

SUPPORTED DECISION MAKING PILOT: A COLLABORATIVE APPROACH

PILOT EVALUATION YEAR 1 REPORT

PREPARED FOR THE CENTER FOR PUBLIC REPRESENTATION
AND NONOTUCK RESOURCE ASSOCIATES, INC.

BY THE HUMAN SERVICES RESEARCH INSTITUTE

November 30, 2015



Elizabeth Pell, MSW, LICSW and Virginia Mulkern, PhD
HUMAN SERVICES RESEARCH INSTITUTE | WWW.HSRI.ORG

SDM Evaluation Report

Year 1: Pilot Design and Adoption of SDM

Year 1 Evaluation Summary

The Center for Public Representation (CPR), a nonprofit law firm focusing on disability rights in Massachusetts and across the country, and Nonotuck Resources Associates, Inc. (Nonotuck), a service provider principally of residential supports, partnered to offer adults with intellectual and/or developmental disabilities living in western Massachusetts an opportunity to use Supported Decision Making (SDM). This SDM pilot is a two-year project.

CPR and Nonotuck initiated this SDM pilot with a collaborative approach from pilot design, to project management and implementation, to conducting project outreach and education to broader communities.

CPR contracted with the Human Services Research Institute, a nonprofit research and consulting organization, to conduct an independent evaluation of the pilot. This evaluation aims to identify challenges and implementation recommendations to inform broader SDM adoption.

This report presents SDM pilot activity and evaluation findings from the first year. Year 1 focused on the project's development and adoption of SDM by pilot participants. Selected evaluation findings for Year 1 of the pilot follow:

- CPR and Nonotuck planned and launched a collaborative, thoughtful SDM pilot faithful to supported decision-making principles.
- The partners created and solicited advice of a stakeholder Advisory Council and implemented Council recommendations.

- CPR and Nonotuck staff engaged in SDM conversations with nine adults with intellectual and developmental disabilities and executed SDM arrangements for seven. SDM adopters range in age from young to older adults with varying levels of intellectual disability. Some adopters have serious medical conditions including dementia. All were considered by pilot team to understand the basic concepts of SDM.
- SDM adopters chose multiple decision supporters and people well-known to them, primarily family members and live-in caregivers. This seems to illustrate the similarities, noted by Nonotuck staff, between shared living (people with disabilities sharing a home with people without disabilities who receive a stipend for providing care) and supported decision making.
- SDM adopters elected decision aid broadly, opting for decision assistance across all the types of decisions (financial, medical, etc.).
- CPR-Nonotuck's SDM pilot provides information useful for development of SDM guidance and tools for replication more widely.

A list of SDM lessons learned during Year 1 of this demonstration project—pilot establishment and individuals' adoption of SDM—is located in Attachment A. During Year 2 the pilot SDM initiative and evaluation will focus on the experience of using SDM and the impact on people's lives.

TABLE OF CONTENTS

Year 1 Evaluation Summary	1
Brief Description of Supported Decision Making and Context for Pilot	3
SDM Pilot Establishment	5
Step 1. Partnership	5
Step 2. Pilot Staff Orientation to SDM	7
Step 3. Initial SDM Planning Meeting	8
Step 4. Pilot Team Communication and Project Management	10
Step 5. Advisory Council Formation and Role	12
Step 6. Independent Evaluation	13
SDM Participant Selection	15
Step 7. Identify SDM Participants	15
Step 8. Participants Select Decision Supporters	21
Step 9. Participants Select Areas for Decision-Making Assistance	24
SDM Adoption	26
Step 10. SDM Documentation	26
Step 11. Structure Safeguards	31
SDM Outreach and Awareness Activity	32
Step 12. Raise Awareness about SDM	32
Step 13. Provide for Sufficient Resources	34
Year 1 SDM Pilot Evaluation Wrap Up	36
List of Charts and Tables	
Chart 1. Relationship of Decision Supporters to Participants	21
Chart 2. Number of Decision Supporters per Participant	23
Chart 3. Length of Time Participants have Known their Nonotuck Care Managers	31
Table A. Personal Characteristics of SDM Participants	20
Table B. Legally Recognized Decision Making: Prior to and After SDM Adoption	28
Table C. Pilot Resource Investment: Pilot Establishment and SDM Adoption	35
Attachments	
A. Pilot-informed Guidelines for Establishing SDM Initiatives in the U.S.	38
B. Supported Decision Making Representation Agreement	41
C. CPR Preparation for Initial SDM Meeting with Pilot Candidate	45
D. Subsequent CPR SDM Meetings with Pilot Candidate	46
Resources and References	48

Brief Description of Supported Decision Making and Context for Pilot

Simply put, Supported Decision Making (SDM) is an alternative to guardianship where a person with a disability keeps his/her legal rights to make decisions and uses designated supporter(s) for decision-making assistance where needed.

SDM is incorporated in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), an international treaty passed in 2006. The purpose of this disability rights treaty is to “...promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.”ⁱ

Article 12 of the treaty lays out principles of SDM, including that people with disabilities have the right to make decisions about their lives, that decisions should be based on the individual’s will and preferences, and there must be legal recognition for decisions.

To date, 149 countries have signed the treaty. America is not yet fully pledged. President Obama signed the treaty in 2009 but the U.S. Senate has since failed to ratify. SDM has been adopted by seven countries and several provinces in Canada.ⁱⁱ

In the United States, adults with intellectual and/or developmental disabilities (I/DD) are particularly at risk for losing their legal right to make decisions about their lives. Decision-making rights are often removed and awarded to a substituted decision maker as occurs under guardianship.

Within the United States, the rate of guardianship for adults with I/DD receiving publicly funded services varies widely by state. National Core Indicators (NCI) data reveal the extent of

variation across 41 member states in the percentage of adults with I/DD receiving publicly funded services under guardianship. In Louisiana, 7 percent of the adult service population with I/DD have court-appointed guardians; whereas in Missouri, 83 percent of individuals with I/DD receiving services are under guardianship.ⁱⁱⁱ

This range in court-appointed guardianship signals that something other than personal characteristics of individuals influences the rate of guardianship adoption across states.

Guardianship laws and practices in the United States are state specific, but in every state guardianship tends to be a permanent loss of decision making rights for individuals with I/DD. Even in states such as Florida—where guardians are required by law to actively assist their wards to gain experience making decisions, to review the need for continued substituted decision making, and to report to the court annually—no examples of rights restored were found when studied.^{iv}

Loss of rights is not the only outcome that accompanies guardianship. NCI data show significantly different life experiences between adults with I/DD with and without guardians. Adults who are not under guardianship are more likely to:^v

- Be employed in an integrated job
- Have more extensive friendships (i.e., friends beyond family members and paid staff)
- Date without restriction (if not married or living with a partner)
- Have unrestricted use of phone and Internet in their homes, and
- Make choices (or have more input into decisions) regarding where they live, who they live with, their daily schedules, and how to spend their personal funds.

SDM aims to be a mechanism to support people with disabilities to make decisions about their lives with support where necessary. SDM avoids the loss of rights and decision making experience that occur under guardianship.

SDM Demonstration Projects in the United States

The SDM pilot described in this report is a partnership between the Center for Public Representation (CPR) and Nonotuck Resource Associates, Inc. (Nonotuck). When CPR and Nonotuck initiated this SDM pilot, there were no similar pilot projects in the United States to explore SDM implementation and determine under what circumstances it is likely to be most successful. Contributing to the knowledge base was one the two major goals for the project:^{vi}

1. Maximize individuals' independence: By directing their own decision-making process and making their own decisions, pilot participants will gain confidence and become better self-advocates. They will have both a voice and a presence in the community.
2. Identify best practices and factors that can be replicated as models that advance supported decision-making as an alternative to restrictive guardianship. How can supported decision-making best be implemented to make a positive difference in an individual's life?

At this point in time, SDM is thick on theory but thin on implementation and best practice guidance. Karrie A. Shogren and Michael Wehmeyer note in "A Framework for Research and Intervention Design in Supported Decision-Making" that information is needed related to how, with whom, and with what supports SDM is most successful. These authors note that SDM tools are needed.^{vii} Information from this pilot is intended to contribute to operationalizing SDM in this country.

Since CPR and Nonotuck initiated their pilot, Texas passed legislation enacting SDM into state law, and the U.S. Administration on Community Living funded a national technical assistance center to research and advance SDM. In 2015, five SDM projects were funded by the National Resource Center on Supported Decision Making to advance SDM for individuals with I/DD and older adults in Delaware, Wisconsin, Maine, North Carolina and Indiana. Each project has a different emphasis and approach. In Wisconsin a hotline offers callers free advice about the continuum of legal decision supports available in Wisconsin, including SDM. In North Carolina, SDM is now incorporated into life planning with adults with I/DD. For more information about the National Resource Center on Supported Decision Making, visit:
<http://supporteddecisionmaking.org>.

CPR-Nonotuck SDM Pilot Duration

The formal period for the pilot partnership and evaluation is two years. However, SDM Agreements are expected to continue indefinitely into the future and to be modified as people's lives change.

Report Format

Although this evaluation report shows pilot development and implementation as a series of 'steps', project activity was not always as linear as the word step implies. HSRI presents lessons learned and successful practices (in this report referred to as 'practice recommendations') as a series of steps to facilitate replication of SDM initiatives.

SDM Pilot Establishment

Step 1. Partnership

Center for Public Representation (CPR)

CPR is a nonprofit law firm focusing on disability rights in Massachusetts and across the country. CPR staff have been working to advance and protect the human and civil rights of people with disabilities for over 40 years. CPR's legal advocacy has been instrumental in changing the landscape by establishing community-based services and enhancing lives. Every several years, CPR engages in a comprehensive priority-setting process to establish its systemic advocacy agenda; this process is undertaken with assistance from CPR staff, Board members, people with disabilities, and advocates from around the nation. In 2013, the overuse of guardianship was identified as a systemic issue and SDM as a response. CPR's Board of Directors prioritized a SDM pilot, and the staff approached Nonotuck to collaborate.

Robert D. Fleischner, lead attorney for this pilot, is a national expert in guardianship law and practice, and has authored numerous articles on the subject of guardianship reform. He has provided technical assistance to the federal Protection and Advocacy System on issues related to guardianship and reform of guardianship law and practice for decades. For additional information on CPR and other staff collaborating on the SDM initiative, visit: <http://www.centerforpublicrep.org>.

To pilot an SDM initiative, CPR looked for a partner with shared human dignity and community integration philosophy and values that served people with intellectual and developmental and other disabilities. Serendipitously, Nonotuck's chief executive officer is also the brother of Attorney Fleischner at CPR. However, this is the first time they and their organizations have directly collaborated.

