Am I slow? Am I missing something?" In another parent group, of suburban parents, one parent told me the guardianship process was upsetting. She said, "I was crying. I felt terrible; but I did it." So I have learned little by little. I just learned guardianship is reversible. And they are growing. At 20 years old I'm not sure what she is capable of yet. She is showing promise. Why do guardianship at a young age when they are becoming a person in society? Why not wait until they are 25 or 30? They start talking about this when 15 years old. It's too early."

“Yes, other parents were definitely guiding you, in support groups, in workshops. As a parent you are trying to digest your child’s disability. You are absorbing information from other parents to understand your child. It’s so overwhelming. You want what’s best, so yes, you are going to accept guidance from other parents who have already gone through this.”

“In general, it’s the ‘You have to have guardianship,’ and ‘You have to take care of them.’ Other parents were not pushing me, but in conversation it’s the expectation. When I learned about guardianship I thought, ‘I can’t do it,’ and thought I was that terrible mother, and would sit there quietly.”

“Everyone thought guardianship was what we had to do. There was no other conversation about decision specific capacity; it was an all or nothing. I felt we needed to do guardianship as there were no alternatives. It was the next step. We have parents with children who were a bit older in school for special ed, and we got the message from them guardianship was the next step. When [name] was turning 18 we pursued guardianship. We found out what was needed, got a lawyer, had a guardian ad litem and evaluations to get guardianship. Then, right around the same time, I went to a SDMNY presentation and put everything guardianship on hold and started SDM.”

“Some families did it themselves and others said you have to have a lawyer. So many questions about the process. Did child need to be in court or not? Person really doesn’t know; it is just the next protective step. Never expect people to talk to their child about it; just did it. No one said we are going to take away your rights; not that we are taking your rights away. No push back when we went SDMNY and changed minds and it was just okay. Especially as this was the only thing to do.”

School Influence

Schools convey a wide array of—and sometimes conflicting—messages to family members, from promoting self-determination to guardianship. One potential guardian mentioned that the school her child attended promotes self-determination and retaining rights:

“No, they (school transition coordinator) said he can make his own decisions. The more he tries, the more experience he gets, and the more responsible he’ll be. We hope he will be fully independent with assistance.”

More typical for evaluation respondents were school recommendations to secure guardianship. Forty percent of potential guardians stated they had been advised by school personnel to secure guardianship. The recent National Council on Disability report, *Turning*

Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities refers to the critical role schools play in promoting guardianship. Called the ‘school-to-guardianship’ pipeline, the report conveys that states’ educational systems actively encourage guardianship and do not advise of less restrictive alternatives.³⁰

Potential guardians stated the influence of schools comes in many forms. Guardianship is listed as a step on a transition checklist and schools host workshops advising family members on how to secure guardianship. Examples of school influence toward guardianship that potential guardians experienced is shared below.

“Didn’t say you have to but gave you a checklist from age 14 to 21 and guardianship is on it as a step. They were adamant that this is what parents do.”

“The transition process is for guardianship.”

“I had applied for guardianship and 5 days before court date, I ended up going to an SDM workshop. I didn’t know the option existed. I had done all the guardianship evaluations, petitions, and taken the day off work. I pulled the petition and entered the project. Because I was misinformed. When [name] was a child, I was not in the mental health field then, I was always told in order to protect your child when she turns 17, I had to start the guardianship process. But I didn’t understand the ramifications, that I was removing or eliminating her constitutional rights. That was not explained to me. It was always in my mind. When you meet other parents at workshops, they are mingling, talking, saying, “Yes, I started the process.” Every year District 75 in NYC, they have a guardianship workshop and I started attending when [name] was 15 so I could be ahead of the game. They bring in a guardianship lawyer who gives you the how-to on guardianship and all the steps. It’s very instructional. I just followed the steps.”

“Cooke (school) is wonderful sharing information with parents and students. We had been to workshops on guardianship a couple of times.”

“Parent workshops from age 5 at school, at public schools, District 75 school for autistic kids.”

Health Care Provider Influence

Forty percent of potential guardians reported being advised by health care practitioners to secure guardianship. These family members conveyed that health and behavioral health care providers sometimes see themselves as being helpful when determining a person with

IDD is incompetent for a guardianship petition. As described in the stories below, accommodations to assist the person with IDD in understanding the assessments and engaging in due process before their rights are removed appear to be absent. Health care providers appear to be motivated to help secure a guardianship and may not understand that a lack of notice regarding assessment and lack of communication accommodations are forms of discrimination.

“For the guardianship, we had an evaluation, a psychological, and they never met person before and do it in an hour and are not interested in best response. We lined it up with YAI. Actual psychiatrist came in and asked [name] about health care decisions and life support and would that be something he wanted. These questions were out of the blue, with no context and no accommodation. Practitioner did not try to help my son understand, so of course they could say he couldn’t understand a living will and so couldn’t make decisions, and this would surely support our guardianship application. One of the many examples of ways things are not constructed to help him be whole, be supported. No one is acknowledging the limits of the assessment; it’s not about helping him flourish. Questions are out of the blue. A discombobulated exam to show he doesn’t understand. They’re not looking for him to understand. So when I heard about SDMNY—I have a background in patient self-determination and decision-specific abilities and honoring participation and agency and autonomy—we pulled guardianship and pursued this. And it has been fantastic. Helped turn our mind and heart for him. So much on our minds of what we needed to do for him instead of what we need to help him do for himself. He needed practice to think about his preferences and his responsibility. Guardianship did not include him much. That is about us [parents] being scared—focusing on dependence, transition. Guardianship lens is different than shared decision-making and SDM. SDMNY is resource intensive and coaching repetition over time. To help person see themselves as a decision-maker and integrate that in their lives.”

“We had one doctor, a neurologist who worked with [name] since she was a baby. When [name] was younger, this neurologist was so positive about our daughter. But as she got older, we were turned off with the neurologist. We had paperwork for the guardianship and gave it to her. Part of the papers are about going to court, and neurologist said, “Oh no, she is not going to understand anything, and it would just make her anxious.” I looked at this doctor in a new way. She is a well-known neurologist working with autism. We went to a special needs attorney who did some paperwork, including a Will, and he mentioned guardianship, and said, “You have to do that.” He has children himself, but he doesn’t know my daughter. He never met her, and he also said, “She won’t understand.” So I had my doubts that it was a good idea. But when I thought about it, I thought mitigating factors would lessen those scary things from occurring. Such as right now, I’m involved in her life. She is not

one to ignore our advice or guidance. I thought we'd be involved. She would trust our advice to some degree. And there are other documents that one can do, a health care proxy, where we can be involved, and she would trust our opinion."

As this last quote illustrates, health care providers may not be aware of alternatives to guardianship or know how to respond when families advise that supported decision making is being utilized:

"When our old pediatrician retired and we went to the new one, the first thing he asked was 'Do you have guardianship?' I tried to explain that we were trying something different, SDM, but felt he wasn't interested in hearing about it at that time."

Guardianship as a Prerequisite for Service

This evaluation examined whether potential guardians experienced pressure from health care providers, school systems, disability service systems, or financial institutions to secure guardianship in order for a decision-maker to receive a service. Although guardianship was not presented as a condition for service delivery, several potential guardians reported being urged to secure other decision-making arrangements—one a health care proxy to proceed with a surgery, and two to become representative payees for SSI benefits. A potential guardian shared this experience: "No, not guardianship. But they wanted to assign a payee because she's in a wheelchair and not able to use her hands. People are judged by the way they look."

Costs Are Not a Factor

Guardianship is a legal process that can entail financial costs related to hiring an attorney, securing assessments, and filing documents with a court. SDMNY staff wanted to know if potential guardians were influenced to adopt SDMNY and not pursue guardianship due to costs. None were. All 15 potential guardians reported that costs were not an influential factor, though for different reasons. Potential guardians either knew ways to self-file (without using an attorney), viewed petition-related costs as just another cost of having a child with a disability and something you must do, or did not know there were costs associated with filing a guardianship petition. Several potential guardians stated that in New York there are institutions that aid family members with filing a petition, including school systems and local Arcs.

"No, cost consideration but didn't drive our decision, and there was a way to do it without attorney. But it was another reason not to do it. Also you hear all these stories about going for guardianship and the judge may turn you down, or if you get a certain judge you won't get guardianship or you'll get a different type, or if your

name falls at a different end of alphabet, you will get a judge that may or may not have your child's interest. It didn't sound like [name]'s interest were of concern. SDM is in the center of what is in [name]'s interest." –Potential guardian

Evaluation Findings: Pressures to Secure Guardianship

- Guardians did not understand there was a choice not to become guardian.
- While not all family members were persuaded to secure guardianship or to seriously contemplate guardianship, all conveyed that guardianship was presented as the recommended path by multiple sources.
- Most persuasive in guiding family members toward guardianship are other parents of children with disabilities, schools, and health care providers.
- Family members are advised that guardianship is necessary to be involved in medical and financial decisions and to help in the rare case of an emergency. Family members report that stories they are told are intended to instill fear and are effective.
- School pressure toward guardianship appears pro forma and not an individualized recommendation. Some schools list securing guardianship as a step in transition to adulthood and host workshops that teach parents how to secure guardianship.
- Health care professionals and special needs attorneys may recommend guardianship without knowledge of an individual, conduct assessments without accommodation, and dismiss the capability and rights of a person with IDD.
- Guardianship was not presented as a condition for service delivery by health care providers, school systems, disability service systems, or financial institutions. Several potential guardians were pressured to secure less restrictive decision-making interventions (health care proxy, representative payee).
- Costs related to guardianship are not a significant factor for family members deciding whether to pursue guardianship.

Guardianship Is Not Well Understood

For many families, guardianship is not a thoroughly understood undertaking. What is and is not covered by guardianship is not clear. A number of evaluation respondents shared their frustration with the lack of concrete, daily life distinctions between what guardianship can and cannot address, as well as what SDM can and cannot address. Below are statements illustrating the confusion, discomfort, and frustrations that family members experience trying to navigate the challenging landscape that is guardianship.

"Because my understanding, what was explained to me, was that if she could not advocate for herself, and if I wasn't guardian, then I could not make decisions for her. So I needed guardianship to assist her with medical care, income, with decisions. As a parent I am to advocate for her. You are being told this since your

child was 5 years old. My daughter has progressed. Her IQ is still within 50 but she has developed a personality. It's a skill set to make decisions and her preferences have been cultivated. And no one has told us this is what you have to cultivate."

–Potential guardian

"What is and is not covered by guardianship is raised through the SDMNY process. Now I am much less concerned than I was. I had a very good lawyer who got to know [name], and if I were to do this again, it would have been good to understand breaking those things [less restrictive options] out separately. It would have made sense in conjunction with the SDM process. In world of best practices all the options would be given to you when your kid was 15 and we could have involved future agents in our place and involved them in the process. Our process would have been very different if more comprehensive pieces earlier on. So many parents haven't planned, and kids get to 18 or 19 or 21 and the easiest thing to do is to get guardianship as they are frightened of not getting medical information. We were proactive and we still ended up in this guardianship process. One of the problems is the education system being the locus for disseminating information about transition. People get pushed off a cliff as there is no consistency from school to school or to foster independence and skills people will need to use. You get a medical diagnosis, they may send you to social services, then to the educational system, and it keeps going on. There's no connection between creating jobs and supporting people or those going on to higher education. It's not just job skills, it is also social skills that aren't taught along the line. SDM is just one piece of a much bigger pie. People should be getting prepared for SDM all along. It's self-advocacy preparation." –Guardian

Guardianship Removes a Person's Rights – News to Me!

