

# Supported Decision-Making: Emerging Paradigm in Research, Law, and Policy

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## Abstract

Supported decision-making (“SDM”) is an emerging paradigm in which people use friends, family members, and professionals to help them understand and address the situations and choices they encounter in everyday life. The aim of SDM is to empower individuals to make their own decisions to the maximum extent possible to increase self-determination. SDM is an alternative to overly restrictive guardianship or substitute decision-making regimes to which persons with cognitive and mental health disabilities historically have been relegated in law and policy. This special series examines emergent issues involving SDM in areas of research, law, and policy. It examines SDM from U.S. and comparative law, research, and policy perspectives, as recognized in Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, and from the perspective of the lived experience.

## Keywords

supported decision-making, self-determination, guardianship, United Nations Convention on the Rights of Persons with Disabilities

Supported decision-making (“SDM”) is an emerging paradigm in which people use friends, family members, and professionals to help them understand and address the situations and choices they encounter in everyday life (Blanck & Martinis, 2015, 2019; Shogren et al., 2019). The aim of SDM is to empower individuals to make their own decisions to the maximum extent possible to increase self-determination. SDM is an alternative to overly restrictive guardianship or substitute decision-making regimes to which persons with cognitive and mental health disabilities, and older adults, historically have been relegated in law and policy (Arstein-Kerslake et al., 2017; Jeste et al., 2018).

SDM has the potential to empower individuals with cognitive, mental health, and other disabilities across the life course in accord with civil and human rights law and policy (National Council on Disability, 2018, 2019). Presently, however, there is not a developed and corresponding body of study as to whether SDM may fulfill those aspirations in practice and under what circumstances (Kohn et al., 2013, p. 1157). This body of practical and basic research is necessary to inform all stakeholders—individuals, and their supporters and families, legal and policymakers, health care, and other professionals, such as in social work and education, governmental agency and criminal justice specialists, and others—about the efficacy and scalability of the SDM paradigm (Blanck, 2017).

This special series examines emergent issues involving SDM in areas of research, law, and policy. It examines SDM

from U.S. and comparative law, research, and policy perspectives. It considers SDM in light of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (“CRPD”) and its commentary (Committee on the Rights of Persons with Disabilities, 2014; CRPD, 2008). It also offers perspective of SDM through the lived experience. The objective is to contribute to a mounting body of study and commentary across disciplines and perspectives as to the nature and operation of the SDM paradigm.

SDM is emergent in myriad ways and forms, which are influenced by local, national, and cross-border norms, culture, laws, and policies. SDM initiatives may include decision-making planning agreements, which have been adopted in some local and national jurisdictions. SDM may be reflected in private agreements, such as in medical or psychiatric advanced directives (sometimes called “PADs”). SDM may be recognized in legally recognized documents such as in powers of attorney. It may be effectuated informally and formally using peer-to-peer support approaches, often in collaboration with supporters, health care professionals, attorneys, and others.

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At their core, SDM arrangements are to reflect individual will and preference in the context of particular circumstances to the maximum extent possible. The SDM paradigm recognizes the individual right, in the CRPD a “human right” (Blanck & Flynn, 2017; Degener, 2017), for legal capacity and standing before the law (Arstein-Kerslake, 2016; Arstein-Kerslake & Flynn, 2016). Yet, the viability and acceptance of SDM engagements often are complicated by local jurisdiction and venue, cultural and societal acceptance, types of decisions considered, and individual life course circumstances, experiences and conditions, access to education and technology, and personal beliefs and values (Blanck, 2014).

## SDM Evolving

Coinciding with the development of the U.S. disability civil rights movement, as embodied in the Americans with Disabilities Act of 1990 (“ADA”) (Blanck, 2019, 2020, 2021a, 2021b), individuals, researchers, and practitioners increasingly are finding that overly restrictive guardianship regimes may be associated with decreased quality of life. By contrast, self-determination, as in actions and life choices that enhance the possibilities for people to be causal agents in their lives, is associated with enhanced quality of life (Shogren et al., 2019).