Nonotuck Resource Associates, Inc. (Nonotuck)

Nonotuck has provided personalized housing and other community based supports to individuals with intellectual and developmental disabilities since 1972. The organization currently supports over 800 people in Massachusetts. Nonotuck's CEO, George Fleischner, established "shared living" as the agency's primary service by closing all of its group homes and moving people into shared living situations. This process was, and still is, a first in Massachusetts.

"Shared living" can mean different things across states. In Massachusetts shared living is when an individual with a disability and a person without a disability choose to live together. Typically they live in the home of the person without a disability who receives a stipend to provide care. Caregivers can be unrelated people (shared living model) or relatives (adult family care model). Shared living promotes relationships, advances choice and control in peoples' daily lives, and is founded on equality between the person served and their caregiver(s). Nonotuck also offers case management (referred to as care management) and in-home nursing case management to promote integration and deter institutionalization. For additional information on Nonotuck, visit: <http://www.nonotuck.com>.

Practice recommendations

1a. Partnership between a legal advocacy and a service provider organization is useful for establishing SDM.

1b. Partnership and collaboration is facilitated when organizations share values.

Leadership and staff from both pilot partners, CPR and Nonotuck, operate with a vision to assist people with disabilities to live lives free of segregation and discrimination. Both organizational cultures share the belief that all

people must be able to exercise choice in all aspects of their lives. Having shared values, and demonstrated experience operating according to those values, is considered by both organizations to be a key component of the pilot's successful collaboration.

Their website on the SDM pilot affirms, "All adults, including individuals with disabilities, have will and preferences, and therefore have the right to make their own decisions, including life decisions about their health care, their finances, their relationships, where they work, where they travel, who they vote for, and where they live and with whom."
<http://www.supporteddecisions.org>.

Step 2. Pilot Staff Orientation to SDM

Practice recommendation

2a. Educate project staff about the legal and social foundation and constructs for SDM.

CPR staff educated themselves by reviewing SDM literature and law review articles, attending conference sessions, and consulting with scholars and practitioners in the United States and in other countries that adopted SDM. Their individual orientations were described by one staff member as “extensive.”

CPR staff prepared a Fact Sheet and internally circulated SDM information. The *Fact Sheet* was published to the Training and Support Center of the National Disability Rights Network and distributed to all the Protection and Advocacy programs in the United States. It summarizes key SDM developments, including the United Nations Civil Rights of Persons with Disabilities treaty, SDM articles, and the state of SDM adoption in other countries.^{viii}

Nonotuck staff were first exposed to the SDM concept when their CEO invited staff from the Center for Public Representation to present on SDM to care managers, supervisors, and other Nonotuck staff instrumental to a joint SDM initiative. CPR shared written materials including a handout outlining a CPR-Nonotuck SDM pilot project, the *Fact Sheet*, and an article titled, *Supported Decision-Making, A Viable Alternative to Guardianship?*^{ix}

Surprising to care managers was how the model of shared living provides people with I/DD everyday assistance with decision making, in some instances even avoiding guardianship. In the view of Nonotuck’s care managers, SDM placed the shared living experience into a legal rights framework.

SDM has really always been a value of our agency. Over time [the topic of] guardianship has come up and we said the person doesn’t need it. So when SDM came up as an option, and knowing guardianship removes people’s decision making rights, it seemed an extension of our agency and personal values.

–Nonotuck care manager

There is a beautiful symmetry between shared living and SDM. The guiding principles of shared living, authentic relationships, mutuality, and interdependence create a training ground for SDM.

–Nonotuck CEO

Since CPR and Nonotuck staff were oriented to SDM, additional information and resources have been published. The National Resource Center on Supported Decision Making posts resources and hosts periodic webinars on SDM, and the American Association on Intellectual and Developmental Disabilities (AAIDD) published a special edition focused on SDM in their March 2015 electronic journal *Inclusion*.^x

Step 3. Initial SDM Planning Meeting

Practice recommendations

3a. Set aside time to discuss SDM initiative framework, resources needed, and foreseeable implementation issues.

3b. Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.

On October 29, 2013, the partners gathered with SDM experts from the United States and Canada, disability rights advocates from the United States and Mexico, service provider representatives, sitting and retired probate judges, staff from the Open Society Foundations, and individuals with I/DD along with their family members and guardians, to kick off the pilot and strategize next steps. Originally conceived as a planning meeting, the kick-off evolved into a day-long forum with presentations and discussions that raised awareness about SDM. Significantly, the forum set aside time to hear from those with different perspectives and collectively consider how to roll out a thoughtful, collaborative initiative.

Over 50 people attended the event, which included presentations by the following:

- CPR and Nonotuck staff, describing their work and plan to launch an SDM pilot.
- SDM expert Michael Bach, presenting “Putting Supported Decision-Making into Practice.” This was noted as very informative for care managers. He shared a key disability rights issue of separating legal capacity from mental capacity. He noted that in Massachusetts, probate court law links legal and mental capacity. A person with cognitive impairment can be viewed as “incapacitated” and therefore at risk. At-risk individuals may be appointed guardians to legally make decisions for them. Mr.

Bach also presented the SDM principle affirmed in the U.N. Convention on the Rights of Persons with Disabilities treaty, that governments accommodate people to express their will and preference (whether verbally or through other means of expression). With such support, an individual would be able to inform third parties, such as a banker or a doctor, about his or her preferences.

- Judge Kristin Booth Glen, who has written about SDM and ordered it while a Surrogate’s Court judge in New York, presenting the importance of accommodation, the means by which a right is made real. “If human rights are about anything, it’s equality and dignity. You have to allow people to have human rights, to make decisions, and have those decisions recognized by others.” To get there, Judge Glen noted, our society must overcome enormous prejudice about people with disabilities.
- Michael Kendrick, a disability rights consultant, spoke about intentionally created networks of supporters. Networks could include “challengers,” people that push you a bit. Networks of supporters could also change over time; people could be in a network for a specified time, even a specific task.
- Kitty Curtin and Angela Procopio-Rahilly, Nonotuck shared living caregivers for 19 and 18 years respectively, spoke about how shared living prepares people in natural ways for SDM.

Forum discussion included safeguards, such as how to avoid exploitation by support networks and general community members. Currently sitting Massachusetts judges participating in the forum were particularly interested in safeguards from abuse. Judges also stressed the importance of public education about SDM

so that rulings in favor of SDM over guardianship would be understood in the context of advancing human rights, one person at a time.

Specific pilot safeguard suggestions were made:

- Create an advisory committee
- Provide for independent monitoring of the pilot project
- Draft regulations to define SDM concepts and accommodations
- Conduct widespread community education

Planning meeting discussions also covered who to approach about SDM. Attendees recommended that the pilot:

- Avoid legal struggles with families at the outset of the demonstration project and select only individuals with supportive families/guardians;
- Include individuals under guardianship or at risk of guardianship; and
- Include at least one adult under a non-family (i.e., paid) guardianship.

From this initial planning meeting, CPR and Nonotuck established an overall approach for the pilot:

1. Assist a small number of individuals with intellectual and other disabilities to test SDM
2. Establish SDM only for individuals whose families and support network are supportive of SDM adoption
3. Make a difference in people's lives; move away from substituted to shared, supported decision making
4. Establish and utilize an advisory group
5. Provide for an independent evaluation
6. Model SDM for use by Protection and Advocacy agencies

7. Raise SDM awareness. Conduct community education and report/publish/share experience and lessons learned.

Initial Planning Meeting Significance

Pilot staff noted the initial planning meeting was a remarkable experience that led to a more intentional pilot initiative. The take-away for staff from both organizations was enthusiasm for going forward, and how much everyone learned from one another.

Nonotuck staff learned about “civil death”—a phrase to describe the experience of people under guardianship whose rights to make everyday decisions (e.g., how to spend their money, who to live with, etc.) is legally given to someone else. CPR staff heard from people with disabilities and their families about their wishes and worries with SDM.

Step 4. Pilot Team Communication and Project Management

Practice recommendation

4a. Establish a clear pilot project team and clarify roles.

“We realized we needed communication more than anything else.” –CPR staff

Pilot Team

An early step was identifying the pilot staff from each organization. Initially eight CPR staff were deeply involved in mapping out the pilot and making decisions. This level of effort could not be continued given other system change initiatives underway. After several months, CPR allotted the day- to- day pilot responsibilities for to three staff members: a senior attorney, an attorney, and a legal advocate who became the project coordinator. The Executive Director and other staff attorneys remain deeply engaged and participate in monthly project team meetings between CPR and Nonotuck and meetings of the Advisory Council.

Nonotuck’s team too initiated the pilot with more staff than currently assigned. Nonotuck began with ten staff: the CEO, three program directors, the VP of Clinical Services, and five care managers with connections to individuals identified as interested in exploring SDM. At the end of the pilot establishment year, five Nonotuck staff are actively involved in the pilot: the CEO, a nurse, the VP of Clinical Services, a care manager and a program director.

Launching this initiative took more time and people from each organization than planned. The ratio of pilot staff to SDM adopters at the outset of Year 1, when activity focused on pilot establishment and SDM execution, was approximately two to one (2:1). At the end of Year 1, with activity focused on discharge of a guardianship and beginning to track use of

SDM, the ratio of pilot staff to participants dropped nearly in half and is now closer to one to one (1:1).

Project Management

Practice recommendation

4b. Schedule regular in person meetings with agendas to update one another and jointly plan next steps.

Pilot staff from CPR and Nonotuck did not start out with monthly meetings and agendas to coordinate next steps. However, they learned that when everyone was clear about each other’s roles and tasks and the timelines, progress was easier. Coordination necessitated regular meetings. Both organizations are headquartered in Northampton, Massachusetts, which and their close proximity helped facilitate communication and project coordination.

Meeting in person meant fewer distractions, and staff got to know one another and build respect for their different areas of expertise. Although most staff from CPR and Nonotuck convened at Nonotuck’s office, video conferencing was set up for remote project staff. HSRI, the evaluation entity, was invited to all monthly CPR-Nonotuck meetings and to share updates on evaluation activity.

CPR took the lead in project oversight and assumed responsibility for setting meeting dates, drafting agendas and suggesting timelines for next steps. CPR also took the lead on developing SDM educational materials and the form for adopting SDM.

Nonotuck took the lead role to identify interested individuals, families and guardians.

Cross-agency Problem Solving

Practice recommendation

4c. Clarify how problems will be resolved.

One early lesson was respecting one another's areas of expertise and consulting when concerns arose, particularly concerns unrelated to the SDM initiative. For example, CPR staff, used to interacting with individuals with an investigative and advocacy perspective, raised a concern about a shared living provider. When CPR mentioned the concern, Nonotuck staff offered information about the home situation and context. From this point forward, pilot staff agreed to check in with each other as soon as an issue of concern arose.