Guardianship entails removal of the person with disability's legal rights. Guardians and potential guardians participating in this evaluation were asked if they were aware that imposing guardianship entailed loss of rights for the decision-maker. The majority of both groups (60%) reported awareness but not a real understanding of what loss of rights means in daily life.

In New York State having a guardian means a person with IDD loses all legal capacity to make decisions about their life, including decisions about their health and health care, their finances, what kind of education, who to associate with, where to live, who to live with, and where to work.

Potential Guardian Awareness That Guardianship Removes Rights

More potential guardians said they were aware that guardianship entailed a loss of rights than those who did not (62% v 38%). But even those who knew that rights would be removed did not fully realize what the removal of rights meant. Some potential guardians, aware of the loss of rights, felt they had no choice. Typical were these expressions of frustration with the lack of reliable, thorough information including that guardianship entails removal of the ward's rights:

"No, they don't tell you. I slowly learned that myself. I heard a person say you can't vote if have a guardian. They use a fear tactic and they don't tell you all the negatives."

"It's never part of the conversation. It's not the definition that is given. It's because he has difficulty you need to do this to protect him. Protective intervention. When I read guardianship documents, I learned that I am speaking for him. And then after I die, his brother would make decisions for him. As a parent, you give up on things, and with guardianship, it's here is another not right thing that I have to settle with. Five years of panic for when school stops; so you plan for adulthood, but there is nothing to plan for. Planning and the anxiety is not helpful. Only guardianship is firm. There is misinformation about guardianship and about SDM. Information is still very unclear."

"Any attorney you ask will suggest that guardianship is the way to go. But then talking to parents, talking to Matt (Senior Project Coordinator), just going to seminars, when they compared what guardianship is and what it might become, I had a bad taste in my mouth about doing it. I had concern about doing it now, right now. I didn't see it as a necessity. From my viewpoint, we'd only heard of guardianship until several months ago. And what we didn't realize until digging deeper was the complete annihilation of [name]'s rights. The way we looked at the guardianship was the opposite of what we've been trying to do for [name] his whole life; it didn't philosophically align."

"When he was 17, no one ever put it that way. Parents say, "This is what we're doing. This is what we are thinking." We were all concerned about some of his decision-making rights were going to be taken away and trying to think if there were any other options. I remember really questioning the whole guardianship thing when I learned he may lose his right to vote. And he really wanted to participate in that. That was the first time for me that guardianship was not the right path for him."

Guardian Awareness That Guardianship Removes Rights

Three of the five interviewed guardians understood at the time they petitioned for guardianship that loss of rights was a consequence, but they undertook guardianship because they did not perceive an alternative. Guardians believed guardianship was necessary to be involved and make decisions in an emergency or crisis. (SDM was not an option when these guardianships were ordered.) Guardians experienced the quandary of striving for both independence of their family members with IDD and emergency protection.

“Good question. I don’t think we had considered that. We were only thinking in terms of our own philosophy which is to promote self-advocacy and independence. There was no choice. It was the whole enchilada or not. We didn’t know there was another choice. People we selected as back up guardians were people who shared our philosophy. We did understand, but our thinking was probably to have guardianship for extreme situations, for the long run, and support our wishes for his independence.”

“Kind of. Sort of. No one told me. I didn’t really think about it. I was wanting to protect him. Nobody informed me about it. Nobody spoke to me about guardianship at all. I think the school may have mentioned it, suggested it as something to do when he was turning 18; he’s 35 now. Nobody told me anything about anything.”

“I first learned about it when as I was a Medicaid service coordinator and sent to a training. They were presenting on SDMNY and I thought, “Wow this could really help [name].” ...I learned how guardianship took [name]’s rights away and we didn’t know that. [Name] is just like anyone else. He should have right to make decisions about his own life.”

SDMNY information sessions were noted by guardians and potential guardians as an important source of clear information regarding the loss of rights that is a consequence of guardianship.

Evaluation Findings: Loss of Rights Accompanies Guardianship

- Most guardians and potential guardians (60%) reported awareness but not a real understanding of the specific loss of rights that accompanies a guardianship order for those with IDD in New York.
- Guardians believed guardianship was necessary to be involved and make decisions in an emergency or crisis.

- SDMNY information sessions were noted by guardians and potential guardians as an important source of clear information regarding the loss of rights that is a consequence of guardianship.

Limited Information Regarding Less Restrictive Voluntary Decision Aids

Prior to the SDMNY initiative, supported decision-making did not exist in New York State, though a number of alternatives to guardianship have been available, such as representative payees for SSI payments, joint or limited bank accounts, credit or bank cards with predetermined limits, powers of attorney for financial decisions—and for health care decisions, people with IDD may execute a healthcare proxy.

Guardians interviewed received almost no information about less restrictive, voluntary forms of decision assistance. Just one of the five guardians interviewed stated the option for representative payee was mentioned and no other alternatives.

Potential guardians interviewed were also more likely not to have heard about one or more less restrictive alternatives to guardianship. Those who were advised of less restrictive decision aids most frequently received information about a health care proxy (53%), followed by power of attorney (40%), and representative payee (33%) for SSI benefits.

Table 6 shows the extent to which guardians and potential guardians were advised, from any source, of less restrictive interventions to guardianship.

Table 6. Guardians and Potential Guardians Advised of Less Restrictive Alternatives

Available Legal Decision Supports	Guardians	Potential Guardians
Representative Payee	1*/5 (20%)	5/15 (33%)
Power of Attorney	0/5 (0%)	6/15 (40%)
Health Care Proxy	0/5 (0%)	8/15 (53%)

*Three guardians stated they are Representative Payees, though not because it was presented as a less restrictive intervention but as a consequence of assuming guardianship. One guardian was advised about payee.

The statements below from potential guardians convey the limited information they received to other forms of legally recognized assisted decision-making available in New York, and the pro forma nature of advice to secure guardianship.

“No, at Board of Education, you have a parent coordinator. I retired from banking and stayed home. I was a parent coordinator at a preschool with special education. It was not my field and I didn’t know about autism and had a child that didn’t speak.

So I went back school, in mental health. What I learned as a parent coordinator is that your job is not to inform parents but to invite outside agencies to come in and present to parents. So, unless they ask an attorney to come in and talk to parents—unless you are related to an attorney or you know one—unless they bring in speaker to specifically talk about alternatives, you as a parent aren't informed. Her pediatrician didn't talk to me about alternatives. Her school didn't talk to me about alternatives."

"No, the Department of Education or medical providers are not promoting options. They're just making a blanket statement that people like her should not have any rights or make any decisions."

"The Medicaid care coordinator told us about SSI and guardianship, but I didn't know you could be a Representative Payee and not be guardian. It wasn't presented that way. The idea at that office was that if he needed support with SSI, that a guardian would have to do that. Not true. But I didn't know. As for Power of Attorney, there was some fuzziness around that. Health care proxy, we do that ourselves. All those in our family have health care proxies. It's the most useful document if you know a person and this is what they would want. It's flexible. And it's not a lawyer document. We do it at home, just need witnesses to sign."

"There should be more information about what guardianship is and clear up misinformation about what guardianship gets you, like you don't have to be guardian to be Rep Payee...lots of broad misinformation."

Evaluation Finding: Less Restrictive Alternatives

- Many family members (guardians and potential guardians) are not fully cognizant that alternatives to guardianship exist and were/are not able to make informed decisions about guardianship or alternatives.

Shared Values Underpin Interest in SDMNY

Guardians and potential guardians align on what led them to engage with SDMNY. It was their desire for people with IDD to have a voice, to speak for themselves, because they want to expand the network of those available to support their family member, and because they felt discomfort with guardianship. Below are statements from guardians and potential guardians regarding what attracted them to engage in SDMNY.

"I want [name] to speak up for himself and advocate for himself and what he wants."
–Guardian

“I want [name] to have as much control over his life as he can, and I thought this was a good way of doing it.” –Guardian

“Fit with our philosophy and [name] was excited about it. I’m not sure my wife still entirely understands it. Bit of skepticism. Let’s see what happens. It hasn’t really been tested over a longer period of time.” –Guardian

“I got an invite to a workshop on SDM. I’m in the mental health field and on various mailing lists. I got an invite to an SDM workshop and I cancelled my appointments and went. Then I sat there and kind of had a little meltdown.” –Potential Guardian

“Guardianship is a business, that’s what I felt at the end of day. There’s a cadre of lawyers that want you to get involved as it’s a payday. SDM doesn’t have the advocacy and legal backing. It’s a riskier path. My son is 18. He is relatively young and healthy; this is the time to do this.” –Potential Guardian

“As parents we don’t know all the answers. To the extent that we can get some assistance for doing the best thing for [name], even though we have good intentions, if we could get some advice, that would be helpful. SDM is an alternative way that is more aligned with our philosophy of what [name] can do in the future.” –Potential Guardian

“We are not going to consider guardianship, so we need to find something. And we are a lot older too. We are the adopted parents of [name]. He is our grandson. We are older to be in his life. We are always thinking when we are not here. In the moment we are having him as our main concern; always try to find some ways to make his life a little easier.” –Potential Guardian

“I said we need to put some things in place should someone pass. That [name] will be taken care of and have rights to make her own decisions. She’s doing great things now. She needs support to keep making her own decisions and have a good life.” –Potential Guardian

“I was turned off on guardianship and this seemed way to go.” –Potential Guardian

“When they said SDM gives them all the say and they choose others who will be with them. He can listen but still want to do it his way. This is exactly what I have been

waiting for. Each individual with disabilities will have their rights kept and they will make the final decision whether or not decision supporters say yes or no. Hopefully with this legal document (SDMA) no one can strip that away from him. His signature and others and contract – here we go!” –Potential Guardian

SDMNY Information Sessions Are Eye-opening!

SDMNY information sessions captured family members’ hearts and minds because making decisions with voluntary supporters aligns with their values and how they want people with IDD to be treated in the world: to have a voice and be heard. Guardians and potential guardians mentioned that several messages relayed in SDMNY information sessions made deep impressions:

- Guardianship permanently removes rights including the right to vote and make decisions about one’s own life.
- Risk-taking is a normal human experience that people with IDD also need to experience.
- Best practices change over time. Current best practice is to honor the human rights of people with disabilities, including use of customized, voluntary decision assistance such as SDM instead of guardianship.

The former judge’s description of evolving best practice (from institutionalization to guardianship to SDM) provided perspective on changing practices and recognition of human rights for people with disabilities. For potential guardians, it was compelling to hear the former judge share her personal experience while on the bench, ordering guardianships until she realized people with IDD had preferences and capacity and should have their right to make decisions about their lives respected.

The quotes below convey the impact of SDMNY presentations on guardians and potential guardians.