Historically, many people labeled “incompetent” or incapacitated, and placed in overly broad and restrictive guardianships, have been deprived of self-determination and the opportunity to be causal agents in their lives. Sometimes, imposing an unnecessary guardianship that is justified to “protect” an individual, or as in his or her “best interests,” may exacerbate those behaviors, such as learned helplessness or crises, which led to the guardianship proceeding in the first place (Blanck & Martinis, 2015).

The trend favoring plenary guardianship continues unabated in the United States, despite federal and state laws and U.S. Supreme Court ADA decisions mandating community integration for people with disabilities (Blanck et al., 2020, 2021). Consequently, there is a compelling need to examine appropriate and developing alternatives to traditional guardianship, which respect individual self-determination and empower individuals to make their own life choices to the maximum extent possible (Kohn et al., 2013).

My colleagues and I are undertaking what we believe are the first randomized control trial studies to examine the efficacy of SDM by individuals with intellectual and developmental disabilities (Blanck et al., 2015). However, this is only a beginning attempt, as a body of rigorous transdisciplinary study is needed to consider the growing use of SDM in the United States and in other countries who are, and are not, parties to the CRPD.

In the United States, there is a clear trend toward acknowledgment of SDM as an alternative to guardianship

in states such as Texas, Delaware, and Missouri, and others that have passed laws authorizing the use of SDM (for a review, Martinis et al., 2021, this issue). In 2013, SDM was brought to national attention, and inspired action across the United States, when 29-year-old Margaret “Jenny” Hatch won a landmark legal battle protecting her right to make her own life decisions using SDM, instead of being subjected to a permanent plenary guardianship.

Jenny was facing a guardianship petition challenging her right to make her own decisions, including choices she had made for herself such as where to live, whether to work, and whom to see. At the request of her parents, a Virginia state court ordered Jenny into a temporary guardianship pending a full trial and placed her in a group home, where her phone and laptop were taken and she was not allowed to go to her job and see her friends.

After a year of litigation and a trial before the state court, Jenny won her right to make her own decisions using SDM (*Ross and Ross v. Hatch*, 2013). Jenny’s victory received national and international attention for reaffirming an individual’s right to choose how to live with the support needed in the community. In national news and blogs, people talked about the impact of Jenny’s victory: One person blogged, “Jenny. Take a seat on the bus, right next to Rosa—I think you’d have a lot to talk about.”

Jenny’s victory highlighted “an individual’s right to choose how to live and the government’s progress in providing the help needed to integrate even those with the most profound needs into the community” (Vargas, 2013). After the trial, Jenny and others partnered to form the Jenny Hatch Justice Project (“JHJP”). In its first year, the JHJP provided representation and technical assistance in over 20 matters and helped to lead coalitions to advance alternatives to guardianship by advocating for changes in state laws, policies, and practices. The JHJP trained and worked with individuals, and with public and private entities, to implement policies advancing the use of SDM and alternatives to guardianship.

As mentioned, SDM is recognized in Article 12 of the CRPD, which presumes that all people enjoy legal capacity and governments must take actions to provide people with access to the supports they need and want to make their own life decisions (Quinn et al., 2018). Countries such as Australia, Ireland, Canada, Peru, and Israel have implemented forms of SDM in law and policy.

As Article 12 states that persons with disabilities have the right to formal recognition as persons before the law, countries that are parties to the CRPD must recognize in their domestic laws that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. It also states that parties to the CRPD are to ensure in law and policy support for the exercise of legal capacity as tailored to the person’s unique circumstances.