Step 5. Advisory Council Formation and Role

Practice recommendation

5a. Establish an Advisory Council to provide multiple perspectives on implementation.

Establishing an advisory group to guide the pilot was a recommendation from the initial planning meeting. Over the course of several weeks, pilot staff solicited potential members in multiple fields. On March 17, 2014, approximately five months after the initial retreat, the first Advisory Council meeting was held.

Pilot staff consider the Advisory Council an important sounding board to think through critical considerations as a group. They view the Council as the SDM pilot's own decision-support network.

Many people on the Advisory Council attended the initial planning retreat. Currently 12 members actively participate and represent key stakeholders. Advisors include people with disabilities, family members of people with disabilities, disability rights advocates, judges, and disability service providers. (See member list on the SDM project website: <http://supporteddecisions.org/pilot-project/mission-history-advisory-council/http://supporteddecisions.org/pilot-project/mission-history-advisory-council>.)

SDM Pilot Advisors are volunteers and meet, typically by video conference, several times a year to offer guidance on pilot structure and implementation. Recommendations are made by consensus.

All recommendations of the Advisory Council to date have been adopted and acted upon by CPR and Nonotuck.

Key recommendations from Advisors thus far include those generated from the initial planning meeting and since establishment of the SDM Advisory Council. A consolidated list of recommendations follows.

- Assist a small number of individuals with intellectual and other disabilities to test SDM. Make a difference in people's lives; move away from substituted to shared, supported decision making.
- Establish SDM only for individuals whose families and support network are supportive of SDM adoption.
- Establish and utilize an advisory group.
- Provide for an independent evaluation.
- Model SDM for use by Protection and Advocacy agencies.
- Simplify the SDM Representation Agreement. (The original version was written in language overly legal and technical.)
- Utilize a notary public to witness signing SDM Agreements so that community members feel more compelled to honor SDM decisions and decision supporters.
- Raise SDM awareness. Conduct community education and report/publish/share experience and lessons learned.
- Solicit funding for spreading the word about SDM and the pilot.

Step 6. Independent Evaluation

Practice recommendation

6a. Early pilot initiatives should establish an independent evaluation to safeguard SDM adopters with external review of implementation and to share lessons learned.

One of the contributions of the initial planning meeting was to recommend an independent evaluation to identify and share lessons learned and good practice information for SDM adoption more widely.

The Open Society Foundations (OSF) had representatives at the initial planning forum. OSF is interested in democracies with accountable governments, open to the participation of all people.^{xi} This mission embraces advancing SDM. OSF provided seed money to support the evaluation.

CPR contracted with the Human Services Research Institute (HSRI) to conduct the evaluation. This is a two-year pilot and evaluation. Year 1 pilot activity and evaluation focused on pilot establishment and adoption of SDM. Year 2 pilot activity and evaluation will focus on the experience of using SDM and the impact on people's lives.

HSRI is conducting a process evaluation, using interviews with pilot staff, SDM adopters and decision supporters to tell the story of project design, the experience of individuals and supporters, any impact on an individuals' life perceived to be linked to adoption/use of SDM, and the acceptance of supported decision making by community members.

Major goals of the evaluation include:

- Describing the experience of using SDM on participants, decision supporters, and involved community members

- Assessing the fidelity with which SDM is implemented
- Determining the degree to which the pilot met its goals/aims
- Assessing the degree to which SDM resulted in significant impacts on participants' lives
- Providing information useful for development of SDM guidance and tools for replication and sustainability

For this Year 1 report interviews were conducted with CPR staff and Nonotuck care managers. HSRI was given full access to project staff and invited to observe/listen in on monthly CPR-Nonotuck meetings, as well as all Advisory Council calls. Participation in the evaluation is voluntary for all pilot participants, including staff.

Institutional Review Board (IRB) Clearance

As this research involves human subjects, HSRI sought review and approval of the proposed evaluation plan and interview instruments from the Massachusetts Department of Developmental Services' Institutional Review Board (IRB). IRBs review research proposals to ensure vulnerable populations, including individuals with I/DD, are not subjected to harmful research practices. IRB review is a safeguard to ensure that research participants understand the nature of the research, that the risks and benefits are transparent, and that consent is informed.

IRB approval was granted for this evaluation and all the interview instruments and consent forms prepared by HSRI. However, IRB committee members asked CPR and Nonotuck to respond to two concerns:

- 1) That guardians already in place be kept in contact with designated supporters; that guardians be kept apprised of what is going on throughout this research; and

2) That designated supporters have appropriate training to be sensitive to the needs of individuals with I/DD, and that the individuals in the pilot exercise independence and freedom from coercion in the selection of designated supporters.

CPR staff responded to the IRB Chair:

At the outset, the pilot included three individuals with guardians. Each guardian voiced support of this project which seeks to advance supported decision-making as an alternative to guardianship. One guardian is a parent who is a designated supporter on her son's team. The project has spoken with attorneys for the parent and the individual, both of whom support terminating guardianship. Another guardian is a brother who will be a designated supporter on his sister's team. The third pilot participant with a guardian died in February. We are inviting her guardian, a long-time paid guardian in the probate court system, to join our Advisory Council. He was supportive of this project for this particular individual, and we hope he joins the Council.

In response to the second concern, it is noteworthy that most, if not all, of the supporters who have been designated thus far by pilot participants are family members and/or present or past providers and caregivers. All are sensitive to, and well apprised of, the individuals' values, preferences, needs and wants. In addition, the project is developing a series of trainings for designated supporters, community leaders, medical personnel, school administrators, and other members of the general public as well as the Advisory Council and CPR and Nonotuck staff.

Further, the pilot participants have been encouraged to be independent in their designations of supporters. As noted above, most have designated family members and/or local past and present providers. One has selected a friend who lives in Pennsylvania; one has selected a parent who appears to have a tangential role in her life. Those independent designations have to be respected. In lieu of face-to-face trainings for designated supporters who are not local or unable to attend for whatever reason, we will provide/send materials, documents, etc., and make ourselves available as needed.

The IRB concern that guardians be kept apprised and in touch with decision supporters makes sense in this pilot. However, it could be a concern when individuals want to contest a guardianship over the objection of the guardian. The case of Jenny Hatch,^{xii} who opposed her parents as guardians, is an example. That judge ruled in favor of Ms. Hatch, removing the guardianship after one year in favor of her adoption of SDM. Likewise in a case called Guardianship of Demaris L, a Surrogate's Court judge in New York removed a woman's guardian over the objection of her mother in favor of a SDM arrangement.^{xiii}

SDM Participant Selection

Step 7. Identify SDM Participants

Practice recommendation

7a. Prior to meeting with putative SDM adopters, prepare plain language educational materials. Include a brief explanation of what SDM is, why it is an important rights issue, and what the practical impact is expected to be if adopted.

Nonotuck Initial Screening for Pilot Participants

Nonotuck had the important role of introducing SDM to its care team and then to individuals, live-in caregivers, family members and guardians. CPR and Nonotuck determined that, for the first year of the pilot, that only people with disabilities whose family members and/or guardians expressed support of SDM were would be considered for inclusion in the pilot. All pilot participants are free to withdraw at any time.

Nonotuck's CEO, care managers, nurses and supervisors discussed and reviewed records of nearly 100 people that met targeted characteristics. Twenty people were identified as potential pilot participants. Nonotuck staff next developed personalized strategies to introduce individuals to SDM and the pilot initiative. All approaches featured in-person conversations and an iterative process.

With some individuals, Nonotuck started with the participant him/herself. For others, care managers began the process with discussions and distribution of information to the participant's caregiver or family members. In some cases, other individuals, such as attorneys and other Nonotuck staff, were included in initial conversations. Those interested in

learning more about SDM gave permission to have their contact information shared with CPR.

As Nonotuck staff met with individuals with I/DD, their live-in caregivers, family, and guardians, they realized having something in writing that described SDM and the pilot would be useful for conversing about SDM and the pilot with reliability, that is, consistently answering questions and using the same terms in the same way. Printed information would be also be useful as it could be left for people to review later.

CPR created written information materials that helped all pilot staff engage with consistency and reliability. An initial one page handout formed the basis of a brochure about the pilot. The brochure went through several reviews, including critique by the Advisory Council. CPR staff stated it would have been useful to have created the information documents earlier, prior to meeting with people.

Nonotuck's list of those interested was in flux for several months. By October of 2014, nine adults were identified as definitely interested in exploring SDM, three of whom were under guardianship. Two of the guardians were family members and one was a corporate guardian. These candidates represented individuals with characteristics recommended by the initial planning meeting advisors, e.g., all participants, family and guardians interested in adopting SDM. Since then the older woman with a corporate guardian died, leaving eight candidates in the pilot, seven of whom currently have executed SDM Agreements.

CPR Conversations with Interested Individuals, Families and Guardians

Practice recommendation

7b. Where legal staff do not have regular communications with people with I/DD, consider utilizing an expert to role model SDM introductory conversations. Review interview guidance for conversations with people with I/DD such as *Disability Etiquette*.

After Nonotuck staff identified interested individuals and families/guardians, CPR staff then met in-person with individuals, their families and guardians, caregivers and Nonotuck care managers to explain and explore SDM in more detail.

Although attorneys are used to meeting with people and talking about issues of concern, CPR staff realized it would be prudent to ask an expert to role model conversations with individuals with I/DD about the amorphous concept of SDM. Michael Kendrick, a disability rights advocate who has consulted with several countries on SDM implementation, facilitated the first few meetings with CPR staff and individuals interested in exploring SDM. Nonotuck care managers were typically present, as were live-in caregivers.

Practice recommendation

7c. Prior to meeting with a person with I/DD, find out about a person's life and communication style.

Nonotuck recommended to CPR that it would be helpful to speak with care managers prior to meeting with an individual to find out what accommodations would be necessary, where that person would feel most comfortable, what the person did during the day, their health and any concerns, how involved the family was, and how they were matched with live in caregiver.

"It was important to go in knowing something about the person that mattered."—CPR staff

Practice recommendation

7d. Allow extra time for individuals with I/DD and their family members and care givers to get comfortable so they can freely express reservations and ask questions.

Most meetings between CPR staff and individuals occurred in the person's home. One staff member stated that meeting at people's homes was helpful and informative. "People were more comfortable, and [we] learned much more about the person and their caregivers, who were frequently identified as decision supporters."—CPR staff

Practice recommendation

7e. Expect to meet more than once with individuals with I/DD to present and discuss SDM.

CPR staff also reported learning to give "much more time" to these meetings than anticipated. Time was needed to get to know a person (what they like, what they don't like, what they do when they are frustrated, etc.) before moving into specific SDM considerations.

CPR staff also revised their expectation that individuals and families would "get SDM" in one meeting. In most cases, CPR-facilitated conversations (which occurred subsequent to Nonotuck's SDM screening meetings) played out over two or three face to face meetings with the individuals and potential supporters. Nonotuck case managers also attended these meetings.