“The presentation at his school, well presented. They told story of how guardianship became the only way and how it is changing. Now there is an opportunity to make a different kind of decision which may be more aligned with how you want to treat your adult child. As described, it aligned with all the other things we wanted for him. It’s okay to postpone guardianship and try SDMNY. Very informative. Answered all our questions. Highlighted what guardianship really is and clearly stated that guardianship takes rights away.” –Potential Guardian

“The SDMNY team came to his school and presented twice. I went both times and [name] came to the second presentation and at the most perfect time. I was so against guardianship that I was going to do nothing and hoped his brothers would have been there for him and that everything would be okay. My favorite story was

from the judge. She told us she was writing up guardianships and working day to day in court with guardianships, and then she realized that so many people with disabilities could make decisions. She said it was “not nice” and “not the best way to treat people with disabilities.” God bless her for keeping her eyes open and realizing that something she thought was good at one point now does not work. That story from a judge who was very involved with guardianships, I will carry that story with me. Made me feel I was correct in not doing guardianship.” –Potential Guardian

“I was so overwhelmed. The person who presented was a judge and she explained legal ramifications of removing your child’s constitutional rights. That hit home. I have no other child than my daughter. When you apply for guardianship, if something happens to you, you can elect someone else to be guardian. I have a small family and so even doing guardianship, I didn’t know who would have followed me. So I had opted for a non-profit agency to be her guardian after I passed. I realized she would be a ward of state and have no say in her life. She has the ability to make progress. This decision for guardianship is permanent. I don’t know if she is going to be more independent at 28 years old, but this is a permanent decision, destined for the rest of her life. And even if she showed progress, then under guardianship she would have no right to make any decisions about her life. I didn’t realize that I would be regressing her because all I wanted was for her to progress. This one decision would be undoing all the work I’d done for 18 years.” –Potential Guardian

“I remember expressing a lot of concerns about decision-making and the risks involved, medical and financial. Joan [the project site coordinator] was good about responding to concerns but also thinking through rights, comparing with typical child, and the right to make mistakes. No one wants mistakes or bad decisions but it’s a personal right she stressed. To make mistakes, that resonated with us. The more we heard about the program, the more we started to see [name]. And he was maturing, becoming clear about goals for himself. In the last year he was more independent. Yes, he needs help with everyday decisions, but big goals, big decisions, he is very good and clear about what he wants for himself. This project was about finding him support and allowing him to keep rights to make those big decisions for himself.” –Potential Guardian

“I want [name] to have as much control over his life as he can, and I thought this was a good way of doing it.” –Guardian

“The guardianship issue. I want [name] to speak up for himself and advocate for himself and what he wants.” –Guardian

Evaluation Findings: SDMNY Appeals to Family Members

- Guardians and potential guardians are interested in SDMNY because SDM aligns with their values for how they want their family members with IDD to live: to have a voice, advocate for themselves, and have more control over their lives.
- SDMNY also appeals to family members because it is a mechanism to engage more people in the decision-maker's life and provide for future decision assistance after parents and other family members pass.
- SDMNY information sessions are very impactful. The information about limits of guardianship, removal of rights, evolution of best practices to SDM, and how deeply it matters allowing people to experience risk-taking and decision-making in their own lives is persuasive to family members.

Confidence in SDMNY

Imagining How Supported Decision-Making Will Work

Guardians expressed a range of expectations on how SDM would work in daily life. Two expressed reservations and have a 'wait and see' approach. Another expects her son to speak up for himself and restore his rights. One guardian views SDMNY exactly as the model for supported decision-making intends:

"I thought he would have a group of people that would be supportive of him and they would help him to talk out goals he had. They would not make goals for him, but talk out whatever goals he wanted, and support him in those decisions."

Potential guardians view SDMNY as continuing what they are already doing, helping their family member to become more adept at decision-making and take steps toward adult life. The statements below are indicative of their expectations, hopes, and doubts for using the SDMNY process.

"In the near term I don't know how things would change anyway. If under guardianship, he would have been stripped of his rights, but he'd still be living at home with us. SDM emphasizes his independence, which is good, and we approve of. We didn't see much downside to SDM. Not different. While SDM is not going to change his life in the near term, we're hoping it will help us on path for future, to set us up."

"I thought it was a great idea, you didn't have one person, like guardian or rep payee, who is in control of every area of your life. You have one person per area of your life. And if they are not working you can change them. You don't have to stick

with one person if they aren't working for you or with you. And they don't have to stay if they don't want to. Let's say there is one person with medical, she doesn't have to wait on that person, she can reach out to someone else. Different people to reach out to."

"Well I still have my doubts. His sister and her fiancé, and my own fiancé, and his sister in FL, among us somebody is going to step in to care for my son. I don't know that [name] is really connected to these specific issues; he is not independent now. He lives with me. I think he can achieve independence—job, home, paying food, but his responsibility to take care of home, maintenance of a life. We have a signed SDMA now, but we are going to have to hover and keep track of him."

"He has 2 brothers and many cousins he is extremely close with. Even without SDM he has a good crew and supporters. Just as they were talking, I was just thinking this is how it would be done even without a contract. I was already talking to them about when I am not here and what should continue for [name]."

"They use a facilitator to teach your child to make their own decisions. Even if I am in the mental health field, sometimes I don't allow my daughter to make her own decisions. I wanted to take a couple of steps back so she could work with the facilitator and learn to make decisions."

Any Concerns With Decision-Makers Exercising SDM Chops?

The SDMNY agreement template includes a reminder to the decision-maker and supporters that the decision-maker is responsible for decisions made. This evaluation asked guardians and potential guardians if they had any concerns about decision-makers using SDM and making decisions per the arrangements outlined in the SDMAs. Guardians were more likely to express confidence than a concern; however, potential guardians were more likely to report concern than confidence.

Guardian Opinion: Concern for Decision-Maker Using SDM

Nearly all (4 of 5) guardians expressed faith in the SDMNY process and the decision-makers' use of SDM. Typical of those without concern is this parent-guardian's comment: "I have no concerns about [name] being able to do it. I have faith in his ability to talk about what he wants, to be realistic about it, and to express what he wants in his life. No doubts."

One guardian expressed apprehension should a decision-maker make a poor decision: "I have my concerns. If I feel he is making a poor decision I wonder what happens."

Potential Guardian Opinion: Concern for Decision-maker Using SDM

Three potential guardians (20%) reported having no concern with decision-makers' use of SDM and three (20%) have not thought about this and have not yet formed an opinion. Most potential guardians responded that they have concerns (n=9/15, 60%) regarding decision-makers' use of SDM though the nature of their concerns differ. They expressed the following concerns:

- Lack of experience using SDM
- Supporters treat decision-maker well
- What happens after a family member is no longer around
- Decisions respected by third parties
- Lack of legislation underpinning SDM

The following statements convey their varied concerns:

"Definitely. One of his challenges—not that he wouldn't know to reach out—but doing it if someone is not there. He is going to have to learn to do that. He is not ready to take advantage of it on his own and learn to use the program. Once he learns, and he learns systems really well, he just has to practice and do it over and over. Time and him being more independent and not having us, it will force him to reach out to other people."

"My worry, we will be his decision supporters now, but if we need people beside us as he gets older, as he matures. He is very careful about the people around him. He can spot a phony a mile away. He knows when someone will hurt him or not hurt him. He knows who not to make friends with. We worry about what happens when we aren't around."

"It's not NY state law yet so that is a concern until it is. I'm waiting to hear."

"So if something were to happen with police and [name] was put in jail due to autism. If I show up and am not guardian, is he on his own because he has no guardian? I'm not saying that I'll never use guardianship. I want to know what that situation would be and know what to do about it. I'm concerned about the 'what if' situations."

"Only concern is if it doesn't go through legislation. More people would opt for this if there is more awareness. Information is just not out there. And it takes time to change people's thinking."

Third Party Respect for Decisions

Important for the adoption of SDM is respecting a decision made using an SDMA by third parties (such as a physician, landlord, banker, etc.). As several evaluation respondents noted, they are told that without guardianship they will lack legal standing to be involved in a medical emergency or other kind of crisis scenario. SDMNY staff wanted to know if the experience of using an SDMA, even if not legally binding on third parties at this time, was honored. But as so few decision-makers currently have signed SDMA's (n=8), this evaluation asked guardians and potential guardians if they had any concern or apprehension about other people respecting a decision made using SDM.

Guardian Opinion: Third Party Acceptance

Three guardians reported not being concerned as they have confidence in the supporters selected by the decision-maker. One guardian had not thought about this and had not formed an opinion. The other guardian has a concern, whether the decision-maker's mother, who is not a supporter, will honor his decisions once guardianship is relinquished.

Potential Guardian Opinion: Third Party Acceptance

Potential guardians are at different places with respect to other people honoring decisions made using the SDM process. A few expressed no opinion at this point (n=3/13, 23%) either because of recent participation in SDMNY or because the nature of such a challenge is unclear. Potential guardians with and without concern are equally divided (n=5/13, 38% each).

Those who expressed no apprehension mentioned several reasons:

- Other decision aids are in place such as a health care proxy or representative payee
- SDMNY is untested, so it is not clear how resistance would manifest
- Confidence in the supporters

Statements from potential guardians who are not concerned about third party acceptance at this point include:

“Not that worried about it. He is still a push over, but I hope there are enough people involved that we can get together and talk about it and watch and wait with him.”

“Hard to anticipate what might come up. We have a lot of trust in the people in the program thus far. Trust it will not be them making the decisions, it's [name]. Not really seen it in play. He's grown so much in 4 years, it's hard to know how much more he'll grow.”

Potential guardians who expressed concerns for recognition of decisions made using SDM explained: it's a crazy world, SDM is not in law yet, and it is a risk that others will treat the decision-maker with respect. Below are a few statements from these family members.

"That is one of my fears. I hope that the people around him, the supporters understand, [name] will have the power to decide, he has the power to decide. Persons who do this will know this. You help him out with a decision and give him a reason why or why not in order so he can understand better. Treat him right. It makes a big difference. How people approach him and say something. We want nice people to be around him, people who care about him."

"It worries me because it's not NY state law. I would feel much better if law and binding. But with his supporters I don't see why anyone would not accept his thought process. He's a smart individual. I don't see him having a problem. I've told him, if anyone says you are not capable, you are to fight tooth and nail, do whatever you have to do, to fight that."

"I want someone to treat him fair."

"I tell him he has to be careful with people. This is a world of craziness and things happen. I have to let him make decisions and live with them. If anything happens to him, then everything falls back to us, his finances, make sure his rent gets paid, if he goes into hospital and bills taken care of. We only help each other."

Formal Recognition Important to Increase Confidence in SDM

The New York State Developmental Disabilities Planning Council, the SDMNY grant funder, anticipated this pilot would provide narratives and data to inform a New York State law reform initiative to advance the use of SDM, reserving guardianship as a last resort. SDMNY staff believe strongly that a change in law is necessary to ensure that third parties accept and honor decisions made with SDM, and to offer family members confidence in SDM's practical utility.

"Potential guardian petitioners have asked why they should go through all the SDMA process if health care providers or financial agency representatives will still be able to insist on a guardian for legally binding and enforceable decisions." –SDMNY staff

Staff envision New York's law as building upon other states and incorporating the facilitation process piloted for achieving an SDMA:

"We need to demonstrate that, with appropriate and chosen supports, people with IDD can make decisions that are as good—or no worse—than neurotypical people."

We need to dispel the myth that guardianship protects. We need to find a way to reallocate existing resources, and the services they pay for, to ensure that there is a robust system of SDM facilitation to enable people with IDD to enter into SDMA's but not limit the recognition of the capability of people with IDD to having an SDMA."

This evaluation explored whether formal recognition of SDM in law or policy would affect guardian and potential guardian confidence in decision-makers' use of SDM, including after the guardian or potential guardian's death. All 5 guardians and all 15 potential guardians responded affirmatively. "Absolutely!" and "Definitely" were frequent responses to this question, although one guardian added, "It really depends on the individual. Case by case."

