
SUPPORTED DECISION MAKING PILOT: Pilot Program Evaluation Year 2 Report

Prepared for the Center for Public Representation
and Nonotuck Resource Associates, Inc.

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Executive Summary

The Center for Public Representation (CPR), a nonprofit law firm focusing on disability rights in Massachusetts and across the country, and Nonotuck Resource Associates, Inc. (Nonotuck), a service provider principally of shared living and adult family care residential supports, partnered to offer adults with intellectual and/or developmental disabilities (I/DD) living in western Massachusetts an opportunity to use Supported Decision Making (SDM).

CPR and Nonotuck conducted their two-year SDM pilot with a collaborative approach across development and implementation stages, from pilot design to SDM outreach and education to broader communities.

CPR contracted with the Human Services Research Institute (HSRI), a nonprofit research and consulting organization, to conduct an independent evaluation of the SDM pilot. The purpose of the evaluation was to identify challenges and recommendations to inform broader SDM adoption.

HSRI's two evaluation reports follow the sequential stages of pilot development. The first report (Year 1) examined activities undertaken to establish the pilot, select volunteers to adopt SDM, and assist SDM adopters through the process of designating decision supporters and completing SDM Representation Agreements.¹ This second evaluation report (Year 2) presents SDM pilot activity and findings regarding the experience of using SDM and an assessment of impacts. Although we refer to the implementation period as Year 2 of the pilot, the dates from SDM Agreement execution to date of HSRI's evaluation interviews, do not correspond exactly to a calendar year.

Evaluation Findings

Nine adults² adopted SDM and utilized SDM for 72 decisions. SDM was most frequently utilized for health care decisions (19 decisions), followed by financial decisions (15 decisions). Least frequent were SDM-arrangement decisions such as changing one's decision supporter (1 decision).

Adults with I/DD who adopted SDM ('SDM adopters') expressed satisfaction with SDM, with their selection of decision supporters, and with the ways in which decision supporters provided decision assistance. Adopters reported that their preferences and decisions were respected. Pilot participants (CPR staff, Nonotuck care managers, and individuals who adopted SDM and their decision supporters) were satisfied with the mechanics of SDM. Although SDM was only in use for a little over a year, this pilot demonstrated that when individuals with I/DD and other disabilities are given opportunities to utilize their decision making capacities with committed and trusted decision supporters, it can be a satisfying experience with positive impact on both adopters and decision supporters.

¹ HSRI Year 1 report, Supported Decision Making Pilot: A Collaborative Approach is located online at: http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf

² Since the Year 1 Evaluation Report was published, a woman under guardianship adopted SDM and selected her brother (guardian), her sister-in-law, and her shared living provider as decision supporters. She and her network are trying out SDM and considering filing a petition to ask the court to discharge the guardianship.

A selection of HSRI's evaluation findings are presented below.

- Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and receiving decision help when they want help. All adopters reported that SDM is a positive experience.
 - Decisions made reflected the preferences of SDM adopters.

 - SDM adopters and decision supporters were satisfied with the process of providing decision assistance as well as with the decisions made.
 - A variety of decisions were made—from everyday decisions to very important decisions. SDM was most frequently used for health care decisions followed by financial decisions, areas of concern that often lead to use of guardianship and conservatorship.
 - Involved community members acted on the expressed preferences of SDM adopters, and did so without documentation of decisional capacity or decision supporter role.
 - Having multiple supporters worked well in this pilot. Decision supporters were committed to regular and ongoing communication.
 - SDM adoption and use made a definite and positive impact on the lives of adopters. One individual's right to make decisions was restored when the probate court discharged his guardianship.
 - Observable differences were noticed in the personal growth of SDM adopters, along with increased self-esteem and self-advocacy, more engagement in decision making, and increased happiness.
 - SDM adopters did not experience abuse, neglect or financial exploitation as a consequence of SDM. Many pilot participants believe that the structure of SDM—selecting people one trusts to help make decisions and having more than one decision supporter—reduces such risks.
 - For the SDM adopters, additional opportunities for expansion of decision making authorities exist, such as utilizing the self-directed services option for services funded through the state developmental disabilities agency.
 - Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision making assistance that allows people to keep their decision making rights, has a positive impact on their self-respect, and can reduce society's use of guardianship.
 - Pilot participants believe SDM would be helpful for other populations whose decision making rights are often removed—specifically older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally recognized adults at age 18, an age when many families are counseled to secure guardianship.
 - This pilot was faithful to the values and principles of SDM.
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Introduction

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, including where to live, what to do during the day, and what kinds of health care they will receive. Decision-making rights for adults with I/DD are often removed and awarded to a substituted decision maker as occurs under guardianship. Supported Decision Making (SDM) is an emerging alternative to guardianship which allows a person with a disability to retain his or her legal right to make decisions with the assistance of designated supporter(s).

SDM is grounded in the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD), an international disability rights treaty.³ The CRPD asserts that people with disabilities share the same legal capacity that people without disabilities enjoy, including recognition for making decisions about their lives, and when necessary, an obligation to support a person with a disability to exercise his or her legal capacity. SDM is a mechanism for recognizing and operationalizing equal legal capacity. SDM avoids the loss of decision making rights that occur under guardianship by providing decision making support where needed.

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 this variation across 41 member states: In Louisiana, 8% of the adult service population with I/DD had court-appointed guardians; in Missouri, 84% of adults with I/DD receiving services were under guardianship.⁴ This wide range signals that something other than personal characteristics of individuals influences the rate of guardianship adoption.

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.⁵

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 receiving publicly funded services who are not under guardianship are more likely to:⁶

- 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)

³ CRPD located online at: <http://www.un.org/disabilities/convention/conventionfull.shtml>. Treaty currently signed by 116 countries. In the U.S., President Obama signed the treaty in 2009, but the Senate has not yet ratified.

⁴ National Core Indicators (NCI) Adult Consumer Survey 2014-15. Located online at:

http://www.nationalcoreindicators.org/upload/core-indicators/ACS_2014-15_Final1.pdf

⁵ 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

⁶ AAIDD National Conference 2015, *Systems Change to Promote Rights: A Supported Decision Making Initiative and National Core Indicators Data Presentation*, Located online at: http://www.nationalcoreindicators.org/upload/presentation/AAIDD_2015_SDM_Pilot_and_NCI_FINAL.pdf

- Have unrestricted use of phone and internet in their homes
- 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 as an Innovative Practice

As a new mechanism for demonstrating legal capacity, demonstration projects are useful to inform successful wider adoption. When CPR and Nonotuck initiated this SDM pilot, there were no similar pilot projects in the United States to explore SDM implementation and determine the circumstances under which it is likely to be most successful. Since CPR and Nonotuck initiated their pilot, Texas and Delaware 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 Making⁷ 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 the state, including SDM. In North Carolina, SDM is now incorporated into life planning with adults with I/DD. Separate from the National Resource Center, Disability Rights Maine initiated a project similar in many respects to the CPR and Nonotuck model, and other innovative projects are getting underway in California, Texas, New York and elsewhere.

CPR-Nonotuck SDM Pilot

The Center for Public Representation (CPR), a nonprofit law firm focusing on disability rights in Massachusetts and across the country, and Nonotuck Resource Associates, Inc. (Nonotuck), an agency principally providing shared living and adult family care residential supports, partnered to offer adults with I/DD living in western Massachusetts an opportunity to use SDM. Pilot participants were drawn from Nonotuck's service recipients: adults with I/DD and other disabilities who had involved people in their lives. This pilot was purposefully limited to a geographic area, western Massachusetts, and to those who volunteered to test the use of SDM.

CPR and Nonotuck conducted their two-year SDM pilot with a collaborative approach across all phases—from pilot design, to project management and implementation, to conducting SDM outreach and education to broader communities. The pilot had two major goals:

1. Assess the degree to which SDM can maximize 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?
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The formal period for this pilot partnership and evaluation was two years. However, SDM Representation Agreements are expected to continue indefinitely into the future and be modified as people's lives change. CPR and Nonotuck are discussing the pilot's future scope and possible expansion.

⁷ National Resource Center on Supported Decision Making is located online at: <http://supporteddecisionmaking.org>

Nine adults with I/DD and other disabilities and chronic health conditions participated in the pilot and adopted SDM with their voluntary decision supporters. During the pilot's first year, eight adults with I/DD adopted SDM and completed SDM Representation Agreements that specified areas for decision making assistance and designated decision supporters. SDM Representation Agreements were signed by adopters and decision supporters and notarized. For some adopters, health care advance directives (called "health care proxies" in Massachusetts) and durable power of attorney documents were simultaneously notarized. During the pilot's second year, an additional individual with I/DD joined the pilot and completed an SDM Representation Agreement.

The number of decision supporters selected by SDM adopters in the pilot ranged from 2 to 10. Supporters included relatives, shared living providers, and a Nonotuck care manager who is also a friend.⁸ All SDM adopters selected to have decision assistance across all categories noted in SDM Representation Agreements: Finances, Health care, Living arrangements, Relationships/Social, Employment, and Legal matters.

SDM adopters represent a wide range of ages, diagnoses, and life experiences. All primarily use spoken language to communicate their preferences. Information about the personal characteristics of SDM adopters (age range, communication, diagnoses, history of institutionalization, employment status, etc.) is located in Attachment C.

Independent Evaluation Research Aims and Data Collection Methods

CPR contracted with the Human Services Research Institute (HSRI), a nonprofit research and consulting organization, to conduct an independent evaluation of this SDM demonstration pilot. HSRI conducted a process evaluation with the primary aim to tell the story of this pilot project and identify lessons learned for expanding the knowledge base of SDM in real-world situations. Evaluation reports are intended to inform a wider audience about the potential benefits of SDM adoption.

HSRI's two evaluation reports follow the sequential stages of pilot development. The first report (Year 1) examined activities undertaken to establish the pilot, select volunteers to adopt SDM, and assist SDM adopters through the process of designating decision supporters and completing SDM Representation Agreements.⁹ This second evaluation report (Year 2) presents SDM pilot activity and findings regarding the experience of using SDM and an assessment of impacts. Although we refer to the implementation period as Year 2 of the pilot, the dates from SDM Agreement execution to date of HSRI's evaluation interviews, do not correspond exactly to a calendar year.

Data collection during Year 2 consisted of: 1) observation of pilot partner project coordination and events, and 2) interviews with pilot participants. HSRI evaluation staff participated in the monthly

⁸CPR and Nonotuck considered whether people who are paid to provide care or services to the adopter should be decision supporters. The conclusion was that if, after any potential conflict of interest was discussed with the decider, he or she chose to select the paid person as a supporter, the decision was for the decider and that it would be inappropriate for the pilot project to limit that choice. Proceeding this way seems most consistent with the principles of supported decision-making. Nevertheless, see the discussion of occasional practical implications of this decision on pages 13-14.

⁹ HSRI Year 1 report, Supported Decision Making Pilot: A Collaborative Approach, is located online at: http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf

meetings between pilot partners and in Advisory Council calls; they also attended pilot SDM events (a celebratory dinner in November 2015 and an SDM planning meeting in March 2016).

The second data collection method consisted of interviews with pilot participants. In-person interviews were conducted with the SDM adopters. Separate in-person interviews were also conducted with the most involved decision supporters for each SDM adopter. (All decision supporters were invited to participate in the evaluation. Nonotuck care managers arranged all meetings between HSRI evaluation staff and adopters and decision supporters.) For two adopters, a single designated decision supporter participated in the evaluation. For seven adopters, two or more decision supporters participated, sharing their views and impressions. Care managers who work with SDM adopters were interviewed either in person or by telephone, whichever was more convenient for them. The four CPR staff primarily engaged in the pilot during Year 2 were interviewed by telephone. For examining the experience and impact of using SDM, HSRI evaluators conducted 31 interviews involving 37 pilot staff and participants:

- 9 SDM adopters
- 15 Decision supporters
- 9 Nonotuck Care manager interviews with 4 care managers (1 care manager is the care manager for 5 SDM adopters and was interviewed separately for each SDM adopter.)
- 4 CPR staff

All interview protocols and procedures underwent ethical review and approval from an Institutional Review Board (IRB). Participation in this evaluation was voluntary for all pilot participants. Details regarding the IRB review are found in HSRI's Year 1 SDM pilot Evaluation Report.