When SDM conversations covered multiple meetings, CPR staff learned not to pick up where they left off but to re-introduce SDM, and summarize information from earlier meeting(s). "We found we had to keep starting

over each time we met. We needed several meetings to gauge if a person really understood.”—CPR staff

CPR also learned how helpful it was that Nonotuck staff were having interim conversations with individuals and others. In between meetings with CPR staff, Nonotuck staff held conversations with interested individuals, their families, SDM supporters, CPR staff, and the Department of Developmental Services staff. Nonotuck staff answered questions, were a link to CPR, explained SDM, reassured families, negotiated issues of SDM between the participant and identified decision supporters, and helped explain the decision supporter role. SDM morphed into an additional item on the Nonotuck care manager job description and home visits now included a lengthy SDM discussion. Nonotuck’s CEO noted his staff took on this responsibility with enthusiasm, purpose and care.

Practice recommendation

7f. Create a script for pilot staff to guide SDM conversations.

CPR also learned not to leave too much time between meetings as people’s lives frequently changed between meetings and to keep written communication brief. “It’s important to have regular ongoing communications with families and people adopting SDM. A stack of papers can be overwhelming, especially if you don’t read. Go over the concept and remind people what they are undertaking, remind them that they are in control, and remind them that they can change their mind.”

The most often requested written material about this SDM initiative was a blank SDM Representation Agreement. “It was comforting to people that this was not an informal guardianship. They could review it and ask

questions about it later. It was useful for everyone.”—CPR staff

In these SDM individualized conversations, CPR staff determined an individual’s preferences for:

- Participating in SDM pilot
- Areas where decision making assistance was needed and wanted
- The specific decision supporter(s) to provide decision assistance in each decision domain in the SDM Agreement
- How the person wanted to use decision supporters, that is, sequentially or jointly, or turning to one supporter for health decisions and another for relationship decisions

While the majority of SDM conversations went smoothly, CPR staff were, on at least one occasion, unnerved by families who related to individuals in dismissive ways. During one SDM meeting a family member initially expressed incredulity that a person “with the mind of a six year old” could use SDM. As raised at the initial planning meeting-forum, mental capacity and legal capacity are strongly linked in the U.S., both in guardianship law and public perception of capacity. When CPR staff encountered such remarks, they turned conversation to positive supports in a person’s life. Most of the individuals and families with whom CPR held conversations to explore SDM described family members and guardians as enthusiastic once they understood SDM.

CPR staff also learned to direct conversation to the participant and avoid conversation only between CPR staff and the caregiver or family member. This is a very important concept to individuals with I/DD when being interviewed. (A useful resource is *Disability Etiquette: Tips on Interviewing People with Disabilities* at this link: <http://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf>.)

CPR developed conversation agendas to guide SDM conversations with interested individuals, both for initial and subsequent meetings. These outlines incorporated their lessons learned. See Attachment C and D for SDM initial and subsequent meeting guidance utilized by legal staff.

Practice recommendation

7g. Establish a protocol with frequency and a responsible entity to periodically communicate to individuals their freedom to choose to withdraw from pilot without repercussion.

A variety of materials were provided to participants and supporters including the CPR Overview, a draft SDM Agreement, and, in one case, a visual that explained each decision area.

Participant Understanding of SDM

Participants in the SDM Pilot appear to have been well supported in learning about the SDM process and in the selection of decision supporters. Care managers were present for meetings to introduce the SDM model to participants and their supporters.

Care managers have known the participants for many years. The range of time was three to thirty years; five participants had known their care manager for ten years or more.

The evaluation asked CPR staff if they were surprised to discover anything during planning stage that should be shared with other legal advocacy organizations supporting SDM adoption. “Yes, how many meetings it took to get to execute SDM Representation Agreement. The interest in advance directives and HCP. The real enthusiasm by participants and families. I thought it would be less accessible, but Nonotuck had pre-selected people.”—CPR staff

Care managers concurred that after the orientation process all participants understood the basic principles of SDM and what their

agreement entailed. Care managers shared the following about participants’ understanding:

She understands the basics. She likes the idea she has a crutch and she expressed this at the first meeting. It’s the first time in her life she is being told you have choice and control (she has tentativeness) and can talk about any decision. But until it’s practiced it is rather nuanced.

[Name] has a clear understanding of who helps him understand his decisions. He understands that there will be a team of people there to help him.

We were there with the lawyers and the benefits of SDM were described. She turned to caregiver and said, “So you all will help me make decisions when I need it? We do that now.”

[Name] understood bits and pieces of SDM from the initial meeting. She does understand who to go to for support. It took a couple of meetings and my one-on-one meetings to help her understand the whole scope of SDM.

[Name] understands fully that when she is unsure of a decision she can get support and help with understanding it through her sisters, as both are supporters.

If someone does not know [name] and understand her processing, she can be looked at as someone who could be a candidate for guardianship. However, she is very competent and just needs support to understand, and time to answer the questions.

Personal Characteristics of SDM Adopters

The eight adults participating in this pilot have some diversity of life experiences and personal characteristics. Table A on page 20 contains

some demographic information about the adults who adopted SDM.

At the outset, there were nine SDM pilot participants, including three individuals under guardianship. One of the participants under guardianship, an older woman, died prior to executing an SDM Agreement. Another participant under guardianship executed an SDM Agreement; and the other is still considering SDM as an alternative to guardianship and has yet to enter into an SDM Agreement.

Table A. Supported Decision Making Pilot Participant Demographic Information

Demographic Category	Pilot Participant Information
Age	24 to 79 years. When pilot initiated, age range was 23 to 78 years.
Gender	6 females, 2 males
Primary means of communication	8 (all) use speech but there is vocal expression range, specifically: <ul style="list-style-type: none"> • 1 primarily uses “yes” and “no” with facial expression • 1 relies heavily on text messaging • 1 needs a lot of time to process information and respond
Intellectual disability diagnoses	2 Mild intellectual disability 5 Moderate intellectual disability 1 Not diagnosed with intellectual disability
Developmental disability diagnoses	3 Down syndrome 3 Other developmental disabilities
Behavioral health diagnoses	1 Borderline personality disorder, history of suicidal preoccupation 2 Bipolar mood disorder 4 Anxiety disorder 2 Depression/dysthymia 1 ADHD (attention deficit hyperactivity disorder) 1 Psychotic disorder 1 Post-traumatic stress disorder (PTSD)
Significant medical conditions	2 Dementia 1 Seizure disorder 1 Obesity 1 Incipient cataracts 2 Hypothyroidism 1 Pre-diabetic 1 Congestive heart failure
Living arrangement	4 live with family (Adult Family Care) 4 live with non-relative care providers in care provider’s home (Shared Living)
Employment status	1 retired (used to own a house cleaning business) and attends a day program 3 have part time community jobs with small groups of people with disabilities 3 have individual jobs in their communities 1 volunteers in a couple of community locations
Risk of guardianship	2 older women with dementia would be at risk if not using shared living service model. (1 experienced a change of home and live in caregiver due to behavior related to dementia progression.)
History of institutionalization	5 have never lived in an institution for persons with disabilities. 2 lived for decades in different Massachusetts state institutions for people with I/DD. 1 resided in residential schools between ages 9 and 22, then lived in group home until her late twenties.

Step 8. Participants Select Decision Supporters

Practice recommendations

8a. Provide opportunity for staff participating in selection discussions to debrief following sessions to insure consistency with respect to assurance of individual's choices and how any persuasion or disagreements might best be handled.

SDM adopters were encouraged to be independent in their designation of decision supporters by all pilot staff. Care managers reported the process of selecting decision supporters was generally smooth.

Three participants did have some selection issues. In one case, a participant wanted to include his grandmother on the support team. However, after discussing his grandmother's failing health with his family, the participant decided not to include her. (His grandmother has since passed away.)

In a second case, a participant wanted to include her job coach in her decision support network. After discussions with CPR about the personal information she would need to share with her job coach in order for the job coach to be able to help with medical and financial decisions, the participant decided to omit her job coach.

A third participant expressed the desire to have a friend, a person with a disability, participate on his decision support team. However, he and the friend have had an unstable relationship. After discussion with his family, he decided not to include the friend at this time.

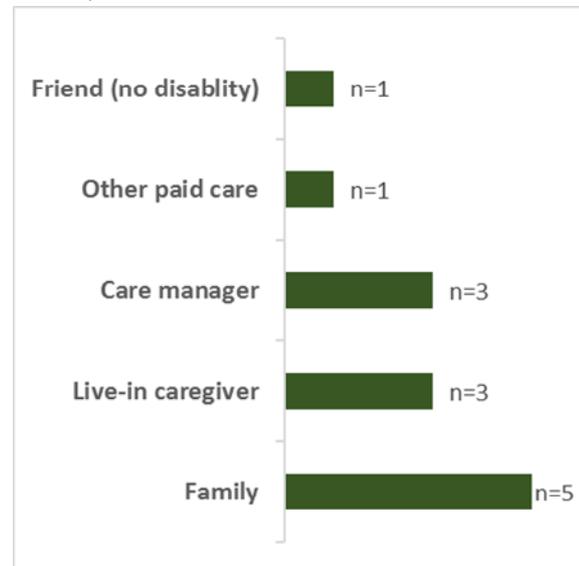
Decision supporters designated by the seven SDM adopters to date are all people well-known to individuals. Most common was selecting family members. All participants with involved family included family members as decision

supporters. Six of the seven participants with executed SDM Agreements selected at least one decision supporter paid to provide support in their life -- either as a live-in caregiver, a care manager or a respite provider. All participants utilizing shared living included their live-in caregiver.

Five participants chose family members to be on their decision support team, three included their Nonotuck care manager, and three chose their live-in caregiver. One participant included a long-time friend who does not have a disability. None of the participants included a friend with a disability as a decision supporter.

Next year HSRI will report on participant satisfaction with decision supporters and decision outcomes. Chart 1 below illustrates the types of relationships in executed SDM Agreements between participants and their selected decision supporters.

Chart 1. Relationship of Decision Supporters to Participants



Practice recommendation

8b. Shared living offered participants a community member as a potential decision supporter they trusted.

Care managers and at least one participant noted the likeness of shared living to SDM. But one of the main concerns with SDM is that people will be unduly influenced by others and there will be insufficient checks and balances.

At least one decision supporter was present when CPR met with participants and discussed decision supporter selection. In all cases, the care manager reported participants would have selected the decision supporter regardless.

