

Implementing Lessons Learned from Supported Decision-Making Pilot Projects

June 9, 2020



- ▶ Independent advocacy and monitoring
- ▶ Children and adults with disabilities
- ▶ Dignity, respect, and autonomy
- ▶ Rights protection and decision-making supports
- ▶ Partnering with families
- ▶ Jenny Hatch Justice Project (2013 to present)
- ▶ National Resource Center for Supported Decision-Making (2014 to present)



Supported Decision-Making: What?

Anne



“Supported Decision-Making means to me making decisions with the support of those close to me.”

For more see “Supported Decision-Making: Your Support, My Decisions,” produced by the Delaware Division of Developmental Disabilities Services, an NRC-SDM state grantee

Supported Decision-Making: What?

Ricardo and Donna



Ricardo: “I can make my own decisions. When I lived in an institution, I wasn’t allowed to make decisions. When I got out, I could move towards making my own decisions with the help I wanted.”

Donna: “I can think for myself. We can do things for ourselves. We can talk up for ourselves.”

For more, see National Council on Disability, Report: “Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities” (June 2019)

Supported Decision-Making: Why?

Ryan



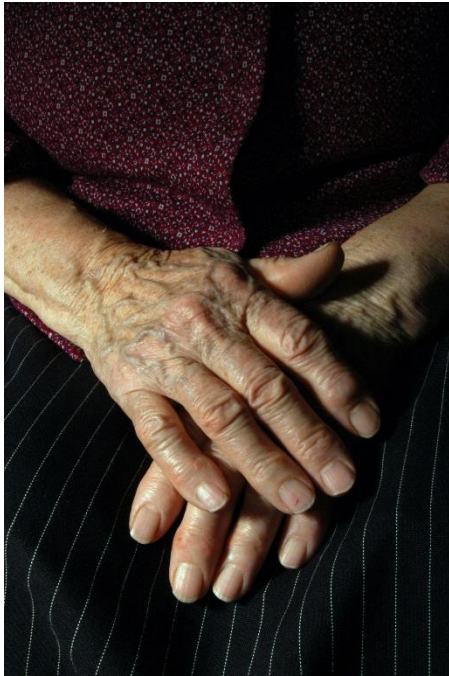
“Don’t judge me before you know me.” – Ryan

“Ryan is a whole person. We want him to be whole. **The decision process is part of being whole . . .** If I try to force Ryan to do something, I am destroying his selfness and being whole. **He is a whole person and he is making decisions and I encourage him.**” – Herb, Ryan’s father

For more, see Susie J. King, “Our Journey of Supported Decision-Making for Ryan,” Impact Feature on Self-Determination and Supported Decision-Making (Vol. 32, No.1, 2019)

Supported Decision-Making: Why?

“Dolores”



“It makes you feel **powerful** to be in charge of your own life. You can have a lot of help everywhere, but **you are your own boss.**”

For more, see Quality Trust Press Release: “DC Senior Freed from Guardianship in Favor of Supported Decision-Making” (June 2018)

U.S. State Trends in SDM

▶ NRC-SDM State Grant Program

- 18 projects so far
- DC, DE, FL, GA, IN, ME, MN, MS, NC, NV, NY, OR, SC, TN, WI

▶ Court Orders and Decisions

- Examples: DC, FL, IN, KY, MA, ME, MN, NV, NY, PA, VA, VT, and more!
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▶ SDM Pilots

- Examples: AK, CA, FL **GA**, IN, KY, **MA**, ME, NY, VT, TX, and more!



SDM Pilots – Trends

- ▶ Rights restoration
- ▶ Diversion
- ▶ “Proof of concept” tied to legislative goals
- ▶ Healthcare
- ▶ Developmental disabilities
- ▶ Interdisciplinary partnerships



U.S. State Trends in SDM

- ▶ At least **33 states and DC** have introduced legislation or **resolutions** referring to SDM
 - AL, AK, AR, CA, CT, DC, DE, IL, IN, KS, KY, LA, ME, MD, MA, MN, MO, MT, NV, NM, NY, NC, ND, OH, OR, OK, RI, TN, TX, UT, VA, WA, WI, WV
- ▶ Of these, **18** have enacted legislation or resolutions referring to SDM.
 - AK, DC, DE, IN, KS, LA, ME, MD, MN, MO, NV, ND, OH, RI, TX, VA, WA, WI
- ▶ SDM has been codified in **various ways**
 - SDM Agreements, UGCOPAA or Less-Restrictive Alternative, Education, Organ Transplantation, SDM Studies, and more!