SDM as a Model to Advance Human Rights

On November 17, 2015, pilot partners held a celebration dinner after the first guardianship was discharged in Massachusetts. SDM adopters, their decision supporters and family members, an Advisory Council member, and key pilot staff attended. Attendees were moved to hear how important SDM is as a mechanism to advance the human rights of persons with disabilities, to correct past harms, and to learn of the particular importance of this vanguard SDM pilot.

During the event, CPR Attorney Robert Fleischner, who represented an SDM adopter in court that day, petitioning the court to set aside a guardianship, relayed that this was a historic day. It was the first time in Massachusetts that an SDM adopter's guardianship was discharged and an SDM adopter's rights to make decisions about his life was restored. Attorney Fleischner also petitioned the court to release the legally appointed substitute decision maker for psychotropic medication decisions; the court did so, returning decision making rights to the SDM adopter. This SDM adopter's parents had been his guardians. They had reluctantly undertaken guardianship because, at the time their son turned 18, there was not an alternative. Now this SDM adopter's parents and sister are his SDM decision supporters.

As part of the celebration, Michael Kendrick, an international disability rights advocate, spoke on the importance of SDM and the values underpinning this international effort to give people with disabilities their voice when making decisions about their lives. Excerpts from Dr. Kendrick's remarks follow.

Everyone has the right to make the wrong decision, but if you don't have the right you can't make the right or wrong decision. In protecting them, we've taken their voice. [Adopter's name] court decision today is that he can now legally be involved in decisions about his life. Some members of society realize we didn't need to do that, to take his voice away. We need to correct, to rebalance. SDM means having a voice in decisions, standing with others. One of the great wisdoms in life is that once you've made a bad decision, not to keep making it. SDM allows us to correct our course, our mistake in removing people's voice. It's important to set things right.

The idealism of SDM is embedded in the UN treaty. Getting SDM launched in other countries is amazing. It's given SDM a lot of legitimacy. The United Nations counts in many countries. It is a very high water mark to have SDM in this treaty and for countries to take action to get things right for people with disabilities. This project will give us lots of reasons to have done this sooner.

SDM is tied up in "right" decision making. But we get to make decisions that some of the time are wrong, so it's not a fair standard to require right decisions be made by people with disabilities. If we do so, then when people using SDM make a decision that others don't agree with, it will be pulled back. We have corrective actions for wrong decisions, for example, divorce when marriage at the time seemed like a good decision.

SDM is different than decision making because it gives support to make decisions. Doesn't mean the supporters are right, but means people are not making decisions alone. SDM is not about letting people sink or swim. Let's be in their corner, so they are not alone or making decisions in isolation. We can guide, correct, affirm decision making – just as we do for everyone else in our lives.

Life is complicated. But the more we help one another and have people in your corner, then we are better off. The big secret is that nobody knows what they are doing. We are all just making it up every day. We are winging it. There is a big learning curve with making decisions. But we don't learn everything there is before we make a decision. Everyone is learning all the time – we are learning and growing and on a journey to figure it out. We are winging it, so we should not expect people with disabilities to be perfectionist in their decisions.

The important questions are why are we here? Why were we born? What is the purpose of living? Life is murky, perplexing for all. We make decisions in context of pressures of living, not in a vacuum. This should produce in us a kindness and patience for others' decision making. It doesn't get easier or better. At every age of living it is complicated. For centuries humans have been on the earth with complicated lives and yet we are still surviving and having families and life goes on. Instead of asking about what decision is in a person's best interest, or what their capacity is to make decisions, the better question is why is life so mystifying?

SDM adopters and decision supporters said this gathering was very significant. They felt part of a larger effort to advance human rights. Pilot partners marked an earlier significant date in March 2015 with a celebration as well. After many of the SDM Representation Agreements were signed and notarized, pilot staff, adopters and decision supporters marked this significant event with a special cake. These events illustrate the importance of Practice Recommendations outlined in the Year 1 evaluation:

- Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.
- Mark SDM adoption as a celebratory event.

Role and Ethical Responsibilities of SDM Designated Decision Supporters

PRACTICE RECOMMENDATION: Clarify the role and ethical responsibilities of decision supporters. Provide guidance in conversation with putative decision supporters as well as in written materials.

SDM is a relationship-based experience. The person with a disability may use the assistance of a person they designate to explain information, help them determine their preference on a matter, and also convey their preference to others—particularly to those who do not know the person well enough to have understood his or her preferences without translation or interpretation from a decision supporter. The role of a decision supporter thus is a weighty one.

A brochure on SDM created by the pilot partners describes the supporter role, "*The supporters assist the person so he or she can reach his or her own decisions. They help the person understand the choices at hand, and review options – the pros and the cons – of the pending issue. The supporters also assist the person in communicating his or her intention to others.*"¹⁰

At this time, SDM guidance for real-world applications, in general and for decision supporters, is evolving. As SDM experience grows and consensus on good practices for application with different

¹⁰ <http://supporteddecisions.org/about-sdm/>

populations evolves, additional guidance in law and standards will be available. In the meantime, using the CPRD, SDM presentations and publications posted online (including the website for this SDM pilot¹¹), and the remarks of Dr. Kendrick, HSRI compiled the following list outlining the role and responsibilities of decision supporters. These do's and don'ts could supplement the pilot's SDM brochure guidance and be useful for consideration by future SDM pilot staff, adopters, and decision supporters.

-
- a. People with disabilities have a right to make decisions about their lives and to have those decisions and their preferences recognized and honored. Decisions should reflect the will and preferences of the individual with a disability.
 - b. People with disabilities adopting SDM may choose one or more decision assistance persons (i.e., decision supporters) to assist them. Decision supporters can include peer support, friends, family, community members, or others.
 - c. People with disabilities using SDM may terminate or change decision supporters at any time.
 - d. People with disabilities using SDM may change the areas for decision assistance (finance, health, relationships, etc.) as well as how they prefer to access and use supporter decision assistance.
 - e. SDM guidance must include how to make changes to SDM Agreements.
 - f. Decision assistance should enable the person to understand the options available and consequences of deciding one way or another.
 - g. Decision support can be offered for decisions that range from everyday to more official matters.
 - h. People with disabilities can make "bad" decisions, decisions not in their best interest, just as people without disabilities are able to make. Decision supporters may simplify the options available, but should not limit options to only those considered "good" for a person with a disability.
 - i. Decision supporters should not make decisions for individuals with disabilities.
 - j. Decision supporters do not have to agree with a decision made by someone using SDM.
 - k. SDM involvement is voluntary. Adopters and supporters are free to use or withdraw from SDM at any time.
 - l. Anyone may object if decision supporters are not following the person's preferences and report decision supporters suspected of abuse, neglect or financial exploitation. (Information should be included in SDM rights and guidance materials on how and to whom to make complaints of concern, whether such complaints can be made anonymously, what entity will investigate the concern, the usual timelines for completing an investigation, and how a determination of findings will be communicated.)
 - m. Decision supporters may need to assist people who do not use speech to communicate and express their preferences and decisions. Assistance may include use of an interpreter, facilitated communication, assistive technologies or other methods.
 - n. A lack of resources should not be a barrier to adopting or making changes to SDM arrangements.

¹¹ <http://supporteddecisions.org/document-library/>

Using SDM: The Decisions

Number and Type of SDM Decisions

EVALUATION FINDING: SDM decisions ranged from everyday choices to very important decisions. With decision assistance, adopters made decisions regarding their health care, dental care, mental and behavioral health care, finances, legal matters, living arrangements, work and day supports, social and leisure activities, relationships, and an SDM-arrangement decision to change a supporter.

To document adoption of SDM, CPR staff created an SDM Representation Agreement, which notes the areas for decision assistance (such as finances or where to live), and the designated decision supporter(s) for each area of decision assistance. Where there is more than one decision supporter for a particular area of assistance, the Agreement template includes the method by which the SDM adopter prefers to receive assistance from multiple supporters—either jointly (supporters confer and then present decision options to adopter) or successively (adopter first consults with decision supporter named first, and if that person is not available, goes to second supporter, and so on).

SDM adopters and designated decision supporters signed these Agreements. Agreements were notarized to mirror the legal weight afforded to other notarized agreements in common use. Additional information about the SDM Representation Agreements is found in the Year 1 Evaluation Report pages 24-27, and on the pilot website under Documents Library.¹²

how many? copy?

Since the adoption of SDM Representation Agreements, pilot staff and participants identified 72 decisions that utilized SDM. HSRI categorized these according to decision areas in the pilot's SDM Representation Agreement form¹³ but also further differentiated behavioral health decisions from the broader health care category. HSRI also added a category for SDM-arrangement decisions and examined social and leisure decisions separately from personal relationship decisions. HSRI did this to show that adopters in this pilot made decisions in all of these domains. For each SDM decision, HSRI identified one primary category. Table 1 shows the 72 decisions categorized by type from most to least frequent reported between March 2015 through July 2016.

Table 1. SDM Decision Categories and Frequency

SDM Decision Categories: Highest to Lowest Frequency	Number of SDM Decisions (3/2015-7/2016)
Health care and dental care	17
Financial	15
Social and leisure	13
Employment/ Volunteer / Day supports	10
Relationship	7
Legal matters	4
Living arrangements	3
Mental health / Behavioral health	2
SDM arrangement decision	1
Total SDM Pilot Decisions	72

added

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¹² <http://supporteddecisions.org/document-library/>

¹³ The pilot SDM Representation Agreement form contains these decision assistance categories: Finances, Health care, Living arrangement, Relationships/Social, Employment, Legal matters, Other (please specify)

Below are examples from each SDM decision category made by adopters in their first year and a half (or less) after adopting SDM.

Table 2. SDM Decision Examples

Category	Decision Example
Health care and dental care	SDM adopter decided after seeing a specialist and two surgeons (one for second opinion) to have surgery on foot. Surgery went well.
Financial	SDM adopter was dissatisfied with bank fees on transactions. Decision supporter advised that banks have different fee structures. Adopter decided to switch to a bank with unlimited free banking activity.
Social and leisure	SDM adopter was invited to a class reunion where alcohol was to be served. Decision supporters conveyed concern of riding in car with people who had been drinking alcohol. SDM adopter made decision to ride in car with friends who had been drinking and join them to eat at a restaurant after the reunion. (Everyone was fine.)
Employment/ Volunteer/ Day supports	SDM adopter was invited to speak at a conference on a panel with Temple Grandin. Adopter made decision to speak with support from others.
Relationships	SDM adopter's boyfriend wants to have children. Adopter discussed with decision supporter the care needs and money required to parent. Adopter has privacy with boyfriend but decided not to be a parent at this time.
Living arrangements	SDM adopter expressed preference to move out of family home to an apartment.
Legal	Legal decisions included whether to purchase a gun to protect loved ones, securing a state authorized form of ID, providing consent for image and story to be posted online, and pursuing a vehicle driver's license.
Mental health / behavioral health	SDM adopter experienced an increase in behavioral health symptoms. With a decision supporter, adopter met with treating practitioner and discussed medication options. Adopter decided to adjust medication and to add a visit with treating practitioner each month until feeling better.
SDM arrangement decision	SDM adopter changed shared living homes and providers. She asked that former shared living provider be removed as a decision supporter and replaced with current provider.

Selection criteria for 1/19

Using SDM: The Experience of Pilot Participants

Adopters' Understanding of SDM

EVALUATION FINDING: All SDM adopters articulated their understanding that SDM means they make decisions about their lives and have assistance from others. Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and receiving decision help when they want help. All adopters reported that SDM is a positive experience.

The Year 1 Evaluation Report relayed care managers' perceptions regarding adopters' understanding of SDM and what they were undertaking. SDM adopters were perceived to understand SDM. Below are several comments by care managers repeated from that report.

- *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."*

This year HSRI evaluators asked SDM adopters directly if they have the right to make decisions about their lives. Nearly all reported that they do (8 of 9 adopters). However, all adopters stated that they had help with making decisions when needed. And all SDM adopters named specific decision supporters who assist them with making decisions.

Decision supporters also perceive that adopters understand SDM, fully or sufficiently, to mean making his or her own decisions but also having a dependable relationship, someone to go to for input when needed. Comments by decision supporters are below.