“We are still trying to grapple with SDM. Philosophically to what degree is it really giving control to an individual and to what degree is the circle a coercive form? The constitution of a team matters. There is a comfort level when one lives with a caregiver. [Participant name] has lived with [caregiver name] for 15 years. They have developed a relationship of trust and know one another.”—Nonotuck care manager

CPR staff too voiced concern about potential in SDM to be coercive, “When used, will SDM express a meaningful voice and decision making process—meaningful in that it is truly about an individual making a decision with support and not another way for others to impose choice? It is important it not be misused. We wouldn’t want anyone in the group of support to think this allows decision making for someone without a court or other oversight.”

As it unfolded, participants chose decision supporters who understand not only intellectual and developmental disabilities and the service system, but the participants’ values, preferences, needs and wants. As noted above, five participants executed SDM Agreements that include family members known over the participants’ entire life.

One unexpected selection process development was nomination of a Nonotuck care manager to the decision support network by three participants. These participants have the same care manager. In these cases, the care manager

has a dual duty. As a care manager, the responsibility to assess the fitness of services and supports and ensure a person’s satisfaction. As an SDM decision supporter, responsibility to explore preferences, ensure preference is made known and decision respected. This care manager sees no conflict of interest with having both roles as both require the same core values to support a person to make informed decisions and have preferences respected by others.

Did SDM Conversations Reveal New Information to Care Managers?

Practice recommendation

8c. Even when individuals and service providers are well-known to one another, SDM conversations can lead service providers to learn something new about people they support.

One of the evaluation questions asked care managers if they learned anything new about individuals from SDM conversation meetings. Half of the care managers noted they did not learn anything new – which they attributed to how long they have known these participants and how much they are involved in their lives. But several reported a deeper understanding did result from SDM conversations.

One care manager with a personal philosophy that one learns something new about people all the time, shared that he learned how one participant understands financial decisions and how to better assist in this area. “I learned that with the proper approach, not just asking him a question, but with the proper understanding of what is being asked, he can answer.”

Another care manager learned that a participant’s father did not realize the individual was under guardianship, “He was shocked.”

And this comment from a care manager who saw SDM conversations empowering for one

participant, “[Person’s name] understood the concept of SDM and made a life decision on his own that he wanted his sister to be there for him and to support him outside of Mom and Dad. It was great hearing his voice!”

One of the evaluation questions asked care managers if there is an expectation that the SDM experience assist pilot participants to move beyond the need for decision-making support. Of the five care managers, three replied no, one replied yes, and two were unsure.

Size of Decision Support Networks

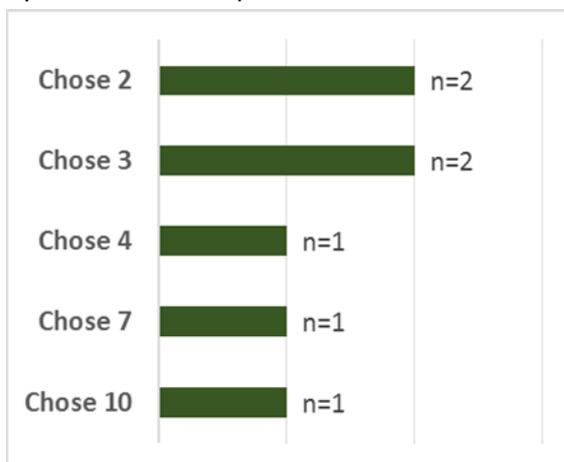
Practice recommendation

8d. Participants were inclusive when nominating decision supporters.

The biggest surprise in the selection of decision supporters was the number of supporters participants selected.

Participants selected from two to 10 decision supporters. None of the participants selected just one decision supporter. Five participants selected three or more decision supporters. See Chart 2 below for the number of decision supporters selected per participant.

Chart 2. Number of Decision Supporters Chosen by SDM Pilot Participants



Step 9. Participants Select Decision Processes and Areas for Decision-Making Assistance

Decision Trees – How will decisions get made with so many supporters?

Practice recommendation

9a. When more than one decision supporter is chosen, describe in the SDM Agreement how multiple supporter consultation is to work.

Given the number of supporters selected by several participants, a clear understanding of how decision support is provided and how potential differences of opinion will be handled is necessary. The original SDM Representation Agreement template did not include decision making procedures because it was not expected participants would choose more than one or two decision supporters.

Where there is more than one supporter, the revised SDM Representation Agreement template offers participants a choice of two decision paths for decision supporters: joint or successive.

Joint decision making

Participants approach any of the designated supporters but expect all supporters to confer and then consult with the participant. Three participants who have two, three and four supporters, respectively, elected this process.

Successive

If supporter #1 is not available, then supporter #2 steps in. Two participants ranked supporters by order in which they should be approached. Four participants, including the one with 10 decision supporters, chose the successive approach.

Areas of Decision-making Assistance

Practice recommendation

9b. Take precaution so that individuals with I/DD understand they can specify which types of decisions they want to use support from designated people, and which types of decisions they want to make on their own. Legal staff should minimize the influence of others (family, guardian, staff, etc.) by meeting with individuals without others present when possible.

The revised SDM Agreement outlines decision categories to define the scope of consultation for each decision supporter:

- Finances
- Healthcare
- Living arrangement
- Relationships/Social
- Employment
- Legal matters
- Other (please specify)

Even though CPR staff prompted discrete decision areas in SDM conversations and in the Agreement template, very little discrimination in decision areas occurred. Each participant elected most or all of their decision supporters to provide assistance across every decision area. Only one participant checked “other” because she wanted to make a distinction between general healthcare and major health issues. She specified assistance from one supporter for major health events, not routine medical appointments.

The revised, final SDM Agreement is located in Attachment B.

CPR staff wonder if when used, SDM would express a meaningful voice and decision making process, “Meaningful in that it is truly about an individual making a decision with support and not another way for others to impose choice. It’s important SDM not be misused; we wouldn’t want anyone in the group of support to think this allows decision making for someone without a court or other oversight.” This concern seems well-placed given the lack of difference found in these initial SDM Agreements.

Modifying Decision Supporters

Practice recommendation

9c. Institute procedures to periodically remind SDM participants and decision supporters of the ability to change decision supporters, as well as change areas for decision assistance.

The SDM Representation Agreement, which participants and decision supporters have a copy of, includes a statement that changes can be made at any time, including removing or replacing a supporter. The statement reads, “I understand I can contact the Supported Decision-Making Project at any time to end this agreement or to add, replace or remove a network supporter.”

According to care managers, all participants understand they can change decision supporters.

In fact, one individual is already in the process of changing her SDM Agreement. She had originally selected three decision supporters (a friend of 20 years, her then live-in caregiver, and a former respite provider and current friend). With a change to new live-in caregiver, she decided to drop the former caregiver. CPR staff met with this participant to ensure she understood naming live-in caregivers was not an expectation, that she is free to nominate anyone. At her request, her SDM Agreement

was altered to replace the former caregiver with the current live-in caregiver. Her other supporters were advised of the change. No change was made to areas for decision assistance.

Practice recommendation

9d. Institute procedures to examine a complaint concerning a decision supporter. Institute procedures to refer investigation of complaints that rise to the level of abuse, neglect or financial exploitation.

Care managers do not believe participants understand that others could object to a choice of supporter, such as if a concern of undue influence or suspected, abuse, neglect or financial exploitation was raised.

At this time there is not yet a process for review or investigation should a concern about a decision supporter be raised that does not rise to the level of suspected abuse, neglect or exploitation.

SDM Adoption

Step 10. SDM Documentation

Supported Decision Making Agreement

Practice recommendation

10a. Create plain language SDM Agreements. Avoid legal language where possible.

Through a series of meetings with people they trust, SDM adopters, hereafter referred to as “participants,” and their families and caregivers were informed of the principles underlying SDM, apprised of potential risks and benefits of participating in the pilot, and agreed to adopt SDM.

Next, SDM decision areas were mapped out and decision supporters selected.

Each SDM participant has legal representation by the Center for Public Representation to assist with executing the SDM Agreements and to provide future representation related to SDM adoption, changes, or use in the community.

All participants (including decision supporters) have been advised that they can stop using SDM and withdraw from the pilot at any time.

Individuals with I/DD participating in the pilot identify their decision making supporter(s) and the kinds of decisions where assistance is expected. These arrangements are documented in a Supported Decision Making Agreement.

The initial SDM Agreement noted the person’s name, a couple of lines to note the decision supporter(s) selected and their relationship to participant, how the participant wanted the supporter to assist (e.g., provide information in a way person can understand, discuss the good and bad things that could happen, express my wishes to other people), and areas for decision support (e.g., financial, legal counsel, health care, personal care, other).

The initial Agreement drafted also included a date by which the participant and decision supporter would review the Agreement. In addition, the names, contact information and signatures of decision supporters were noted. The Agreement further noted who to contact at CPR for making any changes to the Agreement, or to request assistance with use of the Agreement. The Agreement included a CPR staff contact information.

Following review and input from the Advisory Group, pilot staff, participants and their families, the SDM Agreement was revised. Changes to the SDM Agreement included:

- Font size increased to 14 points.
- Font type changed to a more accessible font (Arial).
- Added more specificity to section noting how person expresses and conveys preferences and what she/he wants.
- Added specific areas for decision consultation *assigned* to each designated decision supporter.
- Added specific areas for decision consultation to be *excluded* for each decision supporter.
- Added section on how supporters should cooperate with other supporters (if a participant selected more than one supporter for a certain type of decision). Options are to jointly confer or provide decision support successively.
- Added specific statement that participant understands she/he is free to contact the SDM project at any time to add, replace or remove a decision supporter.
- Added decision supporter section where supporters sign, date and enter the participant’s name in the following statement, “I understand that as _____’s supporter, my job is to honor and present

his/her expressed wishes. In the event I cannot perform my job under this agreement, I will contact the Supported Decision Making Coordinator.”

- For each decision supporter, added date of birth, contact information, signature and printed name.
- Added section for Notary Certification.
- Altered CPR contact from a specific person to organization so that should staff change, a participant will be directed to current SDM involved staff.

Attachment B is the current SDM Agreement template.

SDM Agreement Execution

Practice Recommendations

10b. Require decision supporters to sign SDM Agreements to ensure they understand the commitment, freely consent, and know the agreement is flexible and can be changed as people’s lives change.

10c. Notarize SDM Agreements to convey a formal document with legal stature.

10d. Mark SDM adoption as a celebratory event.

CPR staff recorded these preferences on a Supported Decision Making Representation Agreement. Agreements were signed by participants and decision supporters, and then notarized.

Because people with I/DD have a lot of meetings about their services and lives, it was important to mark the adoption of SDM. A date was set March 26, 2015, and five participants from the same and abutting communities gathered for a ceremony to commemorate the signing and notarization of their SDM Representation Agreements.

“The mood was serious then celebratory. A special cake was made and people were really excited,” Nonotuck care manager. Pictures were taken and posted to Nonotuck’s Facebook page, and by participants and witnesses to their own Facebook pages. The postings generated more than 3000 hits that evening.