"If the legislature adopts this, it would give us a lot more confidence of what could happen in the future. [Name] is young and we'll figure it out. We'll go to guardianship if we have to. But we'd feel better if we had a system that aligns with our philosophy and have it part of law, legalized. I did have a conversation with an attorney and asked if he'd be a notary for Power of Attorney. He expressed concern about it; he was being a professional. I respect his opinion. If SDM is in the law, it would strengthen everyone's role." –Potential Guardian

"Definitely. It's great to have something like this. I have worked with physical disability, mental illness, aged people, people who can't move their body, but have a mind. You should have some authority to make decisions for yourself: health, finances, home, whatever. Disability shouldn't take your rights away. I'm glad they came up with an option to guardianship or payee." –Potential Guardian

"Sure of course, I would be fearful of him perhaps losing some of his rights [mom's statement]. I don't know how it would change things [dad's statement]. If years from now, somewhere down the line, if SDM isn't on the books, people and agencies take advantage of people. Having it as law that would ... I would feel more secure knowing that his rights and desires are protected by a law [mom's statement]."
–Potential Guardian Parents

"Yes! It should be all over! That's why I'm participating in this evaluation, for it to be all over, not just in NY." –Potential Guardian

"Yes, if I wasn't here, it would give me confidence for him to have other decision supporters; then his voice would be heard." –Potential Guardian

Guardian and potential guardian respondents even offered recommendations for provisions in the law that would increase their confidence, noting:

- Include a process for reporting and investigating concerns
- Ensure the SDMA is a legally enforceable contract, but also a contract that can be modified and terminated

A non-statutory suggestion to increase confidence was suggested by a potential guardian, who recommended that SDMNY provide regular updates, particularly legal updates, to those involved with SDMNY:

“No one has offered to provide regular updates. It’s a pilot and there is a presumption that it gets done and then disappears. How am I going to know if law changes or progress made? No one said, “Would you like to sign up for our newsletter?”

This guardian reflects on the importance of formal recognition for decisions made by people with disabilities:

“It has to be funded. It has to be supported financially. If the program is not funded or all voluntary, parents are not going to learn about it when kids are 15. It’s still a program on social services model; we all have to take time off during the day. I am also supportive of a much broader change of social services, including mental health. I see in much larger terms. This is just one part of broader needs of people. We are very privileged to be able to do this (SDMNY). I have two younger brothers who are blind, so I’ve gotten to see how this works over a very long period of time, seen creativity and intelligence of those with disabilities, whether visible or not. It’s a loss to society to not allow people to be themselves and make decisions.”

Evaluation Findings: Confidence in SDM

- Most guardians involved with SDMNY have confidence in decision-makers’ use of SDM.
- Most potential guardians expressed concerns regarding decision-makers’ use of SDM. The nature of their concerns varies:
 - Lack of experience using SDM
 - Supporters treat decision-maker well
 - What happens after a family member is no longer around
 - Decisions respected by third parties
 - Lack of legislation underpinning SDMNY and SDM
- Legal recognition of SDM would increase guardian and potential guardian confidence in SDM viability—for example, that decision-makers’ rights would be protected in the future, that third parties would accept decisions made using SDM, and that SDM will continue to support their family members with IDD even after parents and other family members pass away.

SDMNY Impact

Impact on Decision-Makers

Another significant area explored by this evaluation was whether the experience of learning about SDM, rights, and responsibilities, and whether moving through the SDMNY facilitation process, has had discernable impact on decision-makers. Other SDM evaluations in the U.S. and abroad have found positive impacts on individuals who adopt SDM as well as positive impacts on their relationships with supporters. Table 7, below, compares impact findings from four SDM pilot evaluations including this one.

Table 7. SDM Impact on Individuals Using SDM and Decision Supporters

SDM Pilots with Evaluation Information	Positive Impact on Individuals Using SDM	Positive Impact on Decision Supporters
Supported Decision-Making New York	<p>Impacts reported by guardians and potential guardian family members of persons with IDD including autism engaged in SDMNY:</p> <ul style="list-style-type: none"> • Increased happiness and happy to be making own decisions • Increased self-esteem and self-advocacy • Trying new things, experiences • Gaining skills • Increased confidence • Less anxious • Excited • Feels more mature, grown up 	<p>Some potential guardians reported no change; some noted it's too early in SDMNY process to determine. Potential guardians who reported change noted:</p> <ul style="list-style-type: none"> • They stepped back and allowed decision-maker to make more decisions • Decision-maker increased voice and communication • Increased opportunities for important conversations • Reduced family member fears
CPR-Nonotuck Supported Decision-Making Pilot, Evaluation Report 2016	<p>9 adults with IDD adopted and expressed satisfaction with SDM:</p> <ul style="list-style-type: none"> • More engagement in decision-making • Ways supporters provided decision assistance • Preferences and decisions were respected across all decision areas (e.g., health, finances...) • 1 guardianship vacated; rights restored • Increased self-esteem and self-advocacy • Increased happiness 	<ul style="list-style-type: none"> • Parents who had reluctantly adopted guardianship relinquished that role for a rights-affirming option. • For families that did not have guardianships, SDM offered reassurance for their decision not to petition for guardianship and increased feelings of security knowing decision supporters are committed in SDM agreements.

SDM Pilots with Evaluation Information	Positive Impact on Individuals Using SDM	Positive Impact on Decision Supporters
South Australia Office of the Public Advocate, Supported Decision-Making Project, Evaluation Report 2012	<p>26 adopted SDM. Specific benefits to most of the participants including:</p> <ul style="list-style-type: none"> • Increased confidence in themselves and in their decision-making skills • Growth in their support networks • Many reported that they felt more in control of their lives. • Evidence of increased engagement with the community, either through expanding their options or through making decisions that changed their circumstances 	<p>Supporters reported changes including:</p> <ul style="list-style-type: none"> • Changes to the way they considered decision-making with the participants • Positive improvements in the nature and quality of their interpersonal relationships
Bulgarian Center for Not-for-Profit Law, Cost Benefit Analysis of SDM, Research 2014	<p>36 persons adopted SDM for six months (16 with IDD, 20 with mental health). Measured changes in quality of life (QOL):</p> <ul style="list-style-type: none"> • SDM contributes to increased QOL • SDM contributes to independent living • SDM contributes to inclusion and participation in community life • Increased social network and relations of mutual trust 	<p>Not reported. However, cost savings were evaluated. SDM reduced usage intensity of health care services, reduced intensity of psychiatric consultation and hospitalizations. Greater inclusion improved employment opportunities.</p>

The level and amount of SDMNY impact or change is likely underreported in this evaluation because:

- the evaluation did not explore impact or change with decision-makers themselves; and
- at the time that guardians and potential guardians were interviewed, decision-makers were at various stages of the facilitation process, most without completed SDMA, and thus not yet using SDM out in the world.

Guardian Opinion: Impact on the Decision-Maker

Even though most decision-makers are not yet at the stage where they have an executed SDMA and are using SDM out in the world, four of five guardians reported noticing positive changes. The other guardian stated they are too new to SDMNY to respond to this question. Changes were noticed even when, in one guardian's opinion, the decision-maker may not fully understand what supported decision-making is all about. Positive impacts include:

- Happier
- Greater self-esteem and pride
- Less anxious / learning to calm down
- Doing new things, gaining skills
- Happy to be making own decisions

Guardian reflections on the positive changes in decision-makers are presented below:

“He may not understand what it is. Since his graduation, he keeps a copy of SDMA. Excited. Gave him structure and attention and bringing people into his life. He may be parroting back, but he is making choices. He’s learning to calm himself down. He goes to self-advocacy meetings. He is getting support to make good decisions.”

“I think it’s made him happier and less anxious. Sometimes he is tormented by my mother, as any decision could be overturned. And they listen to him and he feels he is being heard. Yeah, definitely seeing him do things I’ve never seen him do before. I’ve seen him grow.”

“He is happy about being able to make his own decisions. It has helped his self-esteem. He feels better about himself.”

Potential Guardian Opinion: Impact on the Decision-Maker

Family members who are not guardians were split on whether they’ve noticed changes in the decision-maker since enrolling in the SDMNY Diversion pilot: 8 of the 15 potential guardians interviewed noticed a change (53%), 2 did not (13%), and 5 consider the experience too short-lived to ascertain change (33%). Where change was noted, the SDMNY experience is associated only with positive impacts on decision-makers, specifically:

- More mature / feels like an adult
- Greater confidence
- Excited
- Speaking up more / increased advocacy for self and others
- Sees a future and takes more ownership of goals
- Proud of self
- Reaching for more independence, for challenges, willing to take things on

Potential guardians who were unsure if they could discern any SDM-related change noted that it is either too soon in the process to tell, or the decision-maker is at a personal growth stage and developmental changes may or may not be influenced by the SDMNY process.

The following is a selection of statements from potential guardians who note SDMNY-associated positive changes:

“Yeah, I think so. It’s really good for him. Helping him see his future and take more ownership of his goals and his future.”

“I feel he has been more of an advocate for himself. There was a conversation with him, I can’t remember the specifics, and I said, ‘No, you can’t do that’ and he said, ‘No, I can. It’s my decision.’ He has thrown that out a few times. Kudos to you! He is more confident and has a say and is utilizing his say.”

“Yes, I’ll give you an example. Two months ago, she got sick from a restaurant. Before, another time when she was sick, she went to an urgent care with her mom and because she’s in a wheelchair they turned her away! They didn’t let her in the door. This time when they went to hospital, when she got there she asked, ‘Are you trained in disability care?’ ‘Are you trained to help me?’ She had never done this before. Before, this young lady through her teens, she did not speak beyond ‘hi.’ We had to encourage her to find and use her voice. That’s why it’s so important she gives speeches about her story. She’s giving a speech to the Girl Scouts with disabilities on Long Island. She’s opened up tremendously. Even with her mom, she is telling her mom, ‘This is not what I want for my future. I want something different.’

Facilitator Opinion: SDMNY Impact on Decision-Makers

Facilitators surveyed for this evaluation reported that the SDMNY process positively impacted decision-makers. Facilitators either observed positive changes themselves or positive impacts were shared with them. Three of the four facilitators noted an increase in decision-maker self-empowerment as they gained experience and realized more control over their lives.

“This has been and continues to be a rewarding experience for me as I see the decision-maker learning and gaining more and more confidence as he progresses through the phases of the process.” –Facilitator

Impact of SDMNY Experience on Facilitators

The SDMNY facilitation experience impacted facilitators as well as decision-makers. Surveyed facilitators have been in this role from 6 to 19 months. The average experience across the four respondents was just under one year (11.75 months). Regardless of the time they have been engaged in SDMNY, each facilitator reported that they also have been impacted by the SDMNY experience:

- SDM has changed the way they speak about people with IDD.
- They have stopped making assumptions about what people with IDD want and what their goals are.
- They are incorporating SDM into their professional work (occupational therapy and recreational programs).

Impact on Guardian and Potential Guardian Relationships with Decision-Makers

Guardian Opinion: Impact on Relationship with Family Member

Guardians held a range of opinions on whether their relationships with decision-makers had been impacted since engaging in SDMNY. Two guardians reported they did not yet have enough experience to note any changes. Another guardian said the relationship is unchanged; she and the decision-maker had a very close relationship before SDMNY and that continues. One guardian noted a change in the relationship with the decision-maker and stated it has brought them closer, strengthening the relationship. One guardian relayed that the relationship has not yet changed, but he anticipates change as he learns to step back. This guardian stated:

“I look forward to relinquishing authority. Big transition here as I am the primary emotional support person and I’m ready for it to stop. I’ve a strong sense of responsibility but I’m ready to take a step back. He doesn’t like it when I go away. But I don’t want to get calls every morning and evening. Patterns are deep. Not due to SDMNY. If he successfully relies on others in SDM, if they took over to figure out activities to do, then I’ll know that it has made a contribution.”

Potential Guardian Opinion: Impact on Relationship with Family Member

Potential guardians also hold a range of opinions on whether their relationships with decision-makers had been impacted since engaging in SDMNY.

One-third (n=5/15) report no change in their relationships. Four potential guardians said it is too soon in the process to determine, that they are still figuring things out. And one family member mentioned their relationship already aligns with honoring the decision-maker’s preferences and choices:

“We already always consider his opinion. We ask him, ‘What should we do right now?’ We let him make a mistake every once in a while, to see for himself. He respects that.”