- *That she can come to me with any questions or concerns for discussion, and that I'll support her decisions.*
 - *He knows there are three people he can go to. Sometimes he asks what do you think or to confirm his decisions.*
 - *She kind of knows exactly what it is. She enjoys making decisions on her own. She enjoys having this right. She's very opinionated, kind and gentle.*
 - *She likes the support of other people.*
 - *When she asked me to be decision supporter, she was very proud and knew who she wanted to be part of this, to be a decision supporter. I was the one who didn't understand it.*
 - *Not sure she grasps the whole concept. She expects our involvement. She's always signed her own check and makes her own money and makes her own decisions. Now she reads, reads her menu and tells the waitress what she wants. Before, her family ordered for her.*
-

Decision Supporters' Understanding of SDM Role and Responsibilities

EVALUATION FINDING: Decision supporters understood and were able to uphold their duties to assist an individual with disabilities to understand options, help the person express preferences, and honor the person's preferences and decisions.

Pilot partners provided guidance to decision supporters on their role and responsibilities. All supporters interviewed noted that the orientation was sufficient to carry out their responsibilities.¹⁴ Supporters interviewed were aware of their duties to help SDM adopters understand information, express preferences, and to honor the person's decisions. Decision supporters conveyed their understanding of SDM ethical responsibilities as below:

- *To understand what [name] wants, to inform her, to make sure she understands her choices, and honor those choices.*
- *I try to put myself in her position, making sure she has information as a human being. [Name] needs to make her own decisions. I am continuously helping her bring out what she thinks is important. Sometimes we take a long time talking -- me trying to understand -- then getting others to understand. For example, when she wanted to join taekwondo classes, the instructors thought that due to her disability, she should be in a child class. But [name] was thinking adult classes. I pushed adult class and that's where she is.*

Decision supporters are cognizant that they are not required to agree with a decision made by someone using SDM. Sometimes providing decision assistance and having other roles, such as a paid care provider or parent of an adopter, can get complicated. As this mother and decision supporter explained, "Yes, I want him to have a regular relationship with his fiancé, but I also don't want him to have children. But he wants to. I'm not comfortable with their next step."

Decision supporters understand that SDM adopters should be able to make "bad" decisions, particularly decision supporters who attended the celebratory SDM dinner on November 17, 2015, and heard Michael Kendrick speak about the importance of not mixing SDM up with "right" decision making. HSRI asked CPR staff and care managers if they knew of instances in which adopters made decisions that their decision supporters might think were not in the adopter's best interest. CPR staff had knowledge of two decisions, and a care manager referenced a third decision, where adopters' decisions were not what others thought in their best interest.¹⁵ For these three SDM decisions, made by different adopters, the adopters' preferences, not the decision supporters' impression of what was best, were honored.

Nevertheless, avoiding harm did occasionally influence provision of decision assistance. A number of decision supporters mentioned shaping choices in order to keep an individual safe. The duty to present decision options within a reasonable safety framework was mentioned more frequently by shared living providers serving as decision supporters than by family members in this role:

- *As long as not harmful, we are to support [name] decision. Make sure decisions are made to benefit [name]. [Shared living provider]*

¹⁴ At least one decision supporter was interviewed for each SDM adopter. For seven adopters, interviews included two or more of decision supporters.

¹⁵ 1) To ride in car with friends who had been drinking after school reunion. 2) Not to get glasses. 3) Attend a day program where adopter had been wrongly treated as a troublemaker.

- Have her best interests at heart so she is not making decisions that harm her but to enhance her life. Help you get the best care, best places to go, best docs. To have your back. [Shared living provider]
 - Try to get to point to [name] understands, but try to leave decision alone. This is a hard question. I bring some options but do not overwhelm her. I educate and limit choices to all good, and she picks within them. [Shared living provider]
-
- Safe, better chance than she had; helping her when she needs help. [Shared living and day support providers]
 - Morally as a family to see that [name] enjoys her life. SDM responsible for safe, right decisions. [Family]

SDM Implementation Challenge: For both family and paid service providers serving as decision supporters, a concern with safety may occasionally limit an individual's choices. For decision supporters who are paid to provide supports to SDM adopters, state standards for service providers may influence their consideration of safety when providing decision assistance. Balancing support for some risk-taking with safety is not a new challenge for service providers. In Massachusetts, state standards require providers to promote an individual's self-determination and freedom of choice to the individual's fullest capability, and for individuals to undergo typical developmental experiences, even though such experiences may entail an element of risk. However, state standards also require that providers to ensure that an individual's safety and well-being are not unreasonably jeopardized.¹⁶ Where there are dual responsibilities for ensuring safety and offering opportunities for risk-taking, decision supporters may limit or restrict information without advising the SDM adopter that they have done so.

Decision Making Assistance and Support Provided to SDM Adopters

EVALUATION FINDING: Decision supporters tailored decision aids and assistance to the person's needs. They did so through knowing a person well.

Supporters in this pilot did not receive training on how to provide decision assistance, but all supporters interviewed reported that they understood how to do so through knowing a person. This evaluation found a high level of confidence among decision supporters that their techniques and skills in presenting information were useful to SDM adopters. SDM adopters confirmed that decision supporters knew how to be helpful in providing decision-making assistance. As the supporter statements below illustrate, this good fit of presenting information in a way that is helpful—so the adopter understands the choices and consequences—seems to come from knowing one another and having a relationship of trust.

Typical are supporter quotes below sharing how they operationalized providing personalized decision assistance.

- Be honest and spell out step by step pros and consequences, use words, sometimes show him on the internet.

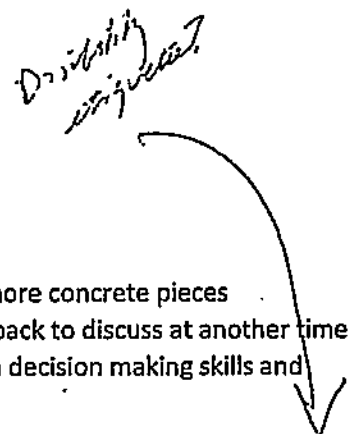
¹⁶ Massachusetts Department of Developmental Services 115 CMR 5.00: STANDARDS TO PROMOTE DIGNITY: 503(c) Self-determination and freedom of choice to the individual's fullest capability; 503(e) The opportunity to undergo typical developmental experiences, even though such experiences may entail an element of risk; provided however, that the individual's safety and well-being shall not be unreasonably jeopardized. Located online at: <http://www.mass.gov/eohhs/docs/dmr/regs/reg-115cmr005.pdf>

- Now with the dementia, doctors talk above her and fast. I slow the conversation down. Repeat. Get eye contact so she doesn't "yes" you.
- It helps her if we research an issue together on the internet. I'm a sounding board. We're equals.
- If we overwhelm him he goes off topic. Then we know to make pros and cons simpler.
- We have a good relationship where she trusts me.
- I say, "Here are your choices." I ask him "What do you think?" I can tell from his answers. Can tell if he's anxious and if he needs to come back to it.
- You can tell when she understands. You can see confusion on her face. It's knowing her.
- Allow her to try and find out if she does or doesn't like it. One example is when she was on vacation in Myrtle Beach she wanted to go on the jet boat. Those gangplanks move and bounce and she fell down. She did get on the boat, but she is never going back on a jet boat again. Another thing she tried out was sitting at a bar stool. She didn't think she could do it, but she did.
- By her telling me that it's helping her. She confides in me. She says it's working for her.

Summarizing the comments from decision supporters in this pilot, skills useful for providing decision making assistance can be described as:

- Be truthful
- Listen to the person
- Repeat/repetition
- Make eye contact
- Slow the conversation down
- Ask adopter to repeat back what was said or heard
- Observe body language
- Offer visual information
- Provide ideas and suggestions to inform decision making
- Conduct online searches together
- Review written information together
- Simplify and break larger concepts or abstractions into smaller, more concrete pieces
- Step away when an adopter appears confused or anxious; come back to discuss at another time
- Provide opportunities to try new things out. Experiences broaden decision making skills and preferences

*Decision making
is a goal?*



These skills have much in common with the approach to supported decision making found in ASK ME, a model based on a positive, relational concept of autonomy.¹⁷ ASK ME is an acronym for decision making steps. The following is an abbreviated description of these steps.

1. ASSESS where the person's strengths and deficits lie to determine how to best simplify/limit the task and maximize the person's understanding.
2. SIMPLIFY the task, avoid jargon, pitch information so that individual can understand.
3. KNOW the person, his or her values and what is important at that time to the person, how they have made decisions previously, and any patterns to decision making. Respect both prior decisions but also person's right to change their mind.

¹⁷ Peisah, Carmelle, et al., Decisional Capacity: Toward an Inclusionary Approach, International Psychogeriatrics (2013), 25:10, 1571-1579.

4. MAXIMIZE the person's ability to understand by giving enough time, modifying format, providing visual aids, creating environment conducive for optimizing decision making including best time of day for cognitive tasks.
 5. ENABLE participation by tailoring the degree of support to the complexity of decision and the seriousness of decision consequences. This step also entails assisting and facilitating with communicating the decision and its implementation.
-

What Additional Supports Do Decision Supporters Need or Want?

EVALUATION FINDING: Even experienced decision supporters would appreciate peer support and opportunities to share experiences with other decision supporters. Establishing learning communities of decision supporters, locally and nationally, could provide for greater decision supporter awareness of issues that arise for supporters, and more comfort that SDM is a sustainable alternative to guardianship.

As noted above, decision supporters reported confidence in customizing their decision aid for adopters. They did not think they needed any assistance or training for this role. However, when asked if there had been another pilot with experienced decision supporters to speak to about the role, several supporters stated that some training and communication with other decision supporters would be helpful, *"Just having a personal conversation with other parents to talk to who have adopted [SDM]."*

Below are recommendations from decision supporters interviewed for those considering this role. Notable is the repetition of advice to let go of controlling a person with a disability.

- *Listen, know what people are capable of, guide in pros and cons, but don't decide for people. Make them feel good to be making their own decisions.*
- *Biggest advice is to separate being parent and being the supporter – that mom is part of a team – not the mother demanding as when he was underage or my ward. It's very important that every family that steps into SDM separates, steps out of parent role and into the job as a decision supporter. Decision supporters should know a person very well.*
- *Always remind supporters not to control people. People love titles and can abuse. Be happy that someone asks you to support them.*
- *Let go of the control that you are the only one who can do this for a person.*

How SDM Worked with Multiple Decision Supporters

EVALUATION FINDING: Multiple decision supporters worked well in this pilot—to a great extent because supporters were already committed to, and had established arrangements for, regular and ongoing communications.

EVALUATION FINDING: In this pilot, adopters utilized supporters who were available

When SDM adopters selected multiple decision supporters (from 2 to 10), pilot staff and HSRI evaluators wondered if the arrangements would be too unwieldy. Such was not the case in this pilot even though five adopters designated three or more decision supporters. The Year 1 pilot Evaluation Report (pages 21-22) provides details about the relationship of supporters to adopters, and how long they have known

adopters. Family members are the largest cohort of decision supporters; six of the nine adopters designated family members.

Decision Supporter Perspective

All decision supporters interviewed noted that communication is important and that they spend time keeping other decision supporters and involved parties up to date. Typical were supporter statements below.

- *Whoever is with him shares information. When a decision is made, we alert each other.*
- *He goes to whoever he wants to. Mom wants him to start using others more. Important for him to practice and know there are other people who he can consult.*

None of the interviewed decision supporters noted disagreement among decision supporters regarding SDM. What has occurred is decision supporters sharing different information or perspectives on an issue. This high degree of cooperation and communication across supporters seems related to having supporters who are deeply involved in a person's life. As this supporter described it,

- *We are always in agreement. Important because she likes to have independence. Are you coercing her in any way, e.g., decision re eating? No. We do stress why we think healthy are better choices, using language she understands. We get information to show her in print material and online. We do not coerce her. We make plans about future rewards for weight loss.*

Another supporter noted that having multiple people in a network was a positive because there is less dependence on one person and more perspectives on knowing a person: *"I'm cool with a group as an alternative to a guardian. What happens if something happens to guardian? Sometimes the people around you who know you, know you better than a guardian. I go to ISPs [service planning meetings] and I'm telling the guardian information."*

Care Manager Perspective

Nonotuck care managers also reported that use of multiple decision supporters in this pilot worked very well. For one adopter, communication among decision supporters is occasionally complicated, but this was described as *not* due to SDM, but a communication habit between an adopter, her mother, and the care manager that preceded SDM.