Health Care Proxy and Durable Power of Attorney

For several individuals, including one with a guardian, SDM Agreements were executed accompanied by a Health Care Proxy and Durable Power of Attorney. Both of these are legally recognized documents to note a person’s designee to make certain kinds of decisions in the event he/she becomes incapable of making decisions even with support. Both are decision making aids utilized in the general population. Neither type of advance directive is a disability service or typically made available to individuals with I/DD.

Health Care Proxies (HCP) address medical and health care decisions. A Durable Power of Attorney (DPOA) addresses legal and financial decisions.

HCPs and DPOAs provide additional decision making safeguards for several participants. CPR staff wonder if SDM can be as well received in the community without a HCP or a DPOA.

“Do parents and guardians need this? Might having these in some way lend a perception that SDM is not sufficient, or is it lowering the standard to what community members are used to and used to respecting?” CPR staff.

HSRI examined the decision making supports in place by pilot participants prior to and after the adoption of SDM. We were interested in the extent to which decision aids used by the general population (such as advanced directives) were utilized by individuals with I/DD in the pilot, and the extent to which disability-

specific service delivery mechanisms to increase people’s control over their lives, such as self-directed service, were utilized.

Table B below shows the pre- and post-SDM decision constructs in place for pilot participants. One participant successfully petitioned the court to terminate guardianship

and a Roger’s monitor in favor of SDM. None of the pilot participants is using the self-directed services model available to people with I/DD receiving state funded services. All have a representative payee, either Nonotuck or a family member, in place for benefit checks. Use of HCP and DPOA was sometimes bundled with executing an SDM Agreement.

Table B. Legally-recognized Decision Making Authorities: Prior to and After SDM Adoption

Legally-recognized Decision Making Authorities	PRIOR to SDM Adoption	AFTER SDM Adoption
Guardianship	2	1*
Roger’s Monitor psychotropic medication consent	2	1*
Representative payee	8	8
Health care proxy	3	6
Durable power of attorney	0	2
Living will / directives for end of life	0	0
Using self-direction service delivery model	0	0
Bank account solo	3	3
Bank account with representative payee	2	3

* One individual successfully petitioned court to terminate guardianship and Roger’s monitor in favor of SDM.

Practice Recommendation

10e. When a representative payee and SDM are both in place for financial decision support, periodically examine the need for the representative payee.

As pilot participants selected financial decision support in their SDM Agreements. All pilot participants have representative payees, either Nonotuck or family members. For individuals with representative payees, the Massachusetts Department of Developmental Disabilities requires teaching plans so that people receive instruction and support to manage their money. Financial teaching plans are to be reviewed and updated at least annually during a person's service planning meeting. With SDM in place, there may be more assistance in teaching financial skills. There may also be less need for representative payees, particularly an agency as representative payee.

Guardianship Dismissal

One pilot participant, who until recently was under full guardianship, executed a SDM Agreement. A hearing was held on November 17th to hear the petition to discharge the guardianship in favor of SDM.

Another pilot participant is under guardianship and has met twice with CPR staff to discuss SDM. This individual has not yet executed an SDM Agreement.

Both individuals and their respective guardians agree that ending guardianship and adopting SDM is worth undertaking.

This year, the evaluation report focuses on preparations for the scheduled court hearing to terminate the first guardianship case. Next year's report will include discussion of court activity to discharge the second guardianship (should that move forward), as well as any

impact of discharging a guardianship and adopting SDM on these individuals' lives.

Practice Recommendation

10f. Even when uncontested, discharging a guardianship is complicated and time consuming. Allow sufficient time to insure that all requirements can be met.

CPR is providing free legal representation to petition the probate court for a "discharge" of the guardianships. Discharge is the legal term for ending a guardianship. A court date of November 17th was set for one individual's hearing. He is 24 years old. His mother has been his guardian since he was 18 years old. He executed a SDM Agreement along with Health Care Proxy and a Durable Power of Attorney in March 2015. His mother, father and sister are his SDM decision supporters.

Finding a court date required balancing a number of timing considerations. For this hearing, it entailed scheduling within the busy court docket and availability of the individual, the family, legal representative for the individual, legal representative for family-guardian, legal representative for the Department of Developmental Services, and the individual's court-appointed Roger's monitor for psychotropic medication consent.

As petitioner for the discharge of guardianship, CPR and Nonotuck worked together to arrange the required evaluations to document the individual's capacity and supports, and ensure that each form was delivered to probate court and in effect on the scheduled hearing date. In Massachusetts, the required probate court documentation to discharge a guardianship is a clinical team report (social worker, psychologist, and primary care physician). Because the SDM participant also had a Roger's monitor who makes psychotropic medication decisions, CPR also secured an updated medical report by a

psychiatrist. Medical reports by psychiatrists are required for imposing a Roger's monitor.

In Massachusetts, these required forms have different life spans. The psychiatrist's report expires in 30 days; the clinical team report expires in 180 days. CPR had to make sure that all evaluations were timed to be current for court hearing date.

Participants and their families or guardians were not charged for any of the court preparation expenses. Medicaid is being billed for the updated clinical evaluations.

Along with the petition to discharge guardianship, this SDM participant has a notarized SDM Agreement, a Health Care Proxy and a Durable Power of Attorney. During the October 2015 Advisory Council meeting, CPR staff relayed that the parties to the guardianship hearing were all in favor of ending guardianship.

An unexpected development was the Department of Developmental Services (DDS) questioning of the legality of the Health Care Proxy and the Durable Power of Attorney documents. DDS' position was that these were executed while the participant was under guardianship and therefore, the individual was legally incompetent to execute them. CPR's position is that the clinical team report finds that with decision supports, the SDM participant is competent and both the Health Care Proxy and Durable Power of Attorney documents should be honored.

If the advanced directives were not recognized, CPR planned to assist the SDM participant to complete a new Health Care Proxy and Durable Power of Attorney.

CPR represented the SDM participant and his family in probate court to terminate the guardianship in favor of SDM. On November 17th, the first discharge of guardianship in favor

of SDM was decided in Massachusetts. The participant chose to draw up new advance directives.

The CPR-Nonotuck SDM pilot website has this quote from the individual's mother:

SDM was the perfect storm for [individual's name] because we always wanted an alternative to guardianship from the beginning, but there was not such an option at the time when he turned 18. We are happy that Nonotuck and CPR have stepped up to meet this need for families and their loved ones.--SDM Participant's mother

That evening, a celebration dinner and reflection on the SDM project was hosted by Nonotuck at a country club in the Berkshires. All SDM participants, their decision supporters, and guardians were invited. After socializing and dinner, Bob Fleischner talked about the day in court and the importance of the decision for SDM in the United States, and the advancement of rights for people with disabilities all over the world through SDM. Michael Kendrick spoke of SDM as symbolic of the international effort to give people with disabilities their voice back, their voice in making decisions about their lives. The international interest in SDM made pilot participants and decision supporters feel part of something much bigger.

Step 11. Structure Safeguards

Practice Recommendation

11a. Incorporate safeguards into SDM initiatives such as no cost, voluntary adoption, free legal assistance, withdrawal from the pilot at any time for any reason, and care manager monthly monitoring.

Participants in this pilot had to express interest in adopting SDM. Interest could have been expressed using any method of communication and was not restricted to verbal language. CPR-Nonotuck's opt-in model extends beyond the person with a disability to including only those whose families/guardians also want to participate in this pilot. Individuals with I/DD who are interested but do not have interested families or guardians are not participating directly. One woman interested in SDM whose family is waiting and observing the pilot unfold, joined the Advisory Council but is not a pilot SDM participant.

All SDM-related activity by CPR and Nonotuck is being offered without charge. There are no financial incentives to participate and no service impact for participating or not.

A key safeguard is monthly visits by Nonotuck's care managers. Visits can occur more frequently when necessary. Monthly visits offer a method for routinely monitoring the person's satisfaction with the SDM arrangement, decision supporters, and use of support for decision making. HSRI developed a SDM tracking log for care managers to utilize on their monthly visits. The log includes noting the type of decision, who was involved including general community members such as a banker or physician, the decision reached, if the person's voice was heard and preference respected, and any impact of decision. Information from SDM tracking forms will be analyzed in the Year 2 evaluation report.

Nonotuck's care managers know these pilot participants well. The shortest relationship between a care manager and pilot participant is three years; the longest is 30 years. Four care managers have known participants for 11 years and longer. In several instances relationships pre-dated being a care manager. Chart 3 below illustrates the length of time individuals and care managers have known one another.

Chart 3. Length of Time Pilot Participants have Known Nonotuck Care Managers



Another safeguard is the option to withdraw from the pilot at any time. Although each participant has been advised of this, there is not yet a standard protocol on how often and at what points in time care managers or other pilot staff will convey this message.

SDM Outreach and Awareness Activity

Step 12. Raise SDM Awareness

Practice recommendation

12a. Prepare for and budget to share information that an alternative to guardianship exists and to disseminate information on the pilot experience.

Once the pilot was underway, requests starting coming in for information, for presentations, for requests for information on how to use SDM elsewhere in Massachusetts and in other states. Pilot staff and SDM participants have been active in sharing their experience but have been amazed at the interest and demand for SDM information. Nonotuck has more expertise in utilizing technologies and social media and has supported the project with creating videos and hosting web-based meetings.

Pilot Initiative Website

With requests for information continuing to come in, it was agreed that a website would be useful to communicate with the general public about the pilot and SDM in general. CPR took the lead on web development. After four months the website was launched In September 2015: <http://supporteddecisions.org/>.

CPR and Nonotuck have been generous sharing their knowledge of SDM and pilot experience. All requests for presentations have been accepted, even when travel and sending multiple staff was involved. Both organizations share responsibility and costs for presenting at conferences and meeting with stakeholders. Since the inaugural pilot forum in October 2013, staff have conducted two webinars, 11 conference presentations (many with multiple pilot staff), and published two SDM resource documents. These outreach and SDM awareness activities are noted below.

