

Issue Brief for Working Group #2: Supporting Decision-Making

Commissioned Papers:

- What Guardians, Persons Seeking Guardianship, and Persons for Whom Guardianship is Sought Need to Know about Supported Decision-Making and Why, by Glen, Costanzo & Krieger
- Supported Decision-Making: Potential and Challenges in Use for Older Persons with Cognitive Decline, by Diller & Whitlatch

Statement of Issue:

Given the variable evolution of supported decision-making (SDM) as a concept and a process within our legal, cultural, educational, and social services landscape, what next steps should be taken to advance the underlying goal of SDM to foster autonomy, independence, dignity, and legal agency of persons of all ages with disabilities.

Background:

Decision-making is an essential function of being human, and a human right. Historically, the right of people with disabilities and older adults to make their own decisions has too frequently been supplanted by a court-appointed guardian who makes decisions based on his or her own determination of the individual's best interest rather than the individual's own values and preferences.

In the last several decades, civil rights activism and advancements in technology have driven a culture change in expectations of autonomy, including the right to make one's own decisions for people with disabilities and older adults. A growing acceptance of the concept, if not the practice, of supported decision-making (SDM) demonstrates a major advance in advocacy to promote the rights of all adults to direct their own lives. This evolution has also added new insights into the opportunities and challenges that arise in promoting self-directedness and autonomy among adults of various population segments.

The United Nations Convention on the Rights of People with Disabilities (CRPD), adopted by the U.N. in 2006, has played an instrumental role in affirming the rights of individuals with disabilities to exercise legal capacity with the necessary supports to do so. The CRPD's Article 12 provides that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life," and that "States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."¹

¹ United Nations Convention on the Rights of People with Disabilities (CRPD), Article 12. The CRPD has been ratified by 181 countries. It has not been ratified by the United States.

Differing views exist as to the implications of Article 12 on the validity and function of traditional forms of surrogate decision-making sanctioned by law, such as powers of attorney and guardianship. Nevertheless, the CRPD Article 12's principles have served as a catalyst and guide for policy and practice reform around the world, including the U.S. even though the U.S. has only signed but not ratified the convention.

Most of the legal reform and practice innovation has focused on people with intellectual or developmental disabilities, although advocates, social service providers, and stakeholders have begun exploring the application of SDM for people with psychiatric disabilities, traumatic brain injuries, and age-related cognitive decline. While there is no one definition of SDM, Robert Dinerstein's definition is commonly quoted, describing SDM as

a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual's life.

It has also been described quite broadly as a whole spectrum of individualized decision supports that individuals may choose to utilize and which may overlap or work in tandem and vary in degree of formality, including:

- Informal support systems such as personal relationships, community settings, religious communities, cultural groups and traditions, and a myriad of other supports systems.
- Direct personal supports from one or more friends, family members or other individuals, including, communication, analytic, or emotional assistance.
- Technology supports (such as a smartphone app or interactive software developed to support particular decisions).
- Environmental supports (such as ensuring decisions are made in less stressful places or without time pressure).
- Financial supports (such as direct deposit, joint accounts, or trusted person designations).
- Contractual supports (such as formal SDM agreements or creation of a power of attorney or trust).
- Court supervised supports (such as the use of guardianship or conservatorship with decision support principles, or a protective arrangement for a single decision or action).

Where We Stand in Practice :

The two commissioned SDM papers provide descriptions of the policy and practice development of SDM to the present.

Policy landmarks have included:

- 2006 – The U.N. Convention on the Rights of Person with Disabilities adopted, signed by the US in 2009, but not ratified.
- 2009 – Texas by statute establishes volunteer SDM advocate pilot programs
- 2014 – The Administration for Community Living awards a grant for the creation of the National Resource Center for Supported Decision.
- 2015 Texas enacts the first state SDM statute recognizing supported decision making agreements.
- 2017 – The Uniform Law Commission adopts the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act, which incorporates SDM as an alternative to guardianship among other changes
- 2018 – By this date, a number of stakeholder organizations had adopted statements or resolutions in support of SDM including the American Bar Association, the National Council on Disability, The Arc, and the National Guardianship Association.
- 2021 -At least 10 states have adopted SDM Agreement statutes and additional states have separately recognized it as an alternative to guardianship.