While disagreement was not reported within an individual's network of supporters, not all supporters are equally engaged, nor was this an expectation. SDM Representation Agreements prepared by CPR staff offered adopters the option to use either a "joint" or "successive" decision making approach to securing assistance from designated supporters. Noting joint or successive preference was expected to inform decision supporters on how SDM was to work in real-world application. Under joint, decision supporters are to work together to assist the individual with decision making or expressing the preference to others. Under successive, if the first supporter is not available, the adopter goes to the next supporter on SDM Agreement, and so on, until the adopter finds an available supporter.

Care managers reported that adopters consulted with the decision supporters on hand. For this pilot in which nearly all decision supporters were designated across all SDM decision categories, this practice of using the most available decision supporter worked. No one participating in the pilot was territorial or concerned with whom an adopter spoke or consulted first.

Potential SDM Implementation Challenge: This pilot showed a high level of cooperation across multiple decision supporters, but such cooperation may not always be the reality. In this pilot, where decision supporters were almost all given authority to assist an adopter in all decision areas, going to a supporter on hand worked. Future SDM pilots where there is more discrimination of supporters and areas of assistance may experience added complications when using multiple supporters.

CPR Staff Perspective

CPR staff note that having multiple supporters provides for accessibility of supporters but also for long term planning similar to when parents include siblings as co-guardian or successor guardians. One adopter's SDM Agreement includes a decision supporter, who at the time the Agreement was notarized, was younger than 18 years old. Although CPR staff viewed this supporter as in a "non-binding" role until he attained legal age, the adopter and the other supporters had confidence in his maturity and close relationship with the adopter.

CPR staff also confirmed what care managers relayed about the SDM process—that adopters went to whomever they chose in the moment to get information for a decision. *"It is really about people interacting. SDM models may need more clarity so people don't get hung up on that [joint v successive model]."*

Potential SDM Implementation Challenge: With multiple supporters, CPR staff raised a concern that a decision making process could result in the supporters discussing and making a decision and then presenting that decision to the adopter. While a risk, this evaluation did not find evidence of that kind of process.

Response to SDM Use by Community Members

EVALUATION FINDINGS: Most SDM decisions did not involve general community members. Where community members were involved, the preferences and decisions of adopters were accepted and acted upon without reviewing documentation of SDM arrangement or decision supporter's role.

SDM is not only about making decisions about one's life (with support if needed) but also having those decisions recognized and honored. This evaluation found that decision supporters had no difficulty conveying adopters' decisions to third parties or in having adopters' decisions honored.

The majority of SDM decisions did not involve community members. Twelve of the 72 SDM decisions involved community members. Where community members were involved, they included a banker, employers, day program management staff, urgent care health care practitioners, psychiatrists, surgeons, a pharmacist, an endocrinologist, a martial arts instructor, and Department of Motor Vehicles employees. These community members acted on the expressed preferences and decisions of adopters, although at times prompts were necessary from decision supporters.

Pilot participants described the interactions with all but one community member as favorable and respectful, understanding and compassionate. Some community members were respectful naturally, and others followed cues offered by decision supporters. Only one of the SDM interactions with a community member was described as "abrasive," and in this case the decision supporter relayed that a surgeon's lack of bedside manner did not seem related to her daughter's disability, but to his general approach to communicating with patients and families. Examples of each type of experience follow.

Naturally positive - This interaction with a pharmacist was described by a decision supporter. The SDM adopter was experiencing hallucinations and the supporter's impression was that this distress was due to the adopter reliving buried trauma from decades of institutionalization now that she is in a safe place. A recurring visual and auditory hallucination began soon after the adopter told this shared living provider and decision supporter about abuse she suffered when she was institutionalized. The adopter's psychiatrist recommended a low dose of Risperdal, a medication with a "black box" warning due to a potential lethal side effect. The service coordinator from state agency for I/DD services was described as concerned about adopter's consent to a medication with a black box warning, and because this older adopter is diagnosed with dementia. The SDM adopter and decision supporter met with the local pharmacist who sat down at eye level with adopter and described the pros and cons in simple terms so that the adopter understood. The SDM adopter decided to take the medication. The hallucinations stopped and no side effects have been experienced.

Responsive to supporter instruction - A supporter accompanied an adopter to an urgent care center for treatment of a dog bite. The health care practitioner advised the adopter that a blood draw was necessary. The adopter refused. The supporter advised the practitioner to tell the adopter *why* a blood draw was necessary. The practitioner then explained why, and the adopter changed decision to allow blood to be drawn and tested.

Not responsive to supporter instruction - The exception to positive interactions with general community members was a surgeon who repeatedly asked the SDM adopter "why" questions even after her mother (also a decision supporter) instructed the surgeon that "why" questions are not well understood by [name]. This surgeon was described by the decision supporter as making statements that dismissed the adopter's expressions of pain and discomfort, and presented the risks of surgery to the adopter as, "You know you can die on the table." The procedure being discussed required local anesthesia. The supporter discussed the possibility of another surgeon for a second opinion and adopter decided to seek a second opinion.

The second opinion surgeon was naturally positive and described as gentle and compassionate. He acknowledged adopter's pain, and determined a less invasive surgical correction was possible. The problem was not a bone that needed fusion to straighten, but a cyst on tendon that could be removed. SDM adopter chose this surgeon and surgery. This surgeon asked the adopter what kind of music she wanted played during the procedure and made sure it was played. This adopter is recovering well and pain is eliminated.

Potential SDM Implementation Challenge: In this pilot supporters were present with adopters for interactions with community members and were able to provide instruction to enhance communication where needed. In some instances, had adopter interactions with community members not included decision supporters, the experiences and outcomes may not have been as favorable.

Use of SDM Representation Agreements

EVALUATION FINDING: Community members acted on the expressed preferences of SDM adopters without documentation of decisional capacity or decision supporter's role.

With one exception, SDM Representation Agreements were not utilized. Involved community members acted on the preferences of SDM adopters without documentation of decision supporter role. In the case where the SDM Agreement was produced, a care manager accompanied an adopter to a local

Department of Motor Vehicles (DMV) office to secure a legal form of state identification. Although SDM Agreements are not on Massachusetts' list of authorized forms of documenting a home address, a DMV supervisor agreed to accept it as proof of address and the adopter's signature, and issued the state ID with photo.

At this time, SDM Representation Agreements have no end date. They are in effect until one or another party decides to make changes or end the arrangement. A suggestion by one care manager is to make SDM Agreements time-limited, similar to other consent forms used in disability service systems. Time-limited SDM Agreements would prompt review, and create a point in time for adopters and decision supporters to re-commit or make changes. This care manager also recommended creating an SDM Agreement Fact Sheet to accompany the document.

Adding to the care manager's suggestions, HSRI offers the following list of items that could be included in an SDM Agreement Fact Sheet:

- The voluntary relationship between adopters and decision supporters, and that both parties are free to withdraw from the arrangement.
- When a decision supporter withdraws, an expected notice period so that the person with a disability has time to find new supporters if desired.
- Agreements can be modified as needed as people's lives change.
- Decision assistance instructions can be modified including who provides decision assistance, as well as how and decision domains (financial, health care, etc.).
- Instruction on what organization or person to contact to make changes to an SDM Agreement, such as add or remove a decision supporter, or add or limit areas for decision assistance.
- Whether there is any charge for making changes to the Agreement.
- Length of time the Agreement is in effect. If an Agreement extends into the future indefinitely, consider time-limits such as one or five years to build in a review date.
- How to secure additional copies of an Agreement, and that copies should be available at no cost.
- Recommendation that Agreements be signed by adopters and supporters and notarized.

SDM Implementation Challenge: Several adopters in the pilot advised HSRI staff that they did not have a copy of their SDM Agreement. In addition, not all care managers or decision supporters had a copy of their Agreement. If a copy was needed, adopters and decision supporters stated they would call a care manager, and care managers noted they would contact their Nonotuck supervisor or CPR staff. It may be useful to periodically check, such as annually, that adopters, supporters, and service providers have copies of the most current SDM Representation Agreement.

Using SDM: Satisfaction

Adopter Satisfaction with Decisions, Supporters, and Decision Assistance

EVALUATION FINDING: SDM adopters were satisfied with making their own decisions, with the decision assistance provided, and with the outcomes of their decisions.

Adopters described themselves as very satisfied with their decisions including their selection of decision supporters. They expressed pride in making their own decisions and in having the right to make their decisions. Care managers and decision supporters confirmed adopters were satisfied with decisions that utilized SDM. For all 72 SDM decisions, the preferences of adopters were reported as being respected and acted upon.

Adopters also expressed satisfaction with their decision supporters and the ways supporters provided decision assistance. All SDM adopters reported that decision supporters treat them with respect, and are nice and polite. All SDM adopters said that their decision supporters ask what they (the adopters) want. *"Yes, she asks me what I want. She asked me if want a bed instead of pull-out sofa."* Most adopters report having decision supporters who understand what they want across the decision support areas of health care, finances, personal life, relationships, etc. HSRI asked supporters what adopters wanted in their life, their dreams. Supporters shared very specific hopes and dreams of adopters, including these below.

- To get a driver's license.
- Be married, have her own home with fiancé, and work at a radio station.
- Things she missed due to living in an institution. Things we all do in life.
- She tells us she wants to live with [shared living provider's name] until she dies. She wants to shop, go on vacation. She is completely different. She was being arrested before living with [provider], when she lived with her mother.

All supporters explain things in a way the adopters can understand in order to make their own decisions. *"She knows those hard words but she puts it into easy words for me. So the other person knows what it means."* Nearly all (8 of 9 adopters) said their decision supporters discuss both the good and bad things that could happen for a particular decision.

One of the values of SDM is that individuals have the right to terminate or change supporters. Others can verify and object if supporters are not following person's preferences. Adopters are currently satisfied with decision supporters. One adopter has already changed one of her three supporters. Two adopters who have family members in their decision support networks shared ambivalence not uncommon when family members are involved, noting satisfaction generally but not all the time. As this adopter noted on whether to change a relative who is a decision supporter, *"Sometimes, but not now, cuz we're family."* And from another adopter, *"Sometimes I'm happy with my mom."* If an adopter wants to change a supporter, most adopters (6 of 9) could name someone they would tell.

While adopters' decisions were respected and they expressed pride in making their own decisions, it does not mean their experiences were all positive or without unpleasant consequences. Adopters had

negative experiences too, such as falling down while boarding a jet boat, not passing a written driver's license exam, and choosing to stay at a day program to be with friends although a program manager falsely accused the adopter of being a trouble maker.

Decision Supporter Satisfaction with Decisions and Responsibilities

EVALUATION FINDING: Decision supporters were satisfied with the SDM decisions in which they were involved, and reported they had not experienced any constraint or dilemma in exercising the role and responsibilities of supporter.

All decision supporters who were interviewed expressed satisfaction with SDM decisions to date. None of the decision supporters interviewed expressed any degree of dissatisfaction with SDM decision-making processes or decisions.

Another SDM value is that decision supporters be free of conflicts of interest. There is discussion in the international community as to whether supporters should be strictly volunteers in a person's life or if there is room for those paid to be in an individual's life, and if so, under what circumstances. This evaluation did not drill deeply into this issue, but did examine whether there appeared to be undue influence on adopters by supporters as well as any evidence of abuse, neglect or financial exploitation. (See next chapter, SDM Safeguards and Monitoring.) HSRI also asked decision supporters about any constraints or dilemmas they may have experienced themselves.

Decision supporter comments below illustrate their reflection on changing role to be a supporter and their feelings of security having multiple supporters involved.