Most potential guardians (n=10/15) have noticed changes in their relationship with the decision-maker, and all changes are welcome and exciting. Potential guardians are taking conscious steps back, allowing decision-makers to become agents of their lives. A few of these family member responses follow.

“He is standing up for his choices with me. We are very attached to each other, but I am trying to take a step back so he can be the independent person he needs to be.

I'm letting him be comfortable in that role and so when I'm not here and not able to help him, he will be fine."

"Progress in that I'm taking steps back. I'm transitioning."

"Definitely...it opened things up a bit for all of us, thinking about the future together. Why don't you ask someone else in addition to us? More moving forward which is good for him and for us."

"Expands my knowledge. Reminder to me of his personhood and separateness, as that can get lost in the nitty gritty of coordinating, making sure he has what he needs. Doing it as his guardian would have been a different feeling. I wouldn't have been checking with him and he would not have been active in it. I would have been doing it to get it done."

"She and I talk every day. It's been a huge difference. She never liked to talk, she used the computer, and now she has to talk, not text. "You have to talk," I tell her. It's amazing to hear her communicate the way she talks now. For her mom it's a bit of a shock, because she never talked like that before."

SDMNY staff who serve as mentors have noticed positive changes in the relationships between decision-makers and supporters and expressed delight in watching the decision-maker take more of an active role in decision-making and how supporters can step back to allow the decision-maker to find her/his voice.

Evaluation Findings: SDMNY Impacts

Impact on Decision-Makers

The SDMNY experience has positively impacted decision-makers, including those with and without guardianship orders. Positive impacts include:

- Increased happiness including happy to be making own decisions
- Increased self-esteem
- Increased self-advocacy
- Trying new things, experiences
- Gaining skills
- Increased confidence
- Less anxious
- Excited
- Feels more mature, grown up

Impact on Facilitators

- Facilitators who participated in this evaluation reported that the SDMNY training and experience changed their perspective and removed some stereotypes about people with IDD. These facilitators are incorporating SDM into their professional work activity.

Impact on Relationship with Family Member Guardian or Potential Guardian

- Where guardians and potential guardians noted changes in their relationship with the decision-maker due to SDMNY involvement, the changes have been positive. Family members are taking steps back and allowing decision-makers to have their own opinions and express them. Family members are engaging decision-makers in important conversations about their future.

Guardian and Potential Guardian Concerns for the Future

This evaluation asked potential guardians and guardians what they are most concerned or worried about for decision-makers' futures. The range of concerns was wide, and what mattered most to each group did not align in priority. However, concerns expressed by guardians and potential guardians are, for the most part, typical of concerns that parents have for their adult children in the general population.

Potential guardians are most concerned about decision-makers being employed, able to support themselves, being independent, having a voice, and able to manage once parents pass away. Guardians are most concerned that decision-makers are not taken advantage of, that decision-making skills are honed for making good decisions, and that affordable housing is available. Table 8 shows the concerns for the decision-maker's futures reported by guardians and potential guardians.

Table 8. Concerns for Decision-Maker's Future

Areas of Concern	Potential Guardians	Guardians
Work/ support self/ meaningful activity	7/15	--
When I am not here	4/15	1/5
Independence / strengthens voice	4/15	--
Have relationships / family	3/15	--
Manage money / be taken advantage of	3/15	3/5
Making decisions/ use supporters	2/15	3/5
Health / healthcare	2/15	--
Everything	2/15	--
Be happy	2/15	--
SDMNY function after pilot ends / monitoring	1/15	--
Housing, affordable	1/15	3/5
Staff to support	--	1/5

Has SDMNY Addressed Concerns That Led, or Could Have Led, to Guardianship?

This evaluation explored whether the SDMNY process reduces or alleviates concerns that lead family members to consider or to become a guardian. On this matter guardians and potential guardians reported different experiences. Potential guardians note their concerns or worries have been reduced due to SDMNY involvement, whereas guardians report that concerns or worries that led them to become a guardian remain.

Potential Guardians: Has SDMNY Reduced Concerns That May Have Led to Guardianship?

Nearly all potential guardians (n=12/15, 80%) interviewed reported that their concerns for the future were lessened due to engaging in SDMNY, though one potential guardian noted, “Guardianship wasn’t going to solve it either.” Another potential guardian, new to SDMNY, stated it was too early to tell. Below are comments from potential guardians who expressed a reduction in fears or concerns due to SDMNY involvement.

“Yes, it’s helpful in life. There are not many options, but with the right training he can go through life. I feel everybody needs guidance and help, a boost, a little coaching in life.”

“Yes, she is going to know who her supports are, and it will be laid out. Could prevent some other problems.”

“I think it’s a great program, but it’s a process. It took almost two years to complete the program. You want to make sure you have the right people. You have to have frequent meetings and it’s hard to get everyone together at the same time. Help people understand that. But it’s a program that is necessary especially if parents are over 50, well, 50 is probably too late. If you don’t put this into place your child may be placed under guardianship or payee and you won’t have choice. And now you have choice. It’s horrible for someone to make decisions for you because you’re disabled; it’s a horrible feeling. Everybody has rights and wants to be involved in decisions about their life. Best thing you can do for a person.”

“Yes it has. I’m less fearful. If we were not in the pilot program, she would not have had opportunities to have conversations with people other than me, to explore her feelings with someone who is not a family member. These conversations aren’t held with anyone else, no one in school, not with her pediatrician, but only with parents. So bringing in facilitators, it’s a good experience. She has had to explore with 3 facilitators. One day when I’m not around she will feel more comfortable talking about her feelings. I would not have ever thought she needed these kinds of conversations, but it’s about how she needs to advocate for herself if I’m not around.”

“It has reduced stress that he has a legal document that says I can and will make my own decisions versus if SDM wasn’t there, I was just going to say God be with him.”

Guardians: Has SDMNY Reduced Concerns That Led to Guardianship?

All five guardians stated their concerns remain and had not been diminished, as yet, by SDMNY involvement. One guardian is hopeful that with more experience, concerns will reduce: “Too early to tell. I hope so, I really don’t know if it will or not. I hope it will have some effect.” Comments from other guardians follow.

“I still worry about his decision-making.”

“The two things that were core were access to health care and financial decision-making, and this doesn’t really address them. I still manage his staff. I manage his finances. He has gotten more assertive with medical care because he likes doctors. He will take himself to the doctor now. But SDM has not contributed to day-to-day structure of his life.”

Evaluation Finding: Has SDMNY Reduced Concerns Leading to, or That Led to, Guardianship

- Most potential guardians report that SDMNY engagement has reduced concerns that may have led to guardianship petitions. For guardians, SDMNY involvement has not yet reduced concerns that led them to petition for guardianship.

For Consideration - It may be useful to ask guardians again, after decision-makers have signed SDMA in place and have been making decisions with supporter assistance for a period of time, whether SDM has reduced concerns that led to guardianship.

Restoration of Rights

One of the goals for SDMNY is to restore the decision-making rights of 45 individuals through adoption of SDMNY and discharge of guardianships. Given that guardians report they have no concerns about decision-makers’ use of SDM, nor concerns about third-parties honoring decisions made using SDMNY, it would seem that guardians would have indicated greater interest in restoring decision-making rights to their adult family members. However, this does not yet seem to be the trajectory. It may be that the lack of statutory grounding for SDM means holding onto a firm legal standing for involvement in medical and financial matters.

One of the five guardians participating in the evaluation is not planning to relinquish guardianship or request to limit the guardianship to cover fewer decision domains. As this guardian stated:

“We are not going back on his guardianship. It was suggested indirectly that we do so. It has been implied that guardianship was not a good thing to do. I’m concerned that attitude comes from people who don’t have children with disabilities. When we got the diagnosis, I started thinking about the life span, because I’ve seen it. I’ve seen resiliency, and the stress, and the social isolation. It’s why I’m an advocate for people to be as full a human being as they possibly can.”

Two guardians are undecided at this stage and need additional time, experience, and information.

“My main concern is protecting [name]. I don’t know the benefits of one over the other. I need to talk to someone familiar with both procedures. My concern is that [name] have as much control over his life as possible while protecting him and making sure he’s safe. How to balance that out. Which would lend itself to balancing his control and making sure he’s safe.”

This guardian also shared some of the difficulty of a decision to relinquish guardianship given her son’s non-verbal communication and history of being mistreated:

“Unsure at this point. It’s a very tough role to be in as a parent. I have to balance his independence and his own wishes against protecting him. Especially because of the language. Because he can’t tell someone and know he will be understood, and his feelings respected. Very often he’s mistreated because of communication, because if he’s frustrated and has no way to express it and if a person doesn’t take time to figure out why he may act in way to express frustration. But his actions get judged by themselves, often out of context, or as behavior that is inappropriate or unacceptable. It is not seen as communication but as a defect in ability to control himself. The management of him gets addressed, not what he wants. That makes him feel that he’s a bad person. Decisions made that are not always in his best interests. Staff are interested in making their work easier, and people aren’t machines, they can’t be looked at as behavior. You have to be willing to put yourself in his shoes, to wake up and not be able to communicate. Be sensitive to the frustration. This is an everyday experience for [name]. I think he handles it heroically. I can’t imagine what that must be like, the frustration that would entail. If people looked at it that way instead of how difficult the person is making the situation, it would be a huge change. When children are young, we are tolerant, but

as they age, we are less tolerant, we put medication on them, put them in hospital. It's a huge problem."

The other two guardians participating in the evaluation plan to petition the court to end guardianship. One of these guardians wants others to know how important it is for people to make decisions about their lives and for their decisions to stand and not be overturned by a guardian:

"I think the world should know what a great person my brother is. Every person who meets him loves him and says what a great person he is. Everybody who is like him should have their own rights. He should be able to speak for himself and his mother should not negate what he wants; it's really unfair. We talk every day. Everyone who meets him says what an amazing person he is."

Evaluation Findings: Restoration of Legal Rights

- Two of five guardians stated an intention to petition the court to terminate the guardianship and restore legal rights to the decision-maker.
- One guardian does not plan to terminate guardianship, but by participating in SDMNY, has noted positive impacts on the decision-maker's self-esteem, mood, and personal growth.
- Two guardians are open to considering termination and need additional time, SDM experience, and information.

Recommendations for Sustaining SDM into the Future

SDMNY provides a model and process for empowering people with IDD to have a voice and make decisions about their lives with trusted supporters of their choosing. SDM can be utilized with or without additional legally recognized decision-making instruments such as Durable Powers of Attorney, Health Care Proxies, and Representative Payees for Social Security and SSI benefits.

This evaluation provides stories and opinion on how SDM can be utilized as an alternative to guardianship for people with IDD in New York State. Below are additional recommendations for sustaining SDM. These recommendations are based on evaluation conversations with family member guardians and potential guardians and surveys of facilitators and staff.

Recommendation 1: Include people with IDD throughout all stages of pilot and evaluation, not as touch points, but as full partners

When asked what they would change if they knew at the outset of the pilot what they know now, pilot staff mentioned engaging people with IDD throughout as full partners—from the establishment of the pilot to research, training, recruitment, and on through planning expansion and system change strategies.