Looking Nationally...

- ▶ U.S. Administration for Community Living
- ▶ National Guardianship Association (2016)
- ▶ Social Security Advisory Board (2016)
- ▶ American Association on Intellectual & Developmental Disabilities & The Arc of the U.S. (2016)
- ▶ American Bar Association (2016 & 2017)
- ▶ Uniform Guardianship, Conservatorship, & Other Protective Arrangements Act (2017)
- ▶ U.S. Department of Education, Office of Special Education and Rehabilitative Services (2017)
- ▶ National Council on Disability Reports (2018 & 2019)
- ▶ U.S. Senate Special Committee on Aging (2018)



Food for Thought

- ▶ Formal versus Informal Approaches?
- ▶ Flexibility versus Required Form?
- ▶ Paid versus Unpaid Supporters?
- ▶ Background Requirements for Formal Supporters?
- ▶ Safeguards Against Abuse, Misuse, and/or Undue Influence?
- ▶ Enforceability of SDM Agreements?
- ▶ Extrajudicial or Court Oversight?
- ▶ SDM within Guardianship?
- ▶ Danger of too many “SDM”s?



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National Resource Center for Supported Decision-Making

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LESSONS FROM CPR'S SEVEN SUPPORTED DECISION-MAKING PILOTS

National Disability Rights Network Conference
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Center for Public
Representation

About CPR

- The Center for Public Representation has been a leading national legal advocacy center in the United States for over forty years.
- CPR uses legal strategies, advocacy, and policy to promote the integration and full community participation of people with disabilities and all others who are devalued in today's society.
- <https://centerforpublicrep.org>

CPR's Supported Decision-Making (SDM) Initiative

- Six pilot projects in Massachusetts
- Established a SDM pilot with the Georgia Advocacy Office, designed to focus on people with disabilities with few personal supports
- Initiatives designed to reach persons and families from cultural and linguistic minorities

HSRI

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- The Human Services Research Institute (HSRI) leads the National Core Indicators Process in 50 states
 - They are highly regarded and well-positioned nationally in terms of their research
 - CPR retained HSRI to conduct independent research for the first two years of our first pilot
 - We wanted to test out our hypotheses and identify promising practices and outcomes for pilot participants

HSRI's Research Findings During 1st Two Years

- SDM adopters understand that SDM means making their own decisions and receiving decision help when they want it
- All adopters reported that SDM is a positive experience
- Decisions made reflected the preferences of SDM adopters
- 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

HSRI's Findings, cont.

- 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 reduces such risks.

HSRI's Findings, cont.

- 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.

What CPR has Learned from the SDM Pilots

- There has been no shortage of interest from individuals & families
- Enlisting organizational provider support has been fairly easy
- Having dedicated staff or “champions” within these organizations is essential
- The practice of SDM in the US is relatively recent compared with other jurisdictions, some who have decades of experience such as in various western Canadian provinces
- Our pilot project experiences appear to largely mirror that of others
- SDM is increasingly of genuine interest to many people and most are deciding to practice it if the opportunity is available.
- Ongoing SDM practice has been initiated and maintained with persons with a wide variety of ages, disabilities and personal life circumstances

What CPR has Learned from the SDM Pilots

- The use of SDM, *in combination with* health care proxies, durable power of attorney, representative payee and similar measures, has *thus far* made guardianship unappealing and unnecessary for existing project participants
- Most participants were largely unaware of both SDM and these other options that can be combined with SDM until their engagement in the pilot projects
- Most people in the pilots have been at risk of guardianship
- Their families had often been urged by schools, medical professionals and human service agencies, etc. to take up guardianship
- Some were actively exploring and seriously considering guardianship prior to hearing about SDM i.e. ongoing SDM involvement seems to have built confidence that guardianship is not needed.