- *No different; I was satisfied before. SDM opened our eyes to wonder are we making decisions for [name]? Make sure she has a voice. She is making her own decisions now and she is so much better in life. SDM gives her more people who know her well and also gives her voice.*
- *So far so good. Having a number of people in network is good, people who have known him for a long time. Especially if there were to be any abuse.*

While confident of their decision assistance skills and sureness that SDM is a worthwhile endeavor, decision supporters also shared examples of times when it was challenging to be a supporter. As this supporter shared, *"Sometimes he doesn't want the responsibility. An example is calling work and saying he's too anxious to come that day."*

Using SDM: Safeguards

People with disabilities are at far greater risk of abuse, neglect and financial exploitation than general community members. A 2012 national survey by the Disability Abuse Project¹⁸ found that more than 70% of people with disabilities have been victims of abuse. Of those who had experienced abuse, the repeated victimization is staggering:

- More than 90% reported they had experienced abuse on multiple occasions
- 57% reported they had been victims of abuse on more than 20 occasions, and
- 46% said abuse happened too many times for them to count.

Article 16 of the CRPD requires that appropriate measures to prevent all forms of exploitation, violence and abuse be undertaken, including providing information and education on how to avoid, recognize and report instances of exploitation, violence and abuse, as well as enacting legislation and policies to ensure that instances of exploitation, violence, or abuse against people with disabilities are identified, investigated, and where appropriate, prosecuted.

As SDM is a new construct, and in almost all states not yet legally sanctioned, there is concern that SDM will not sufficiently protect people with disabilities from harm. This evaluation of CPR and Nonotuck's SDM pilot examined risks and safeguards:

- Perceptions of decision supporter influence on adopters' decision making
- Any reports of abuse, neglect and financial exploitation
- Sharing information with adopters about their SDM-specific rights
- Monitoring of SDM relationships and satisfaction of adopters and supporters, and
- SDM-specific structural safeguards in the pilot's operations.

Did Adoption of SDM Place Individuals with Intellectual and/or Developmental Disabilities at Risk of Abuse, Neglect or Exploitation?

EVALUATION FINDING: SDM adopters did not experience abuse, neglect or financial exploitation through use of SDM. Many pilot participants stated their belief that the structure of SDM, selecting people one trusts to help with decisions, and having more than one decision supporter, reduces risk of abuse.

None of the CPR staff, decision supporters, or care managers interviewed think SDM increased adopters' risk of abuse, neglect or financial exploitation. There was a general understanding that all risk cannot be eliminated, and that relationships built on mutuality and voluntary choice of roles offers the potential for better outcomes.

Decision Supporter Perspective

Decision supporters interviewed acknowledged that abuse, neglect and financial exploitation are a widespread problem for people with disabilities. None, however, think adopters were at any greater risk

¹⁸ Report on the 2012 National Survey on Abuse of People with Disabilities: <http://disability-abuse.com/survey/survey-report.pdf>

due to SDM. Their collective view is that SDM, and especially SDM with multiple decision supporters, reduces risks. The supporter's reflection below was shared by many decision supporters in this pilot.

- *No more than guardianship does, especially if there is more than one decision supporter. I've seen it when a guardian sells someone's house and takes all the money. But if you have three people we can watch one another and if one of us says, "[Name] said she wants to sell her van," then there are two others to check on that.*
-

Educating adopters on areas of vulnerability is one of the roles decision supporters see themselves responsible for. As this supporter said, "Educating him so that he understands people could take advantage of him and that he has to pick decision supporters well."

CPR Staff Perspective

CPR staff reported no knowledge that risk of abuse, neglect or exploitation was either increased or decreased due to using SDM.

Care Manager Perspective

Care managers acknowledge that no system is perfect and can be manipulated. They have known people under guardianship whose families have abused, neglected and financially exploited them. The collective view of care managers is that an SDM arrangement with involved decision supporters is more protective than guardianship. Care managers also believe there is a great deal in common between the experiences of shared living and SDM.

- *Definitely reduced risk because [adopter's name] goes to [supporter's name] about everything and it is reframed. Then decision supporter asks adopter what she wants. [Supporter] never talks over [adopter's name].*
- *There's a ton of people out there to give them their voice and their power and make sure they are asked their decision. Guardians think every decision is theirs and they can approve everything. Guardians should learn about this and learn they are not the be-all-end-all, and need to respect people's preferences. Need to learn SDM does not take away a parents' voice but is a way to help their children with their own voice.*
- *This SDM team is more protective. She wasn't under guardianship before but her family was neglecting and financially exploiting her.*
- *Having a legally assigned guardian does not equate to safety and security. I have worked for Nonotuck for 25 years. There is a persistent thinking that something legally sanctioned, that the 'guardian' term is pixie dust that equates to safety and security. Real security comes through relationship. Shared living and a decision making team only enhances that. It does not make someone more vulnerable. The more centralized and controlled one's life is, that is what can lead to abuse. In shared living we see a lot of really healthy relationships and see people step into role of being very assertive advocates for people with disabilities. Care managers monitor, but we aren't there every day. Group homes may have on-site managers, but I have worked in group home settings and was a manager and money went missing, there were medication errors and missing meds, etc. Under shared living there is singular accountability having a person live in your home. There is mutuality. With SDM there is huge overlap with shared living.*

Decision Supporter Influence

Care Manager Perspective

Care managers reported that, for the most part, decision supporters have not *improperly* influenced adopters either in positive or negative ways. One care manager stated that for one SDM adopter, his parents who are decision supporters, have exerted influence so that their son has positive community experiences. One care manager interviewed did not have an opinion as yet on supporter influence.

Most care managers perceive decision supporters as sharing pros and cons with adopters and offering guidance on what is needed for a healthy life. But as trusted people, decision supporters do have influence with adopters. As this care manager noted, supporters are trying to give adopters the support they need in general, but it is complicated at times as with one adopter who wants help controlling her appetite and also wants to over-eat, “[Adopter’s name] makes major decisions. She is influenced by us for food decisions. We are making strong arguments for better decisions on eating. [Name] doesn’t want us to step away. She still sneaks food. She knows she needs to make better decisions. Decision supporters offer opportunities to grow and learn to make better decisions.”

An example of persuasive influence involved a mother who was concerned her son was not involved in age appropriate community activities. As his care manager stated, “His understanding is limited. Mom tries to help him understand concepts but there are instances of influence. He wanted to go to Buddy Games at his old high school and ride tricycles and obstacles for young kids... [Mother] asked the DDS Service Coordinator for help such as participating in Special Olympics and other age appropriate activity.”

In the former instance of influence, the adopter had asked her decision supporters to influence her to make better food choices. In the later scenario, it is not clear if the adopter requested that his supporters assist him with presenting as age appropriate in the community.

SDM Implementation Challenge: Decision supporters do at times exert influence on an adopter’s decisions. Providing unbiased pros and cons of options can be challenging at times for decision supporters who want adopters to both enjoy new experiences but also reduce potential stigma.

Information as a Form of Safeguard: Knowing Your Rights

PRACTICE RECOMMENDATION: Where SDM is in place, require periodic review of SDM-specific rights, values and principles with both adopters and decision supporters.

One of the principles of SDM is that adopters are free to change decision supporters and areas of decision support at any time. Although pilot SDM adopters had SDM Representation Agreements for less than a year and a half, one adopter did change a SDM Representation Agreement. The adopter released one decision supporter and replaced that individual with a new supporter. In this case the adopter wanted to leave a shared living provider’s home. She was assisted by her care manager to meet and visit with other shared living providers. After choosing and living with a new shared living provider for several months, the adopter asked the new shared living provider to be her decision supporter. This request was accepted and the change made to her SDM Agreement facilitated by CPR staff.

SDM Implementation Challenge: Although adopters and decision supporters were initially advised of their SDM-specific “rights”, there was not a standardized list of rights or a protocol on the frequency or

points in time (e.g., entrance into services, service plan review, quarterly care manager monitoring visit, etc.) care managers or other pilot staff would remind adopters and decision supporters of SDM values and principles of SDM.

In Massachusetts, the annual service planning meeting includes a review of human rights for individuals with I/DD receiving publicly-funded services. SDM-specific principles and expectations could be incorporated into state regulation and a standardized SDM rights form.

Pilot SDM Monitoring and Review

PRACTICE RECOMMENDATION: Where SDM is in place for people with disabilities receiving services, include periodic SDM-specific monitoring in service quality reviews.

SDM oversight in this pilot was primarily through monthly in-person visits by Nonotuck staff, either care managers or nurses. Nonotuck care managers know SDM adopters and supporters well. The shortest relationship between a care manager and an SDM adopter was three years. Four care managers have known participants for 11 years and longer. Such long-term relationships are one element of a safety net, as care managers can tell if a person is experiencing a problem and know how to support the adopter to share their concern.

While all care managers visited SDM adopters at least monthly and asked how things are going, not all included SDM-specific inquiry or monitoring into their visit assessment. As this care manager stated, *"I'm really not monitoring SDM. I did have a conversation with her about decision supporter. But every month I don't ask her."* One care manager has five SDM adopters on her caseload and is a decision supporter for three. This care manager did specifically inquire about use of SDM and completed an SDM tracking log created by HSRI. The tracking form had fields for noting SDM decisions and date, decision supporter(s) involved, community member involved, the circumstances or context in which decision was made, and if adopters were satisfied with the decision and outcome.

SDM Implementation Challenge: Thus far, there is not an SDM-specific assessment or monitoring instrument in use. If care managers note a problem, they stated they would explore and follow up just as they would other concerns. During the course of this pilot, no untoward problems or risks were discerned by care managers. Thus it is not clear if the typical path for problem resolution would be sufficient or require some SDM-specific adjustment.

Periodic SDM check in or monitoring could be as straightforward as the question prompts listed on the next page for individuals who have adopted SDM and their decision supporters.

Individual's satisfaction with:

1. Selection of supporter(s)
2. Supporter's availability to individual
3. Supporter's help to person to understand pros and cons of a decision
4. Supporter's communication (or assistance to individual) to convey individual's preferences and decisions to others
5. Representation Agreement areas for SDM
6. Other: Explain

Supporter's satisfaction with:

1. Being a supporter
2. Demands on time and activity to meet support obligations
3. Feeling capable to assist person to understand pros and cons of a decision; any supporter need for assistance
4. Communicating (or assisting individual to communicate) individual's preferences and decisions to others
5. Representation Agreement areas for SDM
6. Other: Explain

The Year 1 SDM pilot Evaluation Report included these Practice Recommendations:

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

Other SDM Pilot Structural Safeguards

EVALUATION FINDING: A lack of resources was not a barrier to adopting SDM for either adopters or decision supporters.

One of the values of SDM is that it should be accessible and available to all. A lack of resources should not be a barrier to adopting or using SDM. The Year 1 Evaluation Report included this Practice Recommendation, 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.

All these safeguards were attended to and SDM-related activity by CPR and Nonotuck was provided without charge. There were no financial incentives to participate and no service impact for participating in the pilot or not. CPR provided for all court fees and legal representation in the court appearance petitioning the court to remove a guardianship. All SDM Representation Agreements, Health Care Proxies, and Durable Power of Attorney documents were drafted, signed and notarized without direct costs to SDM adopters or decision supporters.

Using SDM: Impact Assessment

Has SDM Made a Difference in Adopters Lives?

EVALUATION FINDING: This pilot demonstrated that positive changes occurred for individuals with I/DD and other disabilities who exercised their decision making rights utilizing tailored decision assistance from trusted decision supporters. Positive impacts included increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more.

Decision supporters, care managers, and CPR staff noted positive differences in adopters. Positive impacts included increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more. None of the interviewed pilot participants were aware of any negative impacts due to use of SDM.

EVALUATION FINDING: Using SDM made a positive difference in decision supporters too, particularly for family members.

One family that had reluctantly adopted guardianship was able to relinquish guardianship and utilize a rights-affirming option. For families that did not have guardianships, SDM made them more comfortable not going to court for guardianship and increased their feelings of security knowing decision supporters were committed in SDM Representation Agreements.