In one of first cases under the CRPD, a case strikingly similar to that of Jenny’s, in 2019 Mexico’s Supreme Court

ordered the removal of guardianship for a fifty-year-old man, named Ernesto, who has an intellectual disability (Espinosa, 2019). In this case, guardianship had removed Ernesto's right to decide for himself whether to marry, and to make key life decisions such as in the areas of spending and saving money, and in employment (Morris et al., 2019; Uyanik et al., 2017). Guardianship denied Ernesto self-determination and autonomy in life decisions by the appointment of another person who unilaterally substituted his decisions for Ernesto's. The Mexican Supreme Court found Ernesto's guardianship in violation with his rights guaranteed by the CRPD as endorsed in Mexican law.

In safeguarding that Jenny and Ernesto were the decision-makers as to their life circumstances, SDM empowered them to be causal agents in their lives, increasing their self-determination (Shogren et al., 2019). Jenny and Ernesto, as with all individuals who receive supports designed to increase life agency, were enabled by law to exercise the right of people to be meaningfully included in society.

## Contributions to this Special Series on SDM

This special series on SDM presents transdisciplinary contributions from U.S. and comparative research, law, and policy. It offers a perspective of SDM from a lived experience.

In the first article, Martinis and colleagues provide a review of U.S. guardianship laws. In a first-of-its-kind analysis, they review the guardianship laws of all fifty states and the District of Columbia. The review uses standardized criteria to determine the extent to which the states recognize or encourage the use of SDM as an alternative to guardianship, and as a way to empower people in guardianship to make decisions and exercise self-determination. Martinis and colleagues discuss the implications of the findings for future SDM education, research, and advocacy.

Raley and colleagues then consider the SDM paradigm in the area of special education services, as in accord with the inclusion principles of the Individuals with Disabilities Education Act ("IDEA") (Blanck, 2020). IDEA requires that schools provide notice to students receiving special education services, and to their parents and guardians, before the student reaches the age of majority that the educational rights afforded to parents and guardians transfer to the student when he or she reach the age of majority. It seems that during this "transfer-of-rights" period, educational professionals often advise parents and guardians to seek legal guardianship over the student with disabilities without considering other options such as the use of SDM (Jameson et al., 2015). Many parents and guardians seek guardianship without consideration of less-restrictive alternatives to help students retain their legal rights. Raley and

colleagues advocate for an amendment to the IDEA to require schools provide students and their families information about SDM options during the "transfer-of-rights" period.

Gooding and colleagues thereafter present a groundbreaking Australian effort in which SDM is provided to accused persons with cognitive disabilities in the Australian criminal justice system. The program is to advance the principles of CRPD Article 12 in regard to unfitness to plead (i.e., "lack of capacity") laws. The project involved community legal services staff and nonlegal supporters trained to work with accused persons alongside legal counsel to maximize their participation in the trial process and avoid the need for unfitness to plead determinations. The findings provide a beginning evidence-base for implementing SDM for persons with disabilities in the criminal justice system.

Eyraud and Taran then present a grassroots French participatory action research (PAR) program on the exercise of individual rights using SDM. This project brings together persons with lived experience, academics, and health and social care and support professionals. It uses PAR to develop collective expertise as to the nature of SDM that persons with mental health and other disabilities may use to more fully participate in society.

Harris then describes his lived experience with SDM. Jason is an autistic person living away from his family and working at his first job. He discusses how SDM empowers him to "know that I am in 'the driver's seat' and the people who support me are there to help with navigation." In an afterward to a recent SDM guidebook for individuals and their supporters that I have written with Jonathan Martinis (Martinis & Blanck, 2019), Jason says SDM "is about realizing that we all need support, [and] we all need different kinds of support, at different times" in our lives.

## Conclusion

Self-determination is central to human experience. It is self-sustaining over the life course because it leads to opportunities for people to be causal agents in their lives (Blanck & Martinis, 2015). In furtherance of self-determination, SDM empowers individuals to be included meaningfully in society and to enhance independence and community integration. This special issue contributes to a growing body of information and study on the nature and operation of the SDM paradigm.

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