“Through this project I have become more acutely aware of the ethical dimensions of a project with clear objectives of systemic change built into the project’s 5-year work plan and grant agreement with the donor that at best is inclusive of persons with IDD but not necessarily tasked with developing a policy or systems-change agenda that is directed primarily by them.” –SDMNY staff

Opportunities to more broadly include people with IDD in SDMNY include roles such as:

- Paid staff involved in planning, implementation and research
- Peer facilitators (Initial exploration could pair a self-advocate with an experienced facilitator)
- Paid presenters in facilitator trainings
- Paid presenters for all information sessions

Recommendation 2: Develop and maintain SDMA-engaged user groups

When initially designed, SDMNY staff planned for facilitators to check in once a month by phone with SDMA users they had assisted; however, given the commitment period for volunteer facilitators (through the signing of an SDMA) and the fact that these check-ins would not have provided decision-makers or supporters with an opportunity to share their experience with others and learn from one another, this expectation was not operationalized. Instead, SDMNY staff began hosting monthly SDMA user group meetings. Thus far, user group sessions have been offered only to decision-makers. In these meetings, staff have reviewed the contents of the SDMA, and discussed how decision-makers have, or could, use their SDMAs in conversations with their supporters.

“At the project’s outset, it was anticipated that facilitators will check in once a month by phone with SDMA users whom they have assisted; however, I believe that a more robust, ongoing forum for communication, troubleshooting, and experience-sharing will be necessary for SDMA users to engage meaningfully with these tools in the future.” –SDMNY staff

Providing an ongoing, regular opportunity to communicate, problem solve and offer mutual support, as well as to gain information about SDMNY experience, is valuable. Access to user groups should be offered to decision-makers as well as supporters.

Recommendation 3: Reform New York guardianship law

This evaluation provides evidence on the lack of accurate information provided to family members about guardianship and a lack of knowledge about less restrictive alternatives to guardianship that guide people to guardianship.

The school-to-guardian pipeline is operating in New York. Schools, attorneys, health care professionals, and other parents with children with IDD exert persuasive influence toward guardianship.

It is a profound finding that 60% of guardians (at the time they filed for guardianship) and 62% of potential guardians did not realize that guardianship removes a person’s rights. These guardians and potential guardians want their family members with IDD to gain independent living skills and live meaningful lives connected to their communities.

With the advent of model law developed by the UGCOPAA, New York has a thoughtful template for revisions that reflects current standards of practice and human rights progress. Reform to New York guardianship law should require examination of the individual’s life experience in decision-making, available and potentially available

assistance and support for decision assistance, and an assessment of informal or other formal supports available in the person's community. Guardianships, in order to meet the last resort expectation, should not be imposed unless SDM and other less restrictive protective arrangements have been tried and found unsuitable.

Recommendation 4: Pass legislation recognizing SDMA created through a planned and evaluated facilitation process, such as SDMNY

The SDMNY initiative aims to deliver evidence to support legislation, regulations, and policies to ensure supported decision-making is a readily available alternative to guardianship in the future. This evaluation contributes the opinion and experience of pilot staff, facilitators, guardians and potential guardians toward that goal. Legislation is necessary to ensure that people with IDD have the right to make their own decisions with support of their choosing, to have those decisions recognized and honored by third parties, and to relieve third parties of liability for good faith reliance on the SDMA decision process.

Guardians and potential guardians interviewed for this evaluation clearly conveyed that legislation would increase their confidence that decisions would be honored and decision-makers would retain rights. Statutory recognition for SDMNY and SDM agreements would legitimize SDM as a viable alternative to guardianship and significantly increase interest and participation in SDMNY.

For SDM sustainability, identify a responsible entity to check on how SDMA are functioning for decision-makers and supporters, and a responsible entity to assist decision-makers with SDMA changes after grant funding ends.

Another independent evaluation of SDMNY is underway. For SDMNY Years 4 and 5, the New York State Developmental Disabilities Planning Council (DDPC) contracted with the Burton Blatt Institute to conduct an evaluation examining SDMNY operations and outcomes in greater depth; that evaluation will likely add to the evidence base for SDM legal standing in New York.

Recommendation 5: Share the News – SDMNY Works!

As demonstrated in similar pilot programs of SDM, SDMNY participation has positive impacts on a person with IDD and the person's relationships with family members. Positive impacts reported for people with IDD participating at this early stage of SDMNY engagement included increased self-advocacy, greater self-confidence, a wider array of experiences and trying new things, reduced anxiety, and greater happiness. Family members report taking steps back and allowing decision-makers to have their own

opinions and express them and are also engaging decision-makers in important conversations about their future.

The SDMNY training and experience also impacts the thinking and actions of facilitators. Facilitators have gained greater awareness of the capabilities of people with IDD and have stopped making assumptions or imposing goals.

The work of SDMNY has impacted SDMNY staff as well. The following are staff reflections on how the SDMNY experience thus far has impacted their thinking and belief in SDM as vehicle for desired social change:

“I think the most impactful change will be societal, consistent with an expressive theory of behavioral change. If SDM can provide decision-makers, supporters, and their allies the vocabulary for voicing their demand for greater respect for their decision-making processes, even if these differ in appearance or substance from those of the general population, then society at large will more readily perceive and be willing to remove the barriers to persons’ with IDD decision-making that arise too frequently in the interactions in informal, everyday settings. If SDM can thematize and visibilize these barriers, then the people in their lives will become more sensitized to whether their conduct either abets or obstructs persons’ with IDD autonomous decision-making. Because SDM assigns a positive value to promoting decision-making autonomy, it can make it easier to make society at large aware of decision-making barriers and to galvanize support for norm changes that eradicate these barriers in service of maximizing autonomy.”

“It really works! It takes time, and is a thoughtful, well-tested process with integrity, not just having someone sign a piece of paper.”

“This is not just signing a piece of paper. It's about a real transformation, that we have now seen over and over, in which people with IDD become real agents of their own lives.”

Previous evaluations of other pilots have been shared with project funders, advisory councils, evaluation participants, state policy makers, posted to SDM pilot websites, and made widely available through the National Resource Center on Supported Decision-Making.

Attachments

A. Evaluation Background, Methods & Approach

Institutional Review Board (IRB) review is a safeguard process to ensure research that involves human subjects does not subject people to harmful research practices. IRB review critiques the researcher's protocols and procedures for ensuring that research participants understand the nature of the research, that risks and benefits are transparent, and that consent is informed.

An IRB package was prepared and submitted to the Hunter/CUNY IRB in September 2018. The IRB package contained background information on SDM internationally and nationally, information about the grant award and the funder's requirement for an independent evaluation, evaluation research questions, evaluation protocols, consent procedures, interview instruments, and data security. For this evaluation research, involving only "non-vulnerable" adults, risks of harm for participating in this evaluation were anticipated to be minimal, if any. Benefits were adding to the knowledge base of SDM in practice. Participation was voluntary with evaluation respondents free to withdraw at any time and to skip any questions they did not want to answer.

IRB authorization to proceed with the evaluation was secured in late December 2018. Due to the shortened timeframe and the requirement that evaluation funds be expended by March 31, 2019, a modification to the evaluation plan was requested to combine the proposed two phone interviews into one. Consolidated interview instruments and revised consent forms and protocols were submitted to the IRB with a request for expedited review. IRB authorization for a combined interview protocol arrived in late January 2019. Data collection began February 1st. (See Attachment B for the combined set of Potential Guardian interview questions. See Attachment C for Guardian and Former Guardian combined interview questions.)

SDMNY Recommendation: Institutional Review Board (IRB)

SDMNY staff recommend that when an independent evaluation is a part of a project, plan for the IRB process from the project start. Include time for preparation of the IRB package and several months for IRB review and approval.

Guardian and Potential Guardian Interview Data Collection

Participating in this evaluation was voluntary and open to all family members with an SDMNY-enrolled decision-maker between December 2018 and May 2019.

After the evaluation plan was reviewed and approved by the Hunter/CUNY IRB, the next step was for SDMNY staff to reach out to involved guardians and potential guardians and offer the opportunity to participate in this research. Staff explained the purpose for an evaluation, that participation was voluntary, and there would be no advantage or disadvantage to participating in the evaluation. For family members interested in learning more about the evaluation, including any risks and benefits, the Senior Project Coordinator shared their preferred contact information with the evaluator. The evaluator contacted guardians and potential guardians and discussed the purpose of the evaluation, time commitment, and risks and benefits. For those who consented to participate, a phone interview was scheduled for a time and date convenient for that guardian or potential guardian.

Staff projected 30 SDMNY-involved potential guardians and guardians would participate in this evaluation. Although the evaluation was extended several times to include as many respondents as possible, 24 guardians and potential guardians gave permission to the Senior Project Coordinator to be contacted by the evaluator to discuss participation in the evaluation. Of the 24 potential evaluation respondents:

- 20 consented to and participated in telephone interviews
- 1 declined to participate
- 3 did not respond to evaluator outreach

Telephone interviews were scheduled for the convenience of respondents. For three interviews, a husband and wife jointly spoke with the evaluator. These interviews were counted as one interview with an exception. When collecting personal characteristic information (such as age, race, etc.), the demographic information was requested for both the husband and wife and is reported in this evaluation. For all other evaluation information, responses of a husband and wife are combined and reported as a single respondent as per their request.

Staff and Facilitator Data Collection

Online surveys were conducted to collect key SDMNY staff reflections (from the Project Director, Senior Project Coordinator, NYC Site Coordinator, and Faculty Associate) and reflections from facilitators. Questions for staff covered the development of the SDMNY model, outreach and recruitment, challenges and strategies, and thoughts for sustaining SDMNY initiatives after grant funding ends. (See Attachment D for the SDMNY Key Staff Online Survey.) Given that the role of facilitator is a volunteer position, the facilitator survey was very short and focused on facilitator impressions regarding training and perceived impacts of SDMNY. (See Attachment E for the Facilitator Online Survey.)

B. Potential Guardian (Diversion Pilot) Evaluation Interview Questions

What is your relationship to [individual's name], the "Decision-maker"? _____
(If not parent or sibling) Length of time you have known [individual's name]: _____

An important question this research seeks to answer is what concerns or advice influence people to consider guardianship of adults with intellectual and/or developmental disabilities (I/DD). The following questions ask if you have considered guardianship, and why.

1. Did you ever consider guardianship for [individual's name]?
 - a. [If no] Why didn't you consider guardianship? (Skip to question 2)
 - b. [If yes] What concerns or advice led you to consider guardianship, or to become a guardian?
 - c. [If yes] How did you think guardianship would have addressed those concerns?
2. At the time you learned about guardianship (or were advised to become a guardian), were you also advised of other decision-making assistance options?
 - a. Representative (or "rep") payee? Yes/No (If yes, please explain)
 - b. Power of attorney? Yes/No (If yes, please explain)
 - c. Health care proxy? Yes/No (If yes, please explain)
 - d. Person-centered planning? Yes/No (If yes, please explain)
 - e. Supported decision-making? Yes/No (If yes, please explain)
3. What were or have been your primary source(s) of information about guardianship?
4. Did you know that guardianship removes an individual's legal rights?
5. Have you had any experiences with health care providers that led you to believe guardianship would have been necessary to provide health care services to [individual's name]? If yes, please describe.
6. Have you had any experiences with schools or teachers that led you to believe guardianship would have been necessary for the school or teachers to provide educational services to [individual's name]? If yes, please describe.
7. Have you had any experiences with disability service providers that led you to believe disability service (such as Medicaid-funded services) delivery required a guardian? If yes, please describe.
8. Have you had any experiences with banks or financial institutions that led you to believe guardianship was necessary to provide financial services to [individual's name]? If yes, please describe.
9. Have you had any experiences with other parents or family members that led you to believe guardianship was necessary for [individual's name]? If yes, please describe.

10. Guardianship is a legal process that has some financial costs; for example, many petitioners choose to hire an attorney. Did costs influence your decision not to pursue guardianship?

This research also wants to learn why people decided to try out Supported Decision-Making New York (SDMNY). The next few questions ask how you learned about SDMNY and what influenced you to get involved.

