

*Supported Decision-making
as an Alternative
to Guardianship*



Supported Decision-making as an Alternative to Guardianship

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As a growing number of states adopt supported decision-making statutes, this option is becoming increasingly relevant to those considering guardianship. While there are some concerns, initial research demonstrates the model's benefits and its potential for either avoiding or supplementing a guardianship.

A guardianship is authority given by a state court for one person to make personal or property decisions for another person who has reduced capacity due to progressive dementia, a severe mental illness, a traumatic brain injury, intellectual disabilities, or other reasons.¹ After years of reforms, limited guardianships and less restrictive alternatives are now preferred to plenary or full guardianships, thus meeting specific needs while preserving the person's autonomy and rights as much as possible. [Recommendation 3.2](#) from the Fourth National Guardianship Summit urges states to eliminate plenary guardianships and for courts to review existing full guardianships to determine if continuation is justified.² However, embedded practices prioritizing protection over autonomy remain. The limited empirical evidence available indicates that the vast majority of guardianships are still plenary ones (Kohn, 2021: 325). Guardianships are often overly broad, unjustifiably denying individuals their basic rights and liberties.

Many advocates for the rights of individuals with disabilities seek supported decision-making (SDM) instead. State law has begun to reflect this shift by statutorily recognizing SDM as an alternative to guardianship. Pilot studies show positive outcomes for those using the new approach. While the model holds great promise, there are noteworthy concerns that might caution advocates who seek to replace guardianship, even limited orders, with formalized supported decision-making arrangements.

The Shift toward Supported Decision-making

SDM has gained traction in large part because of concerns about the continued granting of full guardianships without meaningful consideration of less restrictive alternatives, despite [modern state laws](#) requiring it (ABA Commission on Law and Aging, 2018). Scholars and practitioners generally agree that the gap between law and practice is a big issue, though the lack of data hinders thorough evaluation. Many courts face considerable barriers in successfully considering and implementing limited guardianships, not the least of which are time and resource constraints, an overreliance on information submitted by the petitioner, and limited information on alternatives and supports.

Some SDM proponents wish to discourage guardianships altogether. They see the substituted decision-making that occurs in guardianships as unnecessarily violating an individual's most basic rights and, therefore, as morally wrong. A substituted decision maker decides on behalf of another person, taking over in those areas where it was determined that the individual lacks decision-making capacity. While the person's preference (rather than best interest) is now the guideline, there is no formal mechanism to ensure that the individual's wishes have been seriously considered. Once decision-making rights are removed, there is no enforceable right to participate in the process. As some legal

1 For the sake of brevity, "guardianship" refers here to both guardians of the person and guardians of the property, sometimes called conservators.

2 Available online at <https://perma.cc/8ZGQ-SMQE>.

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scholars argue, guardianships often violate the nondiscrimination principles of the Americans with Disabilities Act. This is due to the person's marginalization and isolation from important areas of social, economic, and civic life, which may frequently contravene the act's mandate to provide services in the most integrated and least restrictive manner (Salzman, 2010: 160).

On the other hand, supported decision-making is a process by which individuals, who might otherwise be unable to, can make personal, financial, or legal decisions with the assistance of supporters. Some descriptions understand it as a process all of us regularly engage in as interdependent beings with capacities dependent on our environment and relationships (Kohn, 2021). Others, rather than focusing on the process, emphasize the series of relationships involving individuals with cognitive disabilities (e.g., Dinerstein, 2012). Supporters can be trusted friends and family members, but also professionals. They help understand available choices, obtain relevant information, offer non-controlling advice, interpret the individual's communication if needed, determine preferences, and communicate the individual's decisions to others.



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The Promise of Supported Decision-making

Different from the typical guardianship approach, supported decision-making models presume capacity (Blanck and Martinis, 2015). The process centers on the kinds of supports needed to exercise legal capacity. Individuals using SDM must be able to express themselves in a way that demonstrates an understanding of information, an appreciation of choices, and an expression of preferences—at least to those who know the person well (Bach and Kerzner, 2010: 63-66).

Research on the effects of self-determination informs other arguments for SDM. A sense of control has been shown to positively influence physical and mental health, the degree of community integration, and how well the person resists abuse. On the other hand, perceived dependence tends to correlate with lower self-esteem, higher passivity, a feeling of incompetency, and generally decreased life outcomes (Pilcher, Greenfield, and Huber, 2019a). Because the perceived sense of control is a major factor, even if guardians make decisions that are consistent with an individual's desires, one can still expect a negative impact on the individual if subjected to substitute decision-making (Kohn, 2006). Supported decision-making practices, on the other hand, as Nina Kohn (2021: 314) writes, "have the potential to transform individuals with disabilities from legal subjects into legal actors, and reduce the need for court-imposed guardianship and other restrictions on self-governance."