National webinars –

- *SDM webinar for the National Disability Rights Network, August 12, 2015*
- *Guardianship Webinar, Shriver Center, May, 2014*

Conferences –

- *Guardianship Policy Institute, Massachusetts Guardianship Colloquium, Boston, MA, November 10, 2015*
- *2015 International Conference: Claiming Full Citizenship, Vancouver, British Columbia, October 15-17, 2015*
- *Americans with Disabilities Act 25th Anniversary Celebration, Hartford, CT, October 3, 2015*
- *Shared Living and Adult Family Care Conference, Marlborough, MA, September 30, 2015*
- *SDM presentation to the Guardianship Reform Task Force on behalf of the Maine Protection & Advocacy Organization, Augusta, Maine, July 17, 2015*
- *Guardianship Law Series: Complexities, Challenges and Latest Developments, Social Law Library, Boston, MA, October 21, 2015*
- *National Association for Rights, Protection and Advocacy, SDM plenary presentation, Washington, D.C., August 21, 2015*
- *National Disability Rights Conference, Indianapolis, Indiana, June 5, 2015*
- *American Association on Intellectual and Developmental Disabilities, Louisville, Kentucky, June 2, 2015*

- *Massachusetts Department of Developmental Disabilities, Central and Western Massachusetts Regional staff and providers, Spring 2015*
- *Shared Living and Adult Family Care Conference, Worcester, MA, October 2014*
- *Transitions Conference, Association of Developmental Disabilities Providers, Devens, MA, Spring 2014*

Publications –

- Updated chapter on Massachusetts guardianship to include SDM, Massachusetts Continuing Legal Education’s Disability Law Handbook published in 2015
- Supported Decision-Making: A promising alternative to guardianship. Brochure, published Spring 2015
- *FACT SHEET Supported Decision Making Instead of Guardianship: An International Overview, Marcia Boundy and Bob Fleischner, CPR, April, 2013*

In addition, CPR staff have consulted on SDM by telephone with Protection and Advocacy programs in South Carolina, Idaho, New York, Texas, Indiana, Delaware, Maine and elsewhere. With the assistance of Open Society Foundations (a member of the SDM Pilot Advisory Council), CPR staff have interacted with SDM projects around the world, particularly in Israel.

Practice recommendation

12b. Prioritize audiences for outreach activities

What is not evident in the outreach activity list is the commitment of time and staff. For example, the presentation at the National American Association on Intellectual and Developmental Disabilities (AAIDD) in Louisville was a panel presentation by a one CPR attorney, a Nonotuck care manager, a pilot participant, a self-advocate member of the Advisory Council, and a staff person from the evaluator, HSRI. Along with time and travel, each presenter was required to pay the conference fee. The presentation was well-received, and the session facilitator declared it the best presentation ever at AAIDD. Nonetheless this conference signifies the significant investment of resources to which pilot partners devoted to community education in 2014-15.

While all outreach activity is considered worthy, at the October 2015 Advisory Council meeting, partners expressed a need to narrow the scope of outreach to Massachusetts and to look for additional funds to support community education about SDM beyond the state. Advisory Council members concurred with this strategy.

Step 13. Provide for Sufficient Resources

Practice recommendation

13a. Prepare for and budget generously for additional staff time to carry out SDM activities, coordinate activities, and share pilot experience

One of the tenets of SDM espoused in the United Nations CRPD treaty is cost should not be a barrier to adopting or using SDM. This stands in contrast to guardianship which requires a petition to be filed in court, representation by attorneys, sometimes fees for professional evaluations, and other costs.

SDM adopters and their decision supporters in this pilot had no direct costs to participation, thus the pilot aligned with the SDM principal that cost not be a barrier. SDM participants and their involved decision supporters, family and guardians did expend indirect costs of their time and transportation.

CPR's representation of individuals to adopt and use SDM is being provided free of charge and will continue to be provided free of charge.

While there were no direct costs to individuals or decision supporters associated with adopting SDM, CPR and Nonotuck committed fully, investing financial, staff and other resources to support this SDM pilot.

To provide other organizations with an estimate of investment activity, the partners offer selected investment information. This does not reflect the full investment of partner organizations, for example, travel time is not included. For Year 1, the Pilot Establishment and SDM Adoption phase, from 9/1/2013

through 8/31/2015, CPR provided 1,190 staff hours and Nonotuck provided 1,702 staff hours.

Table C on the following page shows the staff hour investment by CPR staff for key development activities related to establishing this joint SDM initiative. Nonotuck's staff hour investment activity could not be partitioned into discrete activities.

While the time commitments have been greater than anticipated, CPR and Nonotuck staff believe that they have done a lot of work that other organizations planning to further SDM will not have to repeat.

What is not quantifiable in staff time or dollars is the satisfaction of investing in an SDM endeavor. As Nonotuck's CEO noted in his email to CPR staff when assessing resources contributed to this pilot:

We spent hours on this. We might not want to chase people away but we also want people to understand the reality of the work. ... [T]he beauty of using Nonotuck has been that SDM folded so sweetly into the Project Director and the Care Manager roles. It became just part of their job. A part that Nonotuck staff took seriously and with great desire.

Table C. CPR’s Pilot Resource Investment: Pilot Establishment and SDM Adoption

Center for Public Representation Pilot Establishment Activities September 1, 2013 - August 30, 2015	CPR Staff Hours
Initial organizational meeting: draft agenda; engage speakers; extend invitations to judges, advocates, people with disabilities, attorneys, providers; moderate day-long forum	120
Review recommendations from planning meeting, and set up basic framework for pilot: plans, roles, assignments, goals	35
Establish Advisory Group: solicit members; specify roles, responsibilities	30
Develop accessible, plain language SDM information materials, SDM Representation Agreement template, SDM brochure	70
Meet with 9 SDM pilot candidates to discuss SDM, specify areas for decision-making support, identify supporters, review Representation Agreements, HCPs and DPOAs. Draft, revise documents as needed.	175
Court preparation, meetings, filings to discharge guardianship	55
Research & trainings: research, analyze proposed SDM legislation, SDM agreements in other venues; participate in SDM webinars	75
Grant development for SDM funding	35
Public outreach activities: DDS Human Rights Committees, bar advocate trainings, conference presentations & webinars	280
Website development, maintenance	50
Ongoing project coordination including monthly CPR-Nonotuck meetings, HSRI communication, and quarterly Advisory Council meetings	265
Independent pilot evaluation (\$14,076 contract per year. HSRI donated Principal Investigator’s time.)	--

Year 1 SDM Pilot Evaluation Wrap Up

Did the pilot meet goals?

CPR and Nonotuck's goals for this SDM initiative were not divided up into year 1 and year 2 as are these evaluation reports. SDM has been adopted but the evaluation has not yet examined the impact on pilot participants. Nevertheless, the strategies taken by the partners and the intentional approach demonstrate great effort toward creating means for people to exercise their will and preferences.

Goal 1. Maximize individuals' independence: By directing their own decision-making process and making their own decisions, pilot participants will gain confidence and become better self-advocates. They will have both a voice and a presence in the community.

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

When HSRI examines the strategies undertaken toward pilot goals, we find the partners to have been fully invested and met or in process of meeting their objectives. Pilot project strategies are to:

1. Assist a small number of individuals with intellectual and other disabilities to test SDM
2. Establish SDM only for individuals whose families and support network are supportive of SDM adoption
3. Make a difference in people's lives; move away from substituted to shared, supported decision making
4. Establish and utilize an advisory group
5. Provide for an independent evaluation
6. Model SDM for use by Protection and Advocacy agencies
7. Report/publish/share experience and lessons learned

Limitations of Pilot

This pilot was not undertaken to demonstrate the utility of SDM across all people and situations where such an alternative to guardianship can be conceived. The pilot aim was limited in scope to adults with I/DD who wanted to try SDM and whose family members, putative decision supporters, and guardians also wanted to test out SDM. This pilot was limited to cooperative social networks only.

As well, the nature of shared living, having a shared home with a person responsible for providing 24/7 care entails that individuals with I/DD in this pilot had someone in their social network they may have been comfortable identifying as a decision supporter. In other countries that have adopted SDM, such as Australia, there is concern about provision of decision supporters for people who have no involved family or friends or trusted care providers. Australia is considering piloting volunteer and paid decision supporters.

Another limitation of this pilot is that participants all use spoken language to express their wishes. As well none are considered to be severely or profoundly intellectually disabled, though two have advancing dementias along with I/DD and are losing some cognitive capacities.

Issues for further study

In the next and final pilot evaluation report, HSRI will study and report on the use of SDM since participant adoption. This will include:

- Rights restored or retained including probate court decisions on guardianship cases and execution of advance directives prior to discharge of a guardianship
- Participant's use of SDM: what decisions, how much support required, needs of decision supporters, response of community members, etc.
- How decision making with multiple supporters worked in real life decisions
- Demands on supporters
- Any significant differences post SDM adoption in quality of life
- Identification of any abuse of SDM
- Participant changes to SDM Representation Agreements – decision areas, supporters, other
- Faithfulness to SDM principles
- Recommended state law and regulation changes

Attachment A. Pilot-informed Guidelines for Establishing SDM Initiatives in the U.S.

SDM Pilot Establishment

Step 1. Partnership

- 1a. Partnership between a legal advocacy and a service provider organization are useful for establishing SDM.
- 1b. Partnership and collaboration is facilitated when organizations share values.

Step 2. Pilot Staff Orientation to SDM

- 2a. Educate project staff about the legal and social foundation and constructs for SDM.

Step 3. Initial SDM Planning Meeting

- 3a. Set aside time to discuss SDM initiative framework, resources needed, and foreseeable implementation issues.
- 3b. Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.

Step 4. Pilot Team Communication and Project Management

- 4a. Establish a clear pilot project team and clarify roles.
- 4b. Schedule regular in-person meetings with agendas to update one another and jointly plan next steps.
- 4c. Clarify how problems will be resolved.

Step 5. Advisory Council Formation and Role

- 5a. Establish an Advisory Council to provide multiple perspectives on implementation.

Step 6. Independent Evaluation

- 6a. Early pilot initiatives should establish an independent evaluation to safeguard SDM adopters with external review of implementation and to share lessons learned.

SDM Participant Selection

Step 7. Identify SDM Participants

- 7a. Prior to meeting with putative SDM adopters, prepare plain language educational materials. Include a brief explanation of what SDM is, why it is an important rights issue, and what the practical impact is expected to be if adopted.
- 7b. Where legal staff do not have regular communications with people with I/DD, consider utilizing an expert to role model SDM introduction conversations. Review interviewing guidance for conversations with people with I/DD such as *Disability Etiquette*.
- 7c. Prior to meeting with a person with I/DD find out about a person's life and communication style.
- 7d. Allow extra time for individuals with I/DD and their family members and care givers to get comfortable so they can freely express reservations and ask questions.
- 7e. Expect to meet more than once with individuals with I/DD to present and discuss SDM.
- 7f. Create a script for pilot staff to guide SDM conversations.
- 7g. Establish a protocol with frequency and a responsible entity to periodically communicate to individuals their freedom to withdraw from pilot without repercussion.

Step 8. Participants Select Decision Supporters

- 8a. Provide opportunity for staff participating in selection discussions to debrief following sessions to insure consistency with respect to assurance of individual's choices and how any persuasion or disagreements might best be handled.
- 8b. Shared living appears to offers a community-member to provide those with and without involved family members a decision supporter they trust. (Next year HSRI will track satisfaction with decisions.)
- 8c. Even when well-known to one another, SDM conversations can lead to case managers learning something new about people they support.