11. How did you first learn about SDMNY and what information did you receive?
12. What led you to become involved in SDMNY, if at all?
13. When you first learned about SDMNY, how did you think it would work for [individual's name]?
14. What are your biggest concerns for [individual's name] future? What are you most worried about?

This research is interested in whether Supported Decision-Making New York (SDMNY) appears to have made a difference on Decision-makers.

15. From your perspective, how has participating in SDMNY affected or changed [individual's name], the "Decision-Maker"?
16. Some people have reported that using supported decision-making fosters changes, such as in their self-esteem and self-confidence. What changes, if any, have you noticed or been made aware of in [individual's name] since participating in the SDMNY process?
17. What change, if any, have you noticed in your relationship to [individual's name] since participating in SDMNY?
18. What change, if any, have you observed or been made aware of in how *others* engage with [individual's name] since participating in SDMNY?

This research wants to learn whether the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced concerns that could have led to guardianship.

19. In your opinion, has the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced any concerns or fears that led you to become a guardian? If yes, please explain.
20. Do you have any concerns about [individual's name] using supported decision-making now or in the future?

21. Do you have concerns about other people honoring the Supported Decision-Making Agreement (SDMA) that [individual's name] developed through the SDMNY process?
22. Would you be in favor of formal recognition of supported decision-making (such as in a law or government policy) if formal recognition required others (doctors, schools, lawyers, service providers, etc.) to honor Decision-Makers' SDMAs?
23. Would formal recognition of supported decision-making (such as in a law or government policy) affect your confidence in [individual's name]'s use of supported decision-making in the future, including after when you pass away? If either yes or no, please explain.

Did we miss asking you about something important to you?

24. Is there anything else that I should have asked you, or that you want to tell me about your experience in the SDMNY project?

Thank you! The next few questions are personal such as your age and race. Just as the other questions I've asked you today, these additional questions are voluntary. It is up to you whether to answer or not. You can decline to answer any single question, or all of them. If you do answer it will help us determine if any shared demographic influences may be relevant. Shall I start these questions?

25. What is your age?
26. Please identify one or more race: White, Black or African American, Asian, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, Other _____
27. What is your ethnicity? Hispanic or Latino, Not Hispanic or Latino
28. What is your primary language?
29. What is your legal status in relation to Decision-maker? parent, sibling, other relative, guardian, trustee, etc.
30. Who lives in your home with you?
 - Decision-maker [individual's name]?
 - Spouse or Partner?
 - Children other than the Decision-maker [individual's name]?
31. Do you work outside the home?

Thank you for sharing your opinion and experience for this research! Your answers will help people in New York and other states learn about supported decision making and how best to use it.

C. Guardian and Former Guardian (Restoration Pilot) Evaluation Interview Questions

Length of time as guardian for [individual's name], the "Decision-maker": _____

Personal connection, if any, to [individual's name]: _____

(If not parent or sibling) Length of time known [individual's name]: _____

Were you the original guardianship Petitioner for [individual's name]? _____

An important question this research seeks to answer is what concerns or advice influenced people to become guardians of adults with intellectual and/or developmental disabilities (I/DD). The following questions ask about your experience.

1. What concerns or advice led you to become a guardian for [individual's name]?
2. At the time, were you aware that guardianship removed all of [individual's name]'s legal rights?
3. At the time you learned about guardianship (or were advised to become a guardian), were you also advised of other decision-making assistance options?
 - a. Representative (or "rep") payee? Yes/No (If yes, please explain)
 - b. Power of attorney? Yes/No (If yes, please explain)
 - c. Health care proxy? Yes/No (If yes, please explain)
 - d. Person-centered planning? Yes/No (If yes, please explain)
 - e. Supported decision-making? Yes/No (If yes, please explain)

This research also wants to learn why people decided to try out Supported Decision-Making New York (SDMNY). The next few questions ask how you learned about SDMNY and what influenced you to try it out.

4. How did you first learn about SDMNY and what information did you receive?
5. What led you to become involved in SDMNY, if at all?
6. When you first learned about SDMNY, how did you think it would work for [individual's name]?
7. What are your biggest concerns for [individual's name] future? What are you most worried about?

This research is interested in whether Supported Decision-Making New York (SDMNY) appears to have made a difference, an impact, on Decision-makers.

8. From your perspective, how has participating in SDMNY affected or changed [individual's name], the "Decision-Maker"?
9. Some people have reported that using supported decision-making fosters changes, such as in their self-esteem and self-confidence. What changes, if any, have you noticed or been made aware of in [individual's name] since participating in the SDMNY process?
10. What change, if any, have you noticed in your relationship to the Decision-Maker [individual's name] since participating in SDMNY?
11. What change, if any, have you observed or been made aware of in how *others* engage with [individual's name] since participating in SDMNY?

This research wants to learn whether the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced concerns that had previously led to guardianship.

12. In your opinion, has the Supported Decision-Making New York (SDMNY) facilitation process addressed or reduced any concerns or fears that led you to become a guardian? If yes, please explain.
13. Do you have any concerns about [individual's name] using supported decision-making now or in the future?
14. Do you have concerns about other people honoring the Supported Decision-Making Agreement (SDMA) that [individual's name] developed through the SDMNY process?
15. Would you be in favor of formal recognition of supported decision-making (such as in a law or government policy) if formal recognition required others (doctors, schools, lawyers, service providers, etc.) to honor Decision-Makers' SDMAs?
16. Would formal recognition of supported decision-making (such as in a law or government policy) affect your confidence in [individual's name]'s use of supported decision-making in the future, including after when you pass away? If either yes or no, please explain.
17. What are your thoughts about ending guardianship now that [individual's name] is involved in SDMNY?
18. Are you more likely to consent to end the guardianship or limit the guardianship so that it affects fewer types of decisions?

Did we miss asking you about something important to you?

19. Is there anything else I should have asked you, or that you want to tell me, about your experience in the SDMNY project?

Thank you! The next few questions are personal and, as with earlier questions, completely voluntary to answer – up to you whether to answer or not. You can decline to answer any or all of them. If you choose to answer, it will help us determine if any shared demographic influences are relevant. Shall I start these questions?

20. What is your age?
21. Please identify one or more race: White, Black or African American, Asian, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, Other _____
22. What is your ethnicity: Hispanic or Latino, Not Hispanic or Latino
23. What is your primary language?
24. What is your legal status in relation to Decision-maker: parent, sibling, other relative, guardian, trustee, etc.
25. Who lives in your home with you?
 - a. Decision-maker [individual's name]
 - b. Spouse or Partner
 - c. Children other than the Decision-maker [individual's name]?
26. Do you work outside the home?

Thank you for sharing your opinions and experience for this research! Your answers will help people in New York and other states learn about supported decision making and how best to use it.

D. SDMNY Key Pilot Staff Online Survey

SDMNY Model Development and Advisory Council

1. What is your role in SDMNY? What are you responsible for in this role?
2. How was the SDMNY pilot program model developed? Include influences and modifications from other SDM models.
3. Describe what is unique about the New York SDM model. Describe how this model extends the development of SDM in new ways in the U.S.
4. What SDMNY design elements do you view as most essential to the future success of supported decision-making use by Decision-Makers in NY?
5. How was the Advisory Council constituted and what is its role?
6. What significant contributions, if any, has the Advisory Council or its members made to date?
7. What changes, if any, might enhance the Advisory Council's impact?
8. How might you make better use of Advisory Council expertise?

Facilitators and Mentors

9. Describe the role and function of facilitators.
10. What qualifications (such as degree, language fluency, experience with individuals with I/DD, knowledge of developmental disabilities system, etc.) are required to be a facilitator?
11. What characteristics or traits do you note in the most effective facilitators?
12. What were the original strategies for recruiting facilitators? If there have been any changes to recruitment strategies, describe the change and what led to making a change.
13. How was the training of facilitators developed?
14. Over the course of this pilot, have there been any changes to the facilitator training? If so, describe significant changes and what led to making a change.
15. What issues, if any, have arisen with facilitators, and how have issues been addressed?
16. What is the role of mentors?
17. What are the required qualifications for mentors, if any?
18. What are the most important characteristics of a good mentor?
19. How has the role of mentors changed over the duration of the pilot, if at all?

20. How are mentors recruited and trained?
21. Considering the long-term sustainability of Decision Makers' use of supported decision-making in NY, what do you think is important for recruitment and training of facilitators and mentors?

SDMNY Outreach and Recruitment of Individuals with I/DD

22. What were the original strategies for outreach and recruitment to individuals with I/DD, parents and guardians? If strategies changed over the course of the pilot, please describe the change and what led to the change.
23. What have been the most successful outreach and recruitment activities?
24. What have been the main barrier(s) to outreach and recruitment activity and how have any barriers been addressed?
25. What do you think are the most important lessons learned related to recruitment of individuals with I/DD?

Supported Decision Making Agreements (SDMA)

26. What is the SDMA, and how is it created? Please include in your description the various considerations and stakeholders involved.
27. How long does it generally take for a Decision-Maker to complete an SDMA? Please include number of meetings, frequency of meetings, and over what period of time.
28. Have there been any changes to the SDMA since the pilot was launched? If yes, please describe those changes and what prompted them.
29. How do Decision Makers make changes to SDMAs (to their decision supporter OR to areas for decision assistance)?
30. What is the role of SDMNY after an SDMA is signed? What do you expect for those with executed SDMAs using supported decision-making into the future?

Safeguards

31. How do you address the concerns of parents and others about protection, including protection from abuse, neglect or exploitation?
32. What safeguards for Decision Makers and Supporters are built into the SDMNY pilot process and the SDMA, if any?
33. What mechanisms, if any, are there for concerns or complaints that an SDMA is being misused, or for disputes among or between Supporters and/or the Decision-Maker?

Lessons Learned and Next Steps

34. What would you do differently if you knew at the pilot onset what you know now?
35. What is your estimated percentage of time in FTEs per month allocated to:
 - a. Project management including project coordination with project partners and reporting to funder
 - b. Education and outreach activities
 - c. Recruitment and support to facilitators
36. What, in your opinion, have been the biggest surprises over the course of this pilot?
37. How do you imagine the pilot expanding and continuing after the grant is over?
38. What changes (legal, societal, regulatory, etc.) do you see as necessary to advance supported decision-making as a viable alternative to guardianship?
39. What are key lessons learned from this SDM demonstration pilot important to share with interested stakeholders and the public?

Please use this space for anything else you would like to note for the evaluation.

E. SDMNY Facilitator Online Survey

1. Please note your name and organization.
2. What drew you to SDMNY and to become a facilitator?
3. How long have you been a facilitator?
4. How did the Facilitator training affect your understanding of supported decision-making, and/or your commitment to the SDMNY process?
5. Now that you have experience as a facilitator, what changes if any would enhance the training?
6. What differences, if any, have you observed or heard, about the impact of using facilitated supported decision-making with individuals with I/DD?
7. In what way are you employing or adapting supported decision-making to your own work environment, and what is that environment?
8. Is there anything else you would like to share about your experience as an SDMNY facilitator?