While perhaps not indefinitely avoiding more restrictive options for older adults as symptoms of dementia and cognitive

decline progress, SDM can delay them, especially in combination with other services. Remaining engaged in SDM could mean the difference between improved life outcomes or “learned helplessness” and accelerated decline (Diller and Whitlatch, 2022: 182). Additionally, supporters of an older person with dementia will have learned about the person’s preferences and values during past decision-making and will be better equipped as guardians if substituted decision-making becomes necessary.

Proponents who favor legally recognized SDM arrangements over informal processes point out that such a document explicitly states the supporters’ duties and prohibits substitute decision-making. Proponents also argue that the legal status is necessary vis-à-vis third parties, who often treat a person under guardianship as “incapacitated,” regardless of the court’s order limiting that determination to certain areas (Salzman, 2010: 176). Formalized arrangements help to clarify that the individual retains legal capacity to make decisions and can do so with support. While decisions made with support should be recognized even without such statutes—legal capacity should always be the assumption—the real power of a statutorily recognized agreement lies in the incentive it offers to third parties, as Kohn (2021) suggests. By offering immunity from claims the individual could assert in the future, third parties are encouraged to readily act upon decisions actually or allegedly made with support.³

Emerging Supported Decision-making Legislation

The adoption of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008 expresses the movement toward SDM internationally. It states that persons with disabilities should be recognized to enjoy legal capacity on an equal basis with others in all aspects of life and, further, that people may need support to exercise their legal capacity. In a [recommendation](#) on how to implement Article 12, the CRPD Committee added that such support encompasses both informal and formal arrangements but should never amount to substitute decision-making.⁴ While the United States is one of the few countries that did not ratify the convention, SDM made its way into U.S. state law. An increasing number of state statutes have begun to define legally enforceable SDM arrangements.

About a third of all states have full SDM agreement statutes and formally recognize SDM as an alternative to guardianship. Texas became the first state to do so in 2015, but other states followed soon after, such as Delaware (2016); the District of Columbia, Alaska, and Wisconsin (2018); Nevada, North Dakota, Indiana, and Rhode Island (2019); Louisiana and Washington (2020); Colorado and New Hampshire (2021); and Illinois (limited to intellectual disabilities), Maryland, New York, and California (2022). Virginia law defines SDM agreements but does not have

³ A potential downside to this is discussed further along with other concerns.

⁴ Online at <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>.

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a full statute describing how to enter into one. Some states, such as Oklahoma, Maine, Montana, and Minnesota, define and mention SDM as a less restrictive alternative to be considered in guardianship proceedings, but do not codify a process for doing so.

Similarly, the 2017 [Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act](#) prohibits courts from appointing a guardian where SDM or other supports may meet the needs of the individual.⁵ Federal agencies, too, started to support SDM as a less restrictive alternative to guardianship. The Administration for Community Living of the U.S. Department of Health and Human Services, for instance, endorses the concept and funded the creation of the [National Resource Center for Supported Decision-Making](#) in 2014.⁶

SDM can be informal and does not necessarily require legal authorization. However, in those states that have adopted statutes, SDM can now be documented through statutorily recognized, written supported decision-making agreements. [State laws](#) vary greatly in terms of the requirements for SDM agreements, their scope, who may serve as a supporter, available templates, and the role of third parties (ABA Commission on Law and Aging, 2022). Some states, like Delaware and Alaska, restrict who may serve as supporters to limit the risk of manipulation or exploitation by supporters. In some states, such as Wisconsin and Indiana,

the SDM statute lists triggers for termination, such as neglect or abuse by the supporter. A template for the agreement is sometimes provided (e.g., in Texas), while others simply list the requirements.

Implementation and Outcomes

Systematic research regarding SDM is still lacking. There are some pilot projects that document SDM implementation and most report positive outcomes. However, goals are varied and include using SDM to supplement, avoid, or end guardianships or simply developing a successful SDM process. The Australian Office of the Public Advocate, for instance, conducted an early research project with 26 participants who either had intellectual disabilities, acquired brain injury, or were otherwise under guardianship (Wallace, 2012). Each implemented SDM and chose supporters from friends and family members. At the end of the project, SDM had become a viable alternative for those who had been under guardianship. In the United States, the Center for Public Representation (CPR) and Nonotuck Resource Associates, Inc. collaborated to offer SDM to people with cognitive disabilities (Pell and Mulkern, 2016). Of the initial nine participants who were under guardianship and started participating in SDM, one individual's rights were restored. In a study by Arc of Northern Virginia and the Burton Blatt Institute of Syracuse University,

5 This is model guardianship legislation created by the Uniform Law Commission that states can choose to enact (<https://perma.cc/AL5E-J38S>).