Practice developments in the U.S. have involved litigation in individual cases that have been successful, according to Whitlatch & Diller, in at least 13 states and DC since 2012, generating a small but increasing number of court orders and decisions terminating or refusing to order guardianship because of SDM. While several countries, including Australia, Bulgaria, Canada, the Czech Republic, Israel, Kenya, and Latvia, have preceded U.S. efforts in implementing SDM pilot programs, domestic pilot programs have demonstrated a variety of promising approaches to recruiting participants and supporters, training and mentoring them, utilizing both formal and informal SDM agreements, and assessing impact and sustainability. The “decision-makers” who choose to participate in the pilots also choose their supporters who are most often family members but have also included unrelated volunteers and even paid supporters. Pilots highlighted in the articles include:

- The National Center for Supported Decision-Making – support of pilot programs in DC and 14 states.
- The Massachusetts Center for Public Representation pilots with partner organizations in Massachusetts and Georgia.
- The Supported Decision-Making New York Pilot, led by a consortium of groups and funded by the New York State’s Developmental Disabilities and Planning Council.

In addition, many state WINGS programs and WINGS-like state efforts have included the implementation of SDM policies and practices in their work plans.

Overall, the pilot efforts have been relatively small and, as already noted, focused mainly on people with intellectual and developmental disabilities and much less so on persons with age-related dementias, psychosocial disabilities, and traumatic brain injuries. The Diller-Whitlatch paper describes key challenges in implementing SDM in the aging context:

- Elder service system orientation toward protection rather than rights;
- Need for social safety net supports such as benefits and housing – SDM alone may not be sufficient;
- Lack of recognition of SMD by third parties;
- Isolation, tightening circles of support;
- Risk of financial exploitation and undue influence;
- Progressive nature of cognitive decline

An Australian study conducted by the Cognitive Decline Partnership Center did examine community attitudes, policy, and law related to SDM and dementia and proposed a range of levels and types of support over time as circumstances change. The Center highlighted the following foundational set of principles underlying SDM enumerated by the Australian Law Reform Commission in a 2014 report, “Equality, Capacity and Disability in Commonwealth Laws.”

1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

Pilot programs have generally found that no single type of SDM is suitable for everyone. But, the lessons learned across pilots present common themes, including:

- When done well, SDM makes a real difference in the lives of decision-makers in terms of independence and self-respect. Supporter, too, often found the experience transformative.

- SDM agreements, whether unwritten or formally executed, take time and hard work to work successfully.
- Training is essential for decision-makers and supporters.
- SDM programs need dedicated funding and cost-effective models.
- SDM approaches are applicable to persons already under guardianship.
- Parents, schools, lawyers, courts, and other institutions lack an awareness of SDM.
- Legislation can help validate SDM

Discussion Prompts:

1. What evidence or research is still needed for SDM and its applicability to diverse populations and cultures?
2. What is and isn't included in the concept and practice of SDM?
3. What adaptations to SDM should be piloted to accommodate the diverse special needs of older individuals -- developmental, social (e.g., isolation), economic, physical, medical, other? What specific steps can be taken to address perceived barriers to use of SDM by older persons with dementia?
4. How can or should traditional substituted decision-making tools (durable powers of attorney, health care powers of attorney, guardianship) and technology (e.g., artificial intelligence) be re-shaped as SDM tools?
5. What legislative or other recognition of SDM and/or SDMAs is necessary or advisable to ensure acceptance by third parties?
6. How can SDM be integrated into planning for and access to other social supports and safety net benefits needed by persons with disabilities?
7. What plans (financial and organizational) should be put in place for recruiting and training facilitators, supporters, and program administrators?
8. How can the transformational process of SDM be embedded foremost in policy and practice and not be overshadowed by forms, formalities, and liability concerns?
9. What standards or best practices should be developed and by whom for SDM (e.g., training, program development, SDM Agreements, quality assurance)?
10. What steps can be taken to firmly embed the principles and practice of SMD in the courts and practice of law? In special education transition planning? In long-term supportive services? In medical decision-making?