SDM Adopter Perspective

When asked what is different about their life since having SDM, adopters conveyed pride, strength, independence, helping others, and security. Adopters' responses follow:

- *It's really fun. It helps people with disabilities have their independence even though they have support through it all. It feels so much better because my parents aren't so in charge of me anymore. I have some independence now.*
 - *Stronger.*
 - *Feel good. Life is better. Explain to me. Have people that I trust and like.*
 - *My life here is good. I'm my own guardian. [Decision supporters' names] when they are not busy they come and talk to me. They take me out, take me places, shopping.*
 - *I have a new leaf on family tree.*
 - *Helping people with their problems. I help my co-workers. I feel more confidence and stronger.*
-
- *Sometimes proud of making my own decisions.*
 - *Yes, good.*
 - *SDM is like a home to me.*

Decision Supporter Perspective

Almost all interviewed decision supporters (13 of 15), believe SDM has made a positive difference in adopters, primarily in empowerment, self-confidence and speaking up more about their preferences and decisions, and in some cases, speaking up on behalf of others as well. One decision supporter reported no difference because supporting their family member to make decisions was what their family was doing prior to adoption of SDM, *"I think it put a role on what was being done anyway. We didn't know we were doing SDM with her. SDM put a title on our role."* The other decision supporter that did not report a positive difference is not yet sure what the impact of SDM is. None of the decision supporters believe anything negative has resulted due to adoption or use of SDM.

Follows are statements from supporters who noticed positive change during the first year and a half after SDM was adopted.

- *I believe he speaks up more. Still a work in progress. Getting better.*
- *I think she feels more empowered. She has a chance to discuss, hear pros and cons and make decisions. She seems more confident.*
- *She is more confident in herself. She knows more what she wants. When I first met her she was sad due to past life experiences, and not motivated to do things she does now. SDM has helped motivate her. As things go on she is more confident that she is becoming more independent; she is more comfortable in herself. I see her blossoming.*
- *She's happier, she has more self-esteem. People listen to her; before she was told what to do.*
- *I think she feels more empowered. She has a chance to discuss, hear pros and cons and make decisions.*
- *Yes, self-advocacy and empowerment. At one time the day program wanted to discipline her for something that was happening to her. She was responding to another woman's aggression, but they weren't listening to her and thought she was causing the problems. Care manager went back to day program and they looked at what happened. And [name] was right. So they apologized to her.*
- *He's learned all about his medication. He has a lot – from fish oil to melatonin to anti-anxiety, thyroid, and mood stabilization. I used to do it. He is now taking a more active role with his doctors and psychiatrist.*
- *Reassurance.... Her own decision making rights are important to her. This program helps her maintain that.*

Formalizing SDM relationships was also a comfort to parents and relatives. SDM commitments gave parents a sense of security that others would be involved in the life of their adult children with I/DD, even if they no longer were. And it gave adopters comfort that others had their back and they could look forward to the relationship continuing.

CPR Staff Perspective

Legal staff understand that this pilot has demonstrated positive impact, not only in the discharge of one adopter's guardianship, but also in the changing perspectives of adopters and supporters. Regarding adopter differences, CPR staff stated that others have reported adopters now view themselves with pride for having decision making rights recognized. CPR staff also reported that SDM altered adopters' relationships with supporters. As this CPR staff noted about the transitions initiated by SDM adoption,

- *First, we keep hearing how proud people are, how meaningful it is. This is an important contribution. Second is more practical impact, what does it mean for people in day to day life? For some, they were operating this way already and SDM formalizes an existing informal relationship without making it bureaucratic. But occasionally, when a decision has to be made and is important enough, SDM is dignifying and empowering. When that happens, it is potent. Third, for some participants that had decisions made for them, there is a learning process here. They are learning a new approach to decisions. Instead of talking in the old system, letting preferences be known but they knew their family or guardian would make the decision. This SDM pilot has reversed that and is changing the relationship of individuals to supporters.*

CPR staff stated that SDM has made a difference in decision supporters, particularly family members. Parents who had reluctantly adopted guardianship over their son were able to relinquish that role and utilize a rights-affirming option. These parents now feel empowered and part of a larger international human rights movement. For families that did not have guardianships, SDM made them more comfortable not going to court for guardianship and increased their feelings of security knowing decision supporters are committed in SDM Representation Agreements.

Care Manager Perspective

For most adopters, care managers think SDM has made a positive difference in their lives. For two adopters, care managers cannot distinguish between the positive impact of shared living and SDM. No negative impacts were known to care managers. For one adopter, a care manager noted that the process of being introduced to SDM and considering decision supporters re-engaged a former friend and advocate who had moved to another state. Now they talk weekly and this friend is a decision supporter.

Care managers reported positive impacts on adopters which they attribute to the SDM experience:

- *Yes, because focus is on him. He has to make decisions; mom can't do this for him or without him.*
- *Gives more opportunities for growth. She is more aware of decisions she is making. She has more self-esteem.*
- *She is safer. She is exposing herself as a person with Down's and having capabilities--reading, travel.*
- *Yes, she is taking leadership on her life, she wanted surgery, with work day decisions, making decisions for her life. Before SDM it would only have been mom's decisions. She has opportunities for growth with finances and compulsion to buy.*
- *Yes, because it's increased his ability to understand decisions. He is key now. He needs help and others need to give him ideas.*
- *During the process of learning about it (SDM) and going to city hall to sign document, she had a high sense of pride. When we go to the bank to open her own account she is going to be so proud. That will have her walking on air!*

~~Nonotuck care managers also reported a range of responses to SDM from those closest to SDM adopters, from not much has changed to very significant changes in family and provider dynamics, particularly when the family role legally changed from guardianship to SDM decision supporters.~~

- *SDM dovetails and formalizes legally what is already occurring through shared living.*
- *Roles are challenging. Some don't understand that SDM is not coercing. Bringing up something is not making the decision for her. Raising concern with health and letting [name] make a decision not to*

go to nutritionist, the Nonotuck care manager may see as coercing. We see that as raising her awareness and opportunities to engage in decisions about her life.

- When mother was guardian the hardest decision she had to make was to admit [name] to [name of hospital] when [name] was not safe. [Name] was angry at mom for not asking him about it. This past March, he made decisions to increase his medication and to increase psychiatrist visits. This is a huge change for this family.
- As this care manager noted about an adopter and her sister who is currently both guardian and a decision supporter, SDM has made them both more standardized, more formal about decision making. [Decision supporter] knows it has to be [adopter's name] decision.

Legally Recognized Decision Making Authorities Prior to and Post SDM Adoption

HSRI examined the impact of SDM on other kinds of legally recognized decision authorities in place prior to SDM adoption and after. One of the most profound impacts of this pilot was discharge of a guardianship and restoration of an adopter's decision making rights. The probate court judge also discharged this adopter's Roger's monitor, a court-appointed representative to make psychotropic medication decisions for those found incompetent or incapable of making these decisions. This adopter is now exercising his right to make decisions about his life and medications with decision assistance when needed from his supporters who are family members.

However, there is room for continued experience and growth both as adopters live their lives, and in other areas too. As outlined in Table 3 below, all adopters have Representative Payees for financial management of their Social Security and SSI payments, most adopters do not have their own bank accounts for personal funds, and only one is using the self-directed services option available to all individuals receiving services from the Massachusetts Department of Developmental Services. In addition, none of these SDM adopters have advanced directives for end of life care though two are older adults with advancing dementias.

Table 3. 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*
Representative payee	9	9
Health care proxy	3	8
Durable power of attorney	0	2
Living will / directives for end of life	0	0
Using self-directed service delivery model	0	1
Bank account solo for personal funds	3	3
Bank account with representative payee	3	7

** One guardianship was discharged by court. Another guardian (who is now his sister's decision supporter), is relying on SDM for several months and plans to petition court for discharge of guardianship after an SDM testing period.*

SDM Implementation Challenge: Where SDM is in place, decision assistance and emotional support could be drawn upon to expand adopter experiences in banking, managing funds, and for those receiving publicly-funded services, to self-direct their services. The Year 1 Evaluation Report noted a less broad Practice Recommendation, When a representative payee and SDM are both in place for financial decision support, periodically examine the need for the representative payee. However, with the substantial changes demonstrated in adopters, and in decision supporters, self-directing services should also be considered.

SDM as a Viable Alternative to Guardianship or Conservatorship

EVALUATION FINDING: Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision-making assistance that allows people to keep their decision making rights, has a positive impact on their self-respect, gives people a voice in decisions about their lives, and can reduce society's use of guardianship.

Decision Supporter Perspective

All but one decision supporter interviewed considers SDM a workable alternative to guardianship. One decision supporter is still figuring this out. She and her husband (who continues as guardian for his sister) are currently decision supporters for an SDM adopter. At this point, the decision supporter-guardian has confidence in SDM and plans to petition to remove the guardianship after a few more months of testing out SDM.

There is a societal presumption that guardians are involved and knowledgeable about their wards. But as one supporter mentioned when sharing the benefits of SDM over guardianship, *"Sometimes the people around you, who know you, know you better than a guardian. I go to ISPs [service planning meetings] and I'm telling the guardian information."*

Below are decision supporters' opinions on SDM as an alternative to guardianship.

- Yes, as long as there is a network, having an evaluation and being asked if it is working.*
- Yes, some people may need a guardian, but people who can read, can understand and express themselves, they don't need guardians.*
- SDM gives an individual more chance to express needs and wants, since there is an agency and a signed document to back it up. She has a signed, notarized document.*
- Absolutely without question. "But you never asked me." That's what it's all about. As a parent you make decisions for them. An SDM decision support team will make sure you have what you need to progress and that you will always be asked.*
- Yes, would be a great thing for a lot of people. There's more to people than you know; we don't share everything with everybody. We tell certain people certain things. Different people know different parts of us. This doesn't limit who we are. [Name] may tell you a story she never told*

anyone else. Everyone has a piece of her, a colorful collage that makes a beautiful woman. Can't wait 'til it sprouts out to others.

- *I like having an informal, easier flow of helping, versus formal use of guardianship.*

It is a significant role change to cease being a guardian whose primary task is to make decisions in a person's best interest, to supporting an individual to make his or her own decisions and explore preferences. As this mother and former guardian, now an SDM decision supporter, described her transition, it is challenging but carries a different sense of rewards.

- *Everyone has the right to make the wrong decision, but if you don't have the right you can't make the right or wrong decision. November 17th [court date to discharge guardianship] was also my birthday. There was a little pit in my stomach, 20 years of my life making decisions for him. But I had to have faith in the fact that he had grown enough and SDM would provide protection. I wanted him to grow to use his rights, to make mistakes and learn but never get hurt. And that's what this did. It made me feel comfortable. We had another family member who had a disability and was too dependent on the parent. When the parent died, that family member lost everything at once, and everything changed. We want [name] to have a peaceful, full life after we're gone. He'll mourn us. But that's what SDM does for me. We have ability to help him understand who that team is.*

Care Manager Perspective

Care managers involved in the pilot believe SDM is a useful alternative to guardianship for people with I/DD and believe SDM gave people a voice that guardianship typically does not allow. *"I had an individual under guardianship and the guardian made all decisions and dictated to the younger person."*

One care manager noted that SDM can be a useful alternative to guardianship when guardianship is being transferred to other relatives. A trusted family member who is guardian may die or move away and a successor guardian may not have the same bond. The preference of the person with I/DD regarding whom is appointed guardian would not typically be considered. In cases such as this, the care manager noted that SDM would be very useful. SDM would provide for selection of a trusted decision supporter.

- *Yes, because people are able to process decisions, have pros and cons, and explained in a manner they understand. And this lets them decide. Sometimes they need advice, sometimes different perspectives.*
- *Great project gives people voice they should have had all along. If it is honored by medical and bank and state officials, it is excellent. If it spares a person from being part of a clinical team review (CTR), then it's a wonderful thing. They should not have to be subjected to be in a room where people are discussing whether they are competent to make their own decisions. I sat through one a year ago and did not think this person needed a guardian. She was not fairly presented or understood that in CTR they were deciding if she was capable of making her own decisions. Demeaning. Then you go to court and they find you aren't competent. Her brother decided to go for guardianship.*

CPR Staff Perspective

CPR staff opinion is that while a small pilot, these SDM adopters and decision supporters demonstrated that SDM can be an effective alternative to guardianship.

- *Over time it has potential to reduce reliance on guardianship here and around the country.*

- *SDM may not be possible for every single person, but I hope that it is. Enough smart people are trying it out. We need to keep trying different pilots and different approaches, and seeing what works in other countries.*

Pilot Participants' View of SDM Applicability for Other Groups at Risk of Guardianship

EVALUATION FINDING: Pilot participants believe SDM would be useful for other populations whose decision making rights are often removed, particularly for older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally recognized adults at age 18 when many families are counseled to secure guardianship.