What CPR has Learned from the SDM Pilots

- A small number of SDM participants and their families with guardianship already in place have either explored or successfully obtained the termination of pre-existing guardianships
- Some individuals under guardianship have tried out SDM while still under guardianship and were convinced that it provided the individual with the supports they need
- The SDM experience has *at least thus far* given participants confidence that guardianship is not needed-- none of the pilot project participants have so far considered applying for guardianship
- The ongoing SDM pilots have helped ensure people get the information, education, support and alliances that help get them started and continue with SDM

What CPR has Learned from the SDM Pilots

- An unknown is whether these participants would persevere with SDM without the pilot project supports or some other similar support
- SDM has thus far been introduced to, explored and used on an ongoing basis by persons from minority linguistic and cultural groups i.e. Latino, Russian, Vietnamese, Ukrainian etc.
- Despite different cultural traditions, there was receptivity to the use of SDM among these groups
- In each instance, supporters from within those cultures have been sought, obtained and retained, albeit in small numbers.
- Even so, the pool of such examples is still relatively small in size (approximately a third of all project participants)

What CPR has Learned from the SDM Pilots

- There is not a one size fits all approach to SDM
- There is not a recipe or formula for SDM
- We initially used a standard approach of
 - a facilitated series of conversations
 - the reduction of the SDM Agreement to a document that is notarized and can be shown to an external entity
 - a health care proxy
 - a durable power of attorney
- Some individuals and families wanted to do it differently and we adapted our approach accordingly

What CPR has Learned from the SDM Pilots

- In order for SDM it needs to be highly individualized, the "decision-maker" or person with the disability needs to be in the driver seat
- The reality is that for many people with disabilities there have been few expectations that they should make decisions for themselves
- People are often not taught to make decisions and will often need support and prompting to identify the decisional areas where they need/want support.
- This conversation often takes place over several conversations.
- We do not take a position that family members or trusted staff cannot be supporters

What CPR has Learned from the SDM Pilots

- Many families and others involved often struggle with how to find supporters on their own or are fearful that they may fail to find suitable people
- It is not initially clear to most people what might be involved in sustaining ongoing SDM practice
- Getting people started and persisting with SDM is decidedly helped by being part of a specific SDM project and an extended SDM network
- It is easy for many people initially attempting to undertake SDM to get “stuck” with how to proceed and they may stay that way unless they get some specifically targeted instrumental and emotional support in a timely way
- Proactive intervention is helpful, whereas letting people struggle without progress is discouraging for them

What CPR has Learned from the SDM Pilots

- SDM is not solely about decision making so much as it is about engaging the life experiences and substantive challenges the person is encountering at a given moment that will require decisions by the person
- All life challenges are typically easier to manage with support and SDM can be one source of that support, but it can also be coupled with other forms of both formal and “natural” support
- SDM is inherently a personal developmental process for those involved and thus will require ongoing proactive initiative from participants and supporters to both keep it going and to further evolve its practice
- It is driven by the initiative, commitment and interest of those directly involved plus the positive catalyst influences brought by committed external supporters such as pilot projects

What CPR has Learned from the SDM Pilots

- The use of formal “Supported Decision-Making agreements” has been helpful for clarifying the roles of supporters and selection by the person of the specific supporters they prefer for given areas of their decision making
- Although we all practice SDM in our lives, in many instances it needs to be encouraged for people with disabilities, as they are not familiar or “natural” to many and thus some people may need to be persuaded to try them out.
- In our initial pilot the signing of SDM agreements included a ceremony that brought about added meaning and significance for those present
- The presence of SDM training, mentoring and other learning opportunities are a significant advantage, as they lead to clearer understandings of what SDM is as well as potentially provide an organized way to get questions answered promptly

What CPR has Learned from the SDM Pilots

- There is a greater demand and interest in SDM than we can now accommodate
- There are still no reliable mechanisms for bringing SDM to scale and making it more widely available
- Supported decision making practice typically has strengthened the presence of supporters in the focus person's life in an overall way
- The number of supporters a person has varies – sometimes less is more
- The key is the quality of the supporters and their reliability rather than numbers of supporters
- People typically turn to persons with whom they already have a relationship to be supporters

What We Know

- Courts are receptive but largely uninformed
- Even for Courts that are receptive the question is who can help with this?
- There is a greater interest than capacity to respond
- COVID-19 has created opportunities
 - Captive audiences
 - Individuals and families looking for answers and ways to ensure they are ready and able to make decisions

CPR's SDM Work Beyond Pilots

- CPR has extended our Supported Decision- Making and created a SDM virtual training and technical assistance center.
- CPR has partnered with a diverse coalition in Massachusetts to draft and seek passage of a SDM bill that is currently pending.
 - We recognize that having SDM codified in the law would help promote and further legitimize it
 - The legislation emphasizes the use of SDM as being the preferred and least restrictive place to begin when supporting people in lieu of beginning with guardianship
- Our Supported Decision Making (SDM) work is captured on our SDM dedicated website www.supporteddecisions.org.