Step 9. Participants Select Areas for Decision-Making Assistance

- 9a. When more than one decision supporter is chosen, describe in the SDM Agreement how multiple supporter consultation is to work.
- 9b. Take precaution so that individuals with I/DD understand they can specify which types of decisions they want to use support from designated people, and which types of decisions they want to make on their own. Legal staff should minimize the influence of others (family, guardian, staff, etc.) by meeting with individuals without others present when possible.

9c. Institute procedures to periodically remind SDM participants and decision supporters of the ability to change decision supporters, as well as change areas for decision assistance.

9d. Institute procedures to examine a complaint concerning a decision supporter. Institute procedures to refer investigation of complaints that rise to the level of abuse, neglect or financial exploitation.

SDM Adoption

Step 10. SDM Documentation

10a. Create plain language SDM Agreements. Avoid legal language where possible.

10b. Require decision supporters to sign SDM Agreements to ensure they understand the commitment, freely consent, and know the agreement is flexible and can be changed as people's lives change.

10c. Notarize SDM Agreements to convey a formal document with legal stature.

10d. Mark SDM adoption as a celebratory event.

10e. When a representative payee and SDM are both in place for financial decision support, periodically examine the need for the representative payee.

10f. Even when uncontested, discharging a guardianship is complicated and time consuming. Allow sufficient time to insure that all requirements can be met.

Step 11. Structure Safeguards

11a. Incorporate safeguards into SDM initiatives such as no cost, voluntary adoption, free legal assistance, withdrawal from the pilot at any time for any reason, and care manager monthly monitoring.

SDM Outreach and Awareness Activity

Step 12. Raise Awareness about SDM

12a. Prepare for and budget to share information that an alternative to guardianship exists and pilot experience

12b. Prioritize stakeholder communities for outreach activities

Step 13. Provide for Sufficient Resources

13a. Prepare for and budget for additional staff time and resources to carry out SDM activities, coordinate activities, and share pilot experience.

Attachment B: Supported Decision Making Agreement

**Nonotuck Resource Associates and
Center for Public Representation
Supported Decision-Making Agreement**

This is the Supported Decision-Making Agreement of

Name : _____ Date of birth: _____

Address: _____

Telephone: _____ Email: _____

A. I need supporter(s) to help me make decisions about:

- Taking care of my financial affairs, like banking
- Hiring a lawyer if I need one and working with the lawyer
- My health care, including large and small health care decisions
- Personal care (like where I live, the support services I need, managing the people who work with me, my diet, exercise, education, safety and activities)
- Other matters: _____

B. I expect my supporter(s) to help me in the following ways:

- Giving me information in a way I can understand
- Discussing the good things and bad things (pros and cons) that could happen if I make one decision or another
- Telling other people my wishes
- _____

C. I express myself and show what I want in the following ways:

- Telling people my likes and dislikes.
- Telling people what I do and do not want to do.
- _____
- _____

D. I designate the following individual(s) to be part of my Supported Decision-Making Network to assist me in making decisions.

Network Supporter #1

Name: _____ Date of birth: _____

Address: _____

Telephone: _____ Email: _____

Relationship: _____

Areas of Assistance for Supporter #1: *Check all that apply:*

- Finances**
- Healthcare**
- Living Arrangements**
- Relationships/Social**
- Employment**
- Legal Matters**
- Other** (*please specify*):

Areas I don't want Supporter #1 to assist me with: _____

Network Supporter #2

Name: _____ Date of birth: _____

Address: _____

Telephone: _____ Email: _____

Relationship: _____

Areas of Assistance for Supporter #2: *Check all that apply:*

- Finances**
- Healthcare**
- Living Arrangements**
- Relationships/Social**
- Employment**
- Legal Matters**
- Other** (*please specify*):

Areas I don't want Supporter #2 to assist me with: _____

Network Supporter #3

Name: _____ Date of birth: _____

Address: _____

Telephone: _____ Email: _____

Relationship: _____

Areas of Assistance for Supporter #3: Check all that apply:

- Finances**
- Healthcare**
- Living Arrangements**
- Relationships/Social**
- Employment**
- Legal Matters**
- Other (please specify):**

Areas I don't want Supporter #3 to assist me with: _____

Use the reverse side of this document to list additional supporters.

E. If I have more than one Supporter (Optional, but if you do not fill out this section, your Supporters will act "Successively".)

My Supporters will act (*choose one*)

Jointly (work together to help me)

OR

Successively (For example: Supporter #2 helps me if Supporter #1 is not available)

F. I understand I can contact the Supported Decision-Making Project at any time to end this agreement or to add, replace or remove a network supporter.

Signature Date

G. Notary Certification

Commonwealth of Massachusetts, County of _____

On this _____ day of _____, 20____, before me, the undersigned notary public, personally appeared _____ proved to me through satisfactory evidence of identification, which were _____, to be the person whose name is signed on the preceding or attached document in my presence.

(seal) Notary Public Signature

The Supported Decision-Making Project can be reached at 413-586-6024.

H. Network Supporters' Statements

Network Supporter #1

I understand that as _____'s supporter, my job is to honor and present his/her expressed wishes. In the event I cannot perform my job under this agreement, I will contact the Supported Decision-Making Coordinator.

Signature Date

Network Supporter #2

I understand that as _____'s supporter, my job is to honor and present his/her expressed wishes. In the event I cannot perform my job under this agreement, I will contact the Supported Decision-Making Coordinator.

Signature Date

Network Supporter #3

I understand that as _____'s supporter, my job is to honor and present his/her expressed wishes. In the event I cannot perform my job under this agreement, I will contact the Supported Decision-Making Coordinator.

Signature Date

The Supported Decision-Making Project can be reached at 413-586-6024

Attachment C: CPR Preparation for Initial SDM Meeting with Pilot Candidate

Introductions

What we do; Why we are here

Questions for pilot candidate

Can you tell us a little about yourself? What about you-where do you live? Who do you live with? How long? What are things that you like? Don't like?

Are there things with which you would like to have help?

What kinds of things?

When you need help, do you have people who you trust that you ask for help? Who?

When you ask for help, do you feel like you are in charge?

Do you feel like your decisions are respected? Why/Why not?

When your friends/family help you, what kinds of things do they do that you find helpful?

What types of help is not helpful to you? (When people are trying to help you, are there things that you do not want them to do?)

Do you think that they help you make good decisions?

Do you like having people help you? What do you like?

Are there things for which you do not want help? What are those things?

When you have meetings, do you like to have a lot of people at the meeting or just a few?

What happens if you feel like someone is being pushy or bossy with you about what you should do? How do you deal with them? Do your friends help you with that?

Questions for us?

Introduction of Form - discussion: list of people you trust on the form, but you can change your mind whenever you want. You can add people, change the names, or you can decide that you don't want anyone and don't want to participate whenever you want.

Next Steps?

Attachment D: Subsequent CPR SDM Meetings with Pilot Candidate

Introductions

Recap of Last Meeting

Living arrangements

Types of decisions you ask for help with: medical, legal, financial (help with budgeting)

Supporters:

Review/Additional Questions:

Can you tell us a little about yourself? Who do you live with? How long? Things that you like/don't like?

Do you feel like you have the right to make decisions about your life?

Are there things with which you would like to have help?

What kinds of things?

When you need help, do you have people you trust that you ask for help from? Who?

When you ask for help, do you feel like you are in charge?

Do you feel like your decisions are respected?

When your friends/family help you, what kinds of things do they do that you find helpful?

What types of things are not helpful to you?

Do you think they help you make good decisions?

Do you like having people help you? What do you like?

Are there things you don't like help with?

When you have meetings, do you like to have a lot of people or just a few?

What happens if you feel someone is being bossy or push with you about what you should do?

How do you deal with them? How do your friends/family help you do that?

Supporters:

Confirm who and for each:

Does [supporter] treat you with respect (nice, polite, trustworthy)?

Does [supporter] explain information in a way you understand?

Does [supporter] discuss with you the good and bad things that could happen if you make a decision one way or another?

Do you feel that [supporter] understands what you want decision-making help with? [the types of decisions]

Questions for us?

Introduction of Form: Discussion. List of people you trust on the form, but you can change your mind whenever you want. You can add people, change people and their roles or decide you don't want anyone or don't want to participate whenever you want.

Next Steps: Date to meet to sign SDM with notary? Where?

Resources and References

- ⁱ United Nations Convention on the Rights of Persons with Disabilities (CRPD). Located online at: <http://www.un.org/disabilities/convention/conventionfull.shtml>
- ⁱⁱ Countries that have adopted SDM thus far are: Australia, several provinces of Canada, Germany, Ireland, Scotland, England, Norway, Sweden
- ⁱⁱⁱ National Core Indicators (NCI) Adult Consumer Survey 2013-14. Located online at: www.nationalcoreindicators.org
- ^{iv} *Restoration of Capacity Study and Work Group Report*, Florida Developmental Disabilities Council and Guardian Trust, February 2014. Located online at: http://www.guardianship.org/IRL/Resources/Handouts/Charting%20a%20New%20Course_Restoration%20Report.pdf
- ^v National Core Indicators (NCI) Adult Consumer Survey 2013-14. Located online at: www.nationalcoreindicators.org
- ^{vi} SDM pilot project website: <http://supporteddecisions.org/>
- ^{vii} Karrie A. Shogren and Michael Wehmeyer, *A Framework for Research and Intervention Design in Supported Decision-Making*. Located online at: [http://www.researchgate.net/publication/271966516_A_Framework_for_Research_and_Intervention_Design_in_Supported_Decision_Making](http://www.researchgate.net/publication/271966516_A_Framework_for_Research_and_Intervention_Design_in_Supported_Design_in_Supported_Decision_Making)
- ^{viii} Marcia Boundy and Bob Fleischner, *FACT SHEET: Supported Decision Making Instead of Guardianship: An International Overview*, April 2013. Located online at: http://www.nlrc.aoa.gov/Legal_Issues/Guardianship/Decision.aspx
- ^{ix} Nina A. Kohn, Jeremy A. Blumenthal, & Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?* Penn State Law Review, Volume 117.4. Located online at: [http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20\(final\)%20\(rev2\).pdf](http://www.pennstatelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20(final)%20(rev2).pdf)
- ^x American Association on Intellectual and Developmental Disabilities (AAIDD) electronic journal, *Inclusion*, Volume 3, Issue 1, March 2015. Located online at: <http://aaiddjournals.org/toc/incl/3/1>
- ^{xi} Open Society Foundations website: <https://www.opensocietyfoundations.org/>
- ^{xii} Jenny Hatch legal decision: http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf
- ^{xiii} Guardianship of Demaris L., 38 Misc. 3d. 570 (Surrogate's Court, N.Y. County, NY 2012).