Nonotuck care managers and CPR staff were asked their opinion about applicability of SDM for other populations. All noted SDM had potential for other groups at high risk of guardianship, particularly older adults with early stage dementias and people with psychiatric disabilities. CPR staff and care managers also expressed a desire to pilot SDM with adults with I/DD who do use speech to communicate.

CPR Staff Perspective

CPR staff noted SDM applicability for:

- Transition age individuals with I/DD and/or emotional disabilities. This is a key stage when families with youth using special education services are typically steered to guardianship.
- Teens and adults with psychiatric or psychosocial disabilities whose need for support and assistance with medication decisions is typically intermittent.
- For older adults with cognitive decline, SDM could be offered early in disease progression.
- Adults with psychiatric disabilities using different approaches and strategies

Care Manager Perspective

Care managers interviewed believe SDM could be useful for:

- People do not use speech with I/DD
 - Older adults with early stage dementias
 - People with psychiatric disabilities. One care manager noted that SDM could be more challenging for people with some types of psychiatric disability (schizophrenia, PTSD, and personality disorders) and that for people with psychiatric disabilities, it would be important to execute SDM Agreements when an individual is in a stable mental state.
-

SDM Outreach and Awareness Activity

Sharing Pilot Experiences and Findings

EVALUATION FINDING: SDM outreach and awareness activity was extensive across both years of the pilot. SDM outreach and awareness activity in future can include the pilot experience and impact findings from this evaluation.

SDM, as a new way of thinking about an individual's legal decision making capacity, and as an alternative to use of guardianship, will require a great deal of awareness and education. Formal recognition for SDM will entail changes to state guardianship statutes, regulations and standards of practice.

CPR and Nonotuck expended substantial resources to getting the word out to individuals, families, and care managers supported by Nonotuck Resource Associates that a pilot using SDM was being launched for individuals with I/DD who had available and willing putative decision supporters.

Pilot partners also expended a great deal of effort and resources to share information about SDM and the pilot experience to broader stakeholders in Massachusetts, as well as nationally and internationally:

- 20 Conference presentations
- 20 Consultations (in person and by conference call) with organizations such as protection and advocacy agencies, legal aid, and Federal agencies
- 4 Webinars
- 3 Publication and resource documents
- 1 Website about SDM in general and this pilot. Information is presented in multiple formats (print, pictures and video).
Regular updates about SDM on Nonotuck's Facebook page.

Pilot partners received many calls and requests for consultation and presentations. Future SDM initiatives will find it helpful to have a plan for prioritizing outreach activities and budgeting resources. Evaluation Report Year 1 Practice Recommendations included: Prioritize stakeholder communities for outreach activities; and Prepare for and budget to share information that an alternative to guardianship exists and pilot experience.

Pilot Resource Investment Year 2

Throughout Year 2, pilot partners again invested considerable resources to share information about this collaborative endeavor to test SDM in real-world experiences with adults with I/DD and other co-occurring mental health diagnoses. Below is a summary of outreach and awareness activity about SDM as an alternative to guardianship and the SDM pilot from September 2015 – August 2016. (The Year 1 Evaluation Report noted outreach and awareness activity from October 2013 – November 2015. Five conference presentations are found in both the Year 1 and Year 2 evaluation reports. For the combined total of outreach activity noted above, conferences in both reports were counted only once.)

CONFERENCES & PRESENTATIONS –

- Massachusetts Department of Mental Health Human Rights Officers, September 15, 2015
- Shared Living Conference, Marlborough, MA, September 30, 2015
- Americans with Disabilities Act 25th Anniversary Celebration, Farmington, CT, October 2, 2015
- Claiming Full Citizenship Conference, Vancouver, British Columbia, October 17, 2015

- Guardianship Law Series: Complexities, Challenges and Developments, Boston, MA, October 21, 2015
- Massachusetts Public Guardianship Colloquium, Dedham, MA, November 10, 2015
- National Guardianship Network: Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS), Seattle, WA, March 17, 2016
- Open Society Foundations international meeting on Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, Washington, D.C., April 10-12, 2016
- Massachusetts Continuing Legal Education, Boston, MA, May 2, 2016
- LEND Program, Shriver Center's Leadership and Education in Neurodevelopmental and Related Disabilities, Charlestown, MA, May 6, 2016
- American Association on Intellectual and Developmental Disabilities annual conference. HSRI presented In person using videos created for the conference of two SDM pilot participants, Atlanta, GA, June 6-9, 2016
- National Disability Rights Network, Baltimore, MD, June 13-16, 2016
- Reinventing Quality, conference of the National Association of State Directors of Developmental Disabilities Services, Washington, D.C., August 1, 2016
- Ability Beyond Disability, Bethel, CT, January 20, 2016

WEBINARS –

- American Bar Association sponsored presentation on guardianship termination. Webinar open to ABA members and non-members, March 1, 2016

CONSULTATIONS –

- University of Massachusetts, teleconference with students regarding Massachusetts Uniform Probate Code (Estate and Administration of Probate and Family Court), September 22, 2015
- Confer with Disability Law Center regarding guardianship appeal sought by private attorney, September 29, 2015
- SDM group from international conference Claiming Full Citizenship, teleconference, November 23, 2015
- ACLU Disability Rights Office, phone call, December 15, 2015
- MA Department of Developmental Disability Services, meeting with Commissioner and General Counsel, December 17, 2015
- National Consumer Law Center phone consult regarding SDM for elders, January 21, 2016

- Quality Trust, D.C., teleconference on SDM collaboration, February 9, 2016
- Community Legal Aid in Worcester, MA, teleconference on SDM and transitional planning, March 23, 2016
- Federal Administration on Community Living (ACL) teleconference on SDM, guardianship, and guardianship abuse, May 4, 2016
- New York CUNY Project, teleconference regarding SDM project, May 4, 2016
- New York CUNY Project, skype call, May 23, 2016

- ASAN (Autistic Self Advocacy Network) and TASH, teleconference regarding Administration on Community Living SDM projects, June 1, 2016

PUBLICATIONS –

- National Guardianship Association newsletter article, August 2016

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 shared information for the pilot establishment year and do so again for this implementation year. CPR staff hours and Nonotuck direct costs do not reflect the full investment of partner organizations, for example, travel time is not included and Nonotuck staff time for SDM activity is not separable from regular care manager monthly visits with SDM adopters. However, many of the investments made by these partners are expected not to be incurred by organizations initiating future SDM pilots. In Table 4 below are CPR staff hours dedicated to SDM activity during Year 2, September 1, 2015 through August 31, 2016.

Table 4. SDM Investments Year 2: CPR Staff Hours

SDM Implementation Activity: September 1, 2015 - August 31, 2016	CPR Staff Hours
New pilot participant & decision supporter orientation:	
Meet with new 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. Monitor pilot, update forms, orient new supporters as needed.	27
Guardianship discharge for one individual: <i>work already in progress</i>	37
Court preparation, document filings, court appearance (11/17/2015)	
Research SDM legal issues, analyze proposed and enacted SDM legislation in multiple venues for possible replication; review and comment on Massachusetts proposed legislation	84
Research on possible pilot expansion options to other sites or other populations	40
SDM educational print materials:	6
Update brochure; review guidebooks	
Grant development for SDM funding	30
SDM training, public outreach & education:	130
P&A presentations, lawyer trainings, conference presentations & webinars	
Website - Ongoing development, maintenance, adding video stories	18
Project coordination:	33
Includes monthly CPR-Nonotuck meetings, HSRI communication, and quarterly Advisory Council meetings	
Evaluation activities:	56
Includes communications, CPR staff interviews, reviewing draft evaluation report, gathering time invested information	
Pilot internal gathering and celebration November 2015:	22

SDM Implementation Activity: September 1, 2015 - August 31, 2016

CPR Staff Hours

Secure venue, invite participants, engage speaker. Purpose to share SDM advancement globally, note pilot history and accomplishments, and bring together pilot participants and network supporters for celebratory dinner after court discharge of first guardianship.

Pilot national planning meeting in March 2016:

Draft agenda; engage speakers, secure event venue; extend invitations to judges, advocates, people with disabilities, attorneys, providers; present, moderate and facilitate day-long forum (4 CPR staff)

100

Open Society Foundation international SDM conference in Wash. DC:

Prepare for and participate in four-day event (3 CPR staff). Time does not include travel.

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Nonotuck pilot expenses other than staff and travel over the SDM implementation project Year 2 are below. As in the first year of the pilot establishment, staff hours for SDM could not be separated from the regular monthly care manager visits and communication. As noted in the Year 1 Evaluation Report, Nonotuck's CEO George Fleischner conveyed, *"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 5. SDM Investments Year 2: Nonotuck Resource Associates Direct Expenses

SDM Implementation Expense: September 1, 2015 - August 31, 2016	Nonotuck Direct Costs
SDM pilot website, http://supporteddecisions.org/	\$1,732.50
SDM Celebratory Meeting and buffet dinner, November 17, 2015	\$1,107.00
Pilot national SDM planning meeting, Smith College, Northampton, June 2016	\$1,632.60
Copies	\$ 264.00

Future Training and SDM Guidance

Although pilot partners provided extensive education and training on SDM, care managers suggested creating additional SDM informational materials, with quick reference information on why SDM exists, SDM resources, and where to find more information and education. These suggestions by care managers add depth to Year 1 Evaluation Practice Recommendations:

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

Reflections on SDM Pilot Experience

What Would You Do Differently If Initiating SDM Pilot Today?

CPR staff were asked, "If you were initiating this pilot today, what would you do differently?" CPR staff stated they would allocate more effort to outreach and education in the local communities where SDM adopters live and interact. Outreach would focus on landlords, bankers, and doctors, etc., and ways to let general community members know what SDM is, that an alternative to guardianship is being piloted, and to expect that some of their customers or clients would be using SDM.

CPR staff also would request a formal announcement of support from the state agency (in Massachusetts, the Department of Developmental Disabilities Services). A formal show of support for SDM would help families feel comfortable trying this model of support.

CPR staff reported learning that having an SDM orientation packet with some standardized materials about SDM would have been useful from the beginning. But they also recognized that it was important not to overwhelm people with paper, to keep it simple, and to focus conversation on exploring people's ideas and questions about SDM.

CPR staff also noted how important the SDM pilot website is as a resource for families and others. The website with videos and SDM resources made the concept of SDM real to people not involved with disability rights on a daily basis. One staff mentioned that it would be useful to create and post short videos illustrating the SDM process in action.

A powerful learning experience was the celebratory dinner after discharge of the first guardianship. SDM adopters, decision supporters and pilot staff attended and were moved to hear how important SDM is to correct past harms against people with disabilities, and how important this pilot is. This celebration was the only time pilot staff, SDM adopters and decision supporters were together. Bringing all the pilot participants together led to feeling part of a larger effort that gave meaning to participants. Offering more networking experiences for the pilot participants is a useful strategy for future SDM initiatives. This pilot-informed opinion mirrors the reflection of pilot participants who attended the pilot's initial planning retreat in October 2013, and adds weight to the Year 1 Evaluation Report Practice Recommendation, Create a shared vision of pilot and goals. Include why retaining decision making rights matters to people with disabilities and our society.

Did Pilot Partners Meet SDM Pilot Goals?

Pilot partners, CPR and Nonotuck, met their goals for this demonstration project. Pilot goals are noted below in Table 6. The strategies undertaken by the partners allowed people with I/DD to regain and retain decision making rights, to exercise their will and preferences with support, and to have their decisions recognized by others. CPR and Nonotuck's pilot provides a model for reducing inequality between people with and without disabilities. Pilot evaluation findings and recommendations offer guidance for broader SDM adoption in the U.S.