F. Endnotes and References

- ¹ Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities, National Council on Disability, June 2019. Located online: <https://www.ncd.gov/publications/2019/turning-rights-into-reality>
- ² United Nations Convention on the Rights of Persons with Disabilities (CRPD), Article 12, Equal Recognition Before the Law. Located online: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>
- ³ United Nations Convention on the Rights of Persons with Disabilities (CRPD). Located online: https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en
- ⁴ Links to statutes are posted on SDMNY website. Located online: <https://sdmny.org/sdm-laws>
- ⁵ Survey on Supported Decision-making in Practice, The Quality Trust, National Resource Center on Supported Decision Making, March 31, 2016. Located online: <http://supporteddecisionmaking.org/sites/default/files/Final%20Report-Survey%20on%20Supported%20Decision-Making.pdf>
- ⁶ Center for Public Representation, Supported Decision Making website. Located online: <http://supporteddecisions.org/about-sdm/>
- ⁷ National Core Indicators™ (NCI) Adult Consumer Survey 2017-18. Located online: https://www.nationalcoreindicators.org/upload/core-indicators/17-18_IPS_National_Report_PART_I_3_20_19.pdf
- ⁸ National Core Indicators Data Brief™, *What Do NCI Data Reveal About the Guardianship Status of People With IDD?*, April 2019. Located online: https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf
- ⁹ ELDER ABUSE: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults, GAO-17-33, 2016. Located online: <https://www.gao.gov/assets/690/681088.pdf>
- ¹⁰ Department of Health and Human Services (HHS) launched the National Adult Maltreatment Reporting System to collect information from state Adult Protective Services (APS). Information located online: <https://namrs.acl.gov>
- ¹¹ Supported Decision-Making Agreement, State of Alaska. Located online: dhss.alaska.gov/gcdse/Pages/projects/SDMA/SDMA.aspx

- ¹² Uniform Law Commission, Summary of The Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act 2017. Located online: <https://www.guardianship.org/wp-content/uploads/2018/04/UGCOPAA-Summary-Oct-2017.pdf>
- ¹³ Bifocal, Vol. 38, Issue 6. *ABA Urges Supported Decision Making as Less-Restrictive Alternative to Guardianship*. October 2017. Located online: https://www.americanbar.org/groups/law_aging/publications/bifocal/vol_38/issue-6--august-2017-/aba-urges-supported-decision-making-as-less-restrictive-alternat/
- ¹⁴ PRACTICAL Tool for Lawyers: Steps in Supported Decision Making, 2016. Located online: https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool/
- ¹⁵ *Autonomy, Decision-Making Supports, and Guardianship*, AAIDD and The Arc Joint Position, adopted 2016. Located online: <http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship>
- ¹⁶ *Beyond Guardianship: Towards Alternatives that Promote Greater Self-Determination of People with Disabilities*, National Council on Disability, March 2018 report. Located online: <https://ncd.gov/publications/2018/beyond-guardianship-towardalternatives>
- ¹⁷ Supported Decision-Making, Human Rights, and Legal Capacity for People with IDD. Honorable Kristin Glen, CUNY School of Law. Presentation June 11, 2019, at the National Resource Center on Supported Decision Making symposium. Presentation located online: <http://www.supporteddecisionmaking.org/>
- ¹⁸ National Core Indicators™ (NCI) Adult Consumer Survey 2017-18. See New York state report, p. 13. Located online: https://www.nationalcoreindicators.org/upload/core-indicators/2017_IPS_NY.pdf
- ¹⁹ Glen, Kristin, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, Cardozo Law Review. Vol. 39:495, p. 503. Located online: <https://sdmny.org/download/piloting-personhood-reflections-first-year-supported-decision-making-project/?wpdmdl=1576&ind=Qk9PVEguR0xFTl8uMzkuMi5wZGY>.
- ²⁰ Glen, Kristin, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, Cardozo Law Review. Vol. 39:495, p. 503. Located online: <https://sdmny.org/download/piloting-personhood-reflections-first-year-supported-decision-making-project/?wpdmdl=1576&ind=Qk9PVEguR0xFTl8uMzkuMi5wZGY>.
- ²¹ Evaluation of the Supported Decision Making Project, Office of the Public Advocate, November 2012. Report by Margaret Wallace and Associates, p.8. Located online: http://www.opa.sa.gov.au/resources/supported_decision_making and *SDM Pilot, and Spectrums of Support: A Report on a Project Exploring Supported Decision Making for*

People with Disability in the ACT, ACT Disability, Aged and Carer Advocacy Service, September 2013, p. 7. Located online:
<http://www.adacas.org.au/media/1083/spectrums-of-support-final-20130911.pdf>

- ²² SDMNY Planning Group members: Project Director (Kristin Glen), Hunter College faculty (Michelle Ballan, John Brown, Gina Riley and Michael Siller); NYSACRA, now the New York Alliance for Inclusion and Innovation (Ann Hardiman and then Desiree Loucks Baer); and the Arc Westchester (Larry Faulkner).
- ²³ Glen, Kristin, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, Cardozo Law Review. Vol. 39:495, p. 504. Located online:
http://cardozolawreview.com/wp-content/uploads/2018/08/BOOTH.GLEN_39.2.pdf
- ²⁴ Cher Nicholson, Founder and Lead Trainer, The Practical Facilitation S.D.M. Training. Train the trainer model. Contact information: +61-409-302-687, cher.nicholson@bigpond.com, ASSET SA, Adelaide, South Australia
- ²⁵ Evaluation of the Supported Decision Making Project, Office of the Public Advocate, November 2012. Report by Margaret Wallace and Associates, p.8. Located online:
http://www.opa.sa.gov.au/resources/supported_decision_making
- ²⁶ Pell, E., and Mulkern, V., Supported Decision Making Pilot: Pilot Program Evaluation Year 2 Report, p. 19. Located online:
https://www.hsri.org/files/uploads/publications/SDM_Pilot_Evaluation_Year_2_Report_HSRI_2016_FINAL.pdf
- ²⁷ Report on the 2012 National Survey on Abuse of People with Disabilities:
<http://disabilityabuse.com/survey/survey-report.pdf>
- ²⁸ Pell, E., and Mulkern, V., Supported Decision Making Pilot: Pilot Program Evaluation Year 2 Report, p. 26. Located online:
https://www.hsri.org/files/uploads/publications/SDM_Pilot_Evaluation_Year_2_Report_HSRI_2016_FINAL.pdf
- ²⁹ Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision Making, Rebekah Diller, Benjamin N. Cardozo School of Law. Presentation June 11, 2019, at the National Resource Center on Supported Decision Making symposium. Presentation located online:
<http://www.supporteddecisionmaking.org/>
- ³⁰ National Council on Disability report, Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities, p. 33. Located online: <https://www.ncd.gov/publications/2019/turning-rights-into-reality>

Errata

Page	Original Text	Corrected Text	Explanation
iv	During the third year of the grant, Hunter/CUNY subcontracted with an independent consultant to conduct the one-year focused process evaluation reported here, related to SDMNY Restoration and Diversion pilot activity.	During the third year of the grant, Hunter/CUNY subcontracted with an independent consultant to conduct the one-year focused process evaluation reported here, related to SDMNY Restoration and Diversion pilot activity <u>at SDMNY's New York City pilot program site.</u>	The scope of this evaluation was limited to SDMNY's New York City pilot program site and did not include SDMNY's four additional pilot program sites.
1	The United States, North Korea, and Sudan are among those countries that have yet to do so.	The United States, <u>Botswana</u> , <u>Eritrea</u> , and <u>South</u> Sudan are among those countries that have yet to do so.	Sudan ratified on April 24, 2009, and the Democratic People's Republic of Korea ratified on December 6, 2016. By contrast, neither Botswana, Eritrea, nor South Sudan has done so.
1	The UNCRPD has made it to the Senate floor, but the majority vote has yet to be achieved.	The UNCRPD <u>ratification package</u> has made it to the Senate floor, but the <u>super</u> majority vote has yet to be achieved.	The U.S. Senate votes on the ratification instrument, not the treaty itself, and requires a supermajority for passage.
10	SDMA Facilitators and Mentors	SDMNY Facilitators and Mentors	The heading refers to facilitators and mentors participating in the SDMNY pilot programs.
23	Completing an SDMA using the SDMNY facilitation process typically takes twice as long or longer than expected, from a year up to 18 months.	Completing an SDMA using the SDMNY facilitation process typically takes twice as long or longer than <u>originally</u> expected, from a year up to 18 months.	Since expectations at project outset were for a 6-to-9-month process, 12 to 18 months represents exactly double that duration.
28	Adding video simulations, one for each of the three facilitation phases, in collaboration with Outside Voices, a theater group of people with IDD	Adding video simulations, one for each of the three facilitation phases, in collaboration with Outside Voices <u>Theater Company</u> , a theater group of people with IDD	Group's name corrected.
29	When facilitators have not been able to continue the	When facilitators have not been able to continue the	The Site Coordinator, not the mentor, is responsible

	SDMNY process to its completion (e.g., through the signing ceremony), either the assigned mentor or Site Coordinator has stepped in, or the mentor secured another facilitator.	SDMNY process to its completion (e.g., through the signing ceremony), either the assigned mentor or Site Coordinator has stepped in, or the mentor <u>Site Coordinator</u> secured another facilitator.	for facilitator assignments and reassignments.
30	SDMNY staff initiated SDMA user focus groups facilitated by mentors.	SDMNY staff initiated SDMA user focus groups facilitated by mentors.	The focus groups are not facilitated by mentors.
30	Mentor qualifications are twofold: first, completion of the SDMNY facilitator training, and second, successful facilitation experience with at least one decision-maker through the creation of an SDMA.	Mentor qualifications are twofold: first, completion of the SDMNY facilitator training, and second, successful facilitation experience with at least one decision-maker through the creation of an SDMA.	SDMNY requires that the mentor be further along in the facilitation process than the mentee.
31	Developing a training and resource manual for mentors is planned for Year 4.	Developing a training and resource manual for mentors is planned for Year 4.	SDMNY does not have plans to develop a training for mentors.
53	In New York State having a guardian means a person with IDD loses all legal capacity to make decisions about their life, including decisions about their health and health care, their finances, what kind of education, who to associate with, where to live, who to live with, and where to work.	In New York State having a <u>17A</u> guardian means a person with IDD loses all <u>may lose</u> legal capacity to make decisions about their life, including decisions about their health and health care, their finances, what kind of education, who to associate with, where to live, who to live with, and where to work.	The original statement neglects to account for the difference between 17A guardianships of only the property or only the person, each of which affects a narrower scope of decision-making areas.
56	Prior to the SDMNY initiative, supported decision-making did not exist in New York State, though a number of alternatives to guardianship have been available, such as representative payees for SSI payments, joint or limited bank accounts, credit or bank cards with	Prior to the SDMNY initiative, supported decision-making <u>agreements were not used</u> did not exist in New York State, though a number of alternatives to guardianship have been available, such as representative payees for SSI payments, joint or limited bank accounts,	Supported decision-making, at least informally, has always existed, even if it has not been known by that name. SDMNY introduced SDMAs to New York State, as well as a specific process for developing them.

	predetermined limits, powers of attorney for financial decisions—and for health care decisions, people with IDD may execute a healthcare proxy.	credit or bank cards with predetermined limits, powers of attorney for financial decisions—and for health care decisions, people with IDD may execute a health_care proxy.	
76	One of the goals for SDMNY is to restore the decision-making rights of 45 individuals through adoption of SDMNY and discharge of guardianships.	One of the goals for SDMNY is to assist restore the decision-making rights of 45 individuals <u>subject to guardianship orders to create SDMA</u>s through adoption of SDMNY and discharge of guardianships.	SDMNY’s objectives do not include rights restoration of 45 persons, only the facilitation of agreements through the Restoration pilot program. SDMNY, through its legal arm DRNY, however, remains committed to ensuring that Restoration decision-makers receive legal aid to pursue rights restoration if they so choose.
80	The school-to-guardian pipeline is operating in New York.	The school-to-guardian pipeline is operating in New York.	The school-to-guardianship pipeline generally refers to a causal relationship whereby school personnel recommend that parents of students with IDD seek guardianship as part of their transition planning. However, this conclusion is likely beyond the scope of this evaluation.