Table 6. Examination of Pilot Partners' Goals and Strategies for SDM Demonstration Project

Pilot Partners' Goals and Strategies for SDM Demonstration Project	Met / Not Met
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.	Met
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?	Met
Strategy 1: Assist a small number of individuals with intellectual and other disabilities to test SDM	Met
Strategy 2: Establish SDM only for individuals whose families and support network are supportive of SDM adoption	Met
Strategy 3: Make a difference in people's lives; move away from substituted to shared, supported decision making	Met
Strategy 4: Establish and utilize an advisory group	Met
Strategy 5: Provide for an independent evaluation	Met
Strategy 6: Model SDM for use by Protection and Advocacy agencies	Met
Strategy 7: Report/publish/share experience and lessons learned	Met

Limitations of Pilot

This pilot was not undertaken to demonstrate the utility of SDM across all people and situations where an alternative to guardianship could be conceived. Pilot limitations were purposeful and structural – limited 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. It was important to pilot Advisory Council members and pilot partners that this pilot limit participation to consenting guardians.

Another form of the collaborative approach is that all SDM adopters are supported by Nonotuck Resource Associates, a provider principally of shared living and adult foster care residential supports. Shared living and adult foster care residential service models offer a likely decision supporter(s) for a person with a disability, particularly those without involved family members. For some pilot participants, SDM mirrored their experience of relationship and support found in the shared living and adult foster care models, and could not be separated.

Although some may view piloting with one provider a limitation, for project start up, communication and figuring things out as one goes, beginning with one provider made sense. One CPR staff opined that one provider allowed for making changes on the fly. Additional partners or providers at the outset would likely have reduced flexibility and responsiveness.

Additional limitations of this pilot relate to adopters' personal characteristics. All adopters use spoken language, and none are considered to be severely or profoundly intellectually disabled, although two have advancing dementias and several have serious co-occurring behavioral health diagnoses. These "limitations" mean further SDM experience with those who do not use spoken language or who have more profound intellectual challenges will still be required to demonstrate SDM as an alternative to guardianship for adults with I/DD who do not use speech and those with more significant intellectual disabilities.

Independent Evaluation Contributions and Limitations

Although SDM was in use for a little over a year, this pilot demonstrated that when individuals with I/DD and other disabilities are given opportunities to utilize their decision making capacities with committed and trusted decision supporters, it can be a satisfying experience with positive impact on both adopters and decision supporters.

HSRI's evaluations shared the story of a collaborative, intentional SDM pilot and distilled the experiences of participants, lessons learned and implementation challenges. Attachment A to this report lists the pilot-informed recommendations from both years of the pilot. Attachment B lists Year 2 evaluation findings related to SDM use and examination of impacts.

HSRI had planned to include the first-hand impressions of general community members with whom SDM adopters interacted around decisions in this evaluation. However, for most of the 12 community members reported as involved in an SDM transaction, there was insufficient contact information. Also, there was an extended lag time between the evaluation staff learning about an SDM decision with an involved community member and the event. Another barrier to surveying community members were addressing privacy matters. Thus this evaluation does not report the impressions of community members directly. HSRI collected the response of community members indirectly from decision supporters and care managers. None of the 72 SDM decisions were challenged. Nine of the ten involved community members were reported as treating SDM adopters and their decisions respectfully and professionally.

Next Step Considerations

One of the challenges of a pilot initiative is determining what happens after the time set aside for the pilot ends. For the nine pilot SDM adopters in this pilot, their relationships with decision supporters will continue indefinitely and alter as needed. However, for a number of pilot participants interviewed, there is uncertainty about next steps. Going forward, partners may find it helpful to clarify the following:

- Care managers occasionally leave their positions and also use medical and family leave time. How will SDM training for new care managers be accomplished for those with SDM adopters on their caseloads?
- Will SDM monitoring continue as a care manager responsibility?
- Will there be periodic meetings of pilot SDM adopters, decision supporters, and care managers to sustain their commitment to SDM and to share developments, problem solve, and mentor new decision supporters?

- Will SDM be offered to adults supported by Nonotuck at risk of guardianship in future? If legal representation to advise a court of SDM option, will legal services be made available? If yes, from CPR or another organization with experience representing people with disabilities without cost to person with a disability?
 - Will SDM be offered to other adults supported by Nonotuck who are not under guardianship and have people interested in serving as decision supporters?
-
- Will SDM be offered to adults who do not use spoken language to communicate, or to adults with more significant intellectual disability?
 - How do partners plan to parlay the experience and outcomes to date for SDM as a model to limit the use of guardianship? Are there plans to update the Massachusetts' guardianship statute to legally recognize SDM? To advocate with state agencies to formally recognize SDM?

In March 2016, CPR organized an all-day SDM discussion meeting. National and international disability rights advocates and legal thinkers met to explore and discuss strategies for advancing SDM as a mechanism to promote equal rights for individuals who are, or might be exposed to, compromised participation in society due to guardianship. In addition to CPR staff and Nonotuck leaders, participants included SDM pilot Advisory Council members, CPR Board members, SDM adopters, a care manager who is also a decision supporter for several adopters, and an Advisory Council member who is a self-advocate. Representatives from organizations included the Open Society Foundations, ASAN, the Massachusetts DD Council, the Maine and New York Protection and Advocacy agencies, elder law experts, and the National Resource Center for Supported Decision Making. HSRI's evaluation team attended.

The day was thought-provoking and the discussion informed CPR's and Nonotuck's planning of next steps to advance supported decision-making. HSRI's evaluation reports will be shared with the SDM pilot's Advisory Council so that members can contribute to the ongoing conversation about SDM. Activities under discussion include expanding the pilot beyond Western Massachusetts and publishing SDM resources, such as a white paper or research article, based on pilot experiences and evaluation findings.

Attachment A. Pilot-Informed Guidance for Establishing SDM Initiatives in the U.S.

Practice Recommendations were drawn from both pilot years.

SDM Pilot Establishment

Partnership Practice Recommendations

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

Partnership and collaboration is facilitated when organizations share values.

Pilot Staff Orientation to SDM Practice Recommendations

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

Initial SDM Planning Meeting Practice Recommendations

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

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

Pilot Team Communication and Project Management Practice Recommendations

Establish a clear pilot project team and clarify roles.

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

Clarify how problems will be resolved.

Advisory Council Formation and Role Practice Recommendation

Establish an Advisory Council to provide multiple perspectives on implementation.

Independent Evaluation Practice Recommendation

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

Identify SDM Participants Practice Recommendations

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.

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* located online at:

<https://www.unitedspinal.org/disability-etiquette/>

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

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.

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

Create a script for pilot staff to guide SDM conversations.

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

Participants Select Decision Supporters Practice Recommendations

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.

Shared living appears to offer 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.)

Even when well-known to one another, SDM conversations can lead to case managers learning something new about people they support.

Participants Select Areas for Decision-Making Assistance Practice Recommendations

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

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.

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.

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

SDM Documentation Practice Recommendations

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

~~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.~~

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

Mark SDM adoption as a celebratory event.

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

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

Structure Safeguards Practice Recommendations

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.

Clarify the role and ethical responsibilities of decision supporters. Provide guidance in conversation with putative decision supporters as well as in written materials.

Where SDM is in place, require periodic review of SDM-specific rights, values and principles with both adopters and decision supporters.

Where SDM is in place for people with disabilities receiving services, include periodic SDM-specific monitoring in service quality reviews.

SDM Outreach and Awareness Activity

Raise Awareness about SDM Practice Recommendations

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

Prioritize stakeholder communities for outreach activities

Provide for Sufficient Resources Practice Recommendations

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

Attachment B. Pilot Evaluation Findings Related to Use of SDM

Number and Type of SDM Decisions

Evaluation Finding: SDM decisions ranged from everyday choices to very important decisions. With decision assistance, adopters made decisions regarding their health care, dental care, mental and behavioral health care, finances, legal matters, living arrangements, work and day supports, social and leisure activities, relationships, and an SDM-arrangement decision to change a supporter.

Adopters' Understanding of SDM

Evaluation Finding: All SDM adopters in this pilot articulated their understanding that SDM means they make decisions about their lives and have assistance from others. Regardless of age, diagnoses, or life histories, these SDM adopters understand that SDM means making their own decisions and receiving decision help when they want help. All adopters reported that SDM is a positive experience.

Decision Supporters' Understanding of SDM Role and Responsibilities

Evaluation Finding: Decision supporters understood and were able to uphold their duties to assist an individual with disabilities to understand options, help the person express preferences, and honor the person's preferences and decisions.

Decision Making Assistance and Support Provided to SDM Adopters

Evaluation Finding: Decision supporters tailored decision aids and assistance to the person's needs. They did so through knowing a person well.

What Additional Supports Do Decision Supporters Need or Want?

Evaluation Finding: Even experienced decision supporters would appreciate peer support and opportunities to share experiences with other decision supporters. Establishing learning communities of decision supporters, locally and nationally, could provide for greater decision supporter awareness of issues that arise for supporters, and more comfort that SDM is a sustainable alternative to guardianship.

How SDM Worked with Multiple Decision Supporters

~~**Evaluation Finding:** Multiple decision supporters worked well in this pilot—to a great extent because supporters were already committed to, and had established arrangements for, regular and ongoing communications.~~

Evaluation Finding: In this pilot, adopters utilized supporters who were available.

Response to SDM Use by Community Members

Evaluation Findings: Most SDM decisions did not involve general community members. Where community members were involved, the preferences and decisions of adopters were accepted and acted upon without reviewing documentation of SDM arrangement or decision supporter's role.

Use of SDM Representation Agreements

Evaluation Finding: Community members acted on the expressed preferences of SDM adopters without documentation of decisional capacity or decision supporter's role.

Adopter Satisfaction with Decisions, Supporters, and Decision Assistance

Evaluation Finding: SDM adopters were satisfied with making their own decisions, with the decision assistance provided, and with the outcomes of their decisions.

Decision Supporter Satisfaction with Decisions and Responsibilities

Evaluation Finding: Decision supporters were satisfied with the SDM decisions in which they were involved, and reported they had not experienced any constraint or dilemma in exercising the role and responsibilities of supporter.

Did Adoption of SDM Place Individuals with Intellectual and/or Developmental Disabilities at Risk of Abuse, Neglect or Exploitation?

Evaluation Finding: SDM adopters did not experience abuse, neglect or financial exploitation through use of SDM. Many pilot participants stated their belief that the structure of SDM, selecting people one trusts to help make decisions, and having more than one decision supporter, reduces risk of abuse.

Other SDM Pilot Structural Safeguards

Evaluation Finding: A lack of resources was not a barrier to adopting SDM for either adopters or decision supporters.

Has SDM Made a Difference in Adopters Lives?

Evaluation Finding: This pilot demonstrated that positive changes occurred for individuals with I/DD and ~~other disabilities who exercised their decision-making rights utilizing tailored decision assistance from~~ trusted decision supporters. Positive impacts included increased pride, increased self-confidence, increased happiness, trying new experiences, taking more control of their own health care, and helping others more.

Evaluation Finding: SDM made a positive difference in decision supporters too, particularly for family members.

SDM as a Viable Alternative to Guardianship or Conservatorship

Evaluation Finding: Decision supporters, care managers and CPR staff believe this intentional SDM pilot demonstrated that SDM is a viable means to provide people with I/DD and other disabilities customized decision-making assistance that allows people to keep their decision making rights, has a positive impact on their self-respect, gives people a voice in decisions about their lives, and can reduce society's use of guardianship.

Pilot Participants' View of SDM Applicability for Other Groups at Risk of Guardianship

Evaluation Finding: Pilot participants believe SDM would be useful for other populations whose decision making rights are often removed, particularly for older adults with early stage dementias, adults with psychiatric disabilities, and youth with I/DD who become legally-recognized adults at age 18 when many families are counseled to secure guardianship.

SDM Outreach and Awareness Activity

Evaluation Finding: SDM outreach and awareness activity was extensive across both years of the pilot. SDM outreach and awareness activity in future can include the pilot experience and impact findings from this evaluation.

Attachment C. Demographic Information Regarding SDM Adopters

Category	SDM Adopter Information
Age	24 to 79 years. When pilot initiated, age range was 23 to 78 years.
Gender	6 females, 3 males
Primary means of communication	9 (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 6 Moderate intellectual disability 1 Not diagnosed with intellectual disability
Developmental disability diagnoses	4 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 1 Congenital heart defect 1 Asthma
Living arrangement	5 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	6 have never lived in an institution for persons with disabilities. 2 lived for decades in different 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.