6 Online at <https://perma.cc/XLA3-EDMT>.

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ten young adults with intellectual and developmental disabilities started implementing SDM. Half of them were under guardianship but indicated at the end that they would like to modify or end the guardianship (Beadnell and Martinis, 2021). Hunter College/CUNY led a five-year, multiagency pilot in New York, targeting young people at risk of guardianship (Pell, 2019). The pilot recruited 79 people with cognitive disabilities and 200 volunteers to develop an SDM facilitation model. Despite this support, only a handful of the original recruits finalized SDM agreements.

Across projects, SDM was described as a positive experience by all who adopted the process, regardless of age, diagnosis, or life history, and led to a reduction of guardianships (Beadnell and Martinis, 2021; Pell and Mulkern, 2016; Wallace, 2012). Quality facilitation to guide the SDM process long-term was a common, crucial factor leading to success. Overall, increased self-confidence led to improved self-advocacy and greater skills in decision-making. This, in turn, led to new experiences and improved life outcomes, including independent living, opening a bank account, negotiating contracts, community activities, employment, and decreased isolation. Participants in the Nonotuck and New York projects also felt reassured that having trusted supporters, and often multiple supporters, reduced the risk of abuse, neglect, and exploitation. The Australian and Northern Arc participants reported a growth in support networks and community engagement, greater control over their own lives, and reduced anxiety. The New York family members reported reduced concerns that may have otherwise led them to seek guardianship, although those that were already guardians did not experience the same.

These and other initial studies contribute to a repertoire of support strategies and information on the ideal context, timing, and scope of decision support. Typical barriers include the supporters' lack of adaptive communication skills, finding the right balance between safety and "dignity of risk," lack of trust, and avoiding undue influence. Douglas and colleagues (2015) found that SDM is more successful with supporters that had a previous trusting relationship with the individual, understood the nature of the individual's limitations and levels of functioning, and had a basic knowledge of their goals and previous decisions.

While the initial evidence shows that SDM can be empowering, there is little empirical evidence on the extent to which SDM can replace guardianship, how SDM functions in practice, and the conditions under which the goals can be achieved. The National Resource Center for Supported Decision-Making developed an assessment tool to systematically implement and further study decision-making supports and to collect more data (Shogren et al., 2018). For now, the advantages of SDM in lieu of guardianship are still largely theoretical.

Concerns

The lack of available evidence calls for caution. One concern noted by Kohn (2021) is that once formalized agreements become the norm, third parties might not accept decisions made with informal support as valid without the presence of a recognized supporter. Additional concerns are that appointed supporters could use the agreement to exploit the individual, exert undue influence, or engage in substituted decision-making. State statutes that give supporters

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legal status, enabling them to enforce decisions without requiring the individual's presence or consent, also remove the right of the supported individual to hold a service provider liable for acting upon the direction of a supporter.

Furthermore, individuals in need of such support may not readily identify or report abuse by the supporter. Safeguards recommended by the CRPD Committee do not yet exist. It is feasible, as Kohn, Blumenthal, and Campbell note, that SDM could even have effects that are opposite to the stated goals of self-determination (2013: 1157). In contrast, guardians are (at least in theory) monitored and held accountable. When there are issues, the individual under guardianship or a supporter can turn to the court.

A popular argument for SDM is based on the principle that supported persons can practice decision-making and with experience develop their abilities and become independent. For older participants, however, the lifetime of independent decision-making practice was sometimes found to hinder a willingness to discuss supports (Pilcher, Greenfield, and Huber, 2019b). Older adults can also be more isolated. While this increases the risk of noticing too late that they need support, it also increases the challenge of identifying trusted supporters. Successful SDM may depend on preexisting relationships.

Conclusion

Given the scarcity of empirical evidence, SDM may not yet have earned the status that would warrant a general recommendation in support of SDM in most cases where otherwise limited guardianship seems necessary. However, it can be a viable alternative on a continuum of options ranging in restrictiveness, with independent decision-making on the one end, SDM along the middle, limited guardianships toward the more restrictive end, and plenary guardianships at the extreme. Prudence might be advisable when it comes to giving unsupervised supporters legal status via formal agreements. Even proponents of formally recognized SDM acknowledge that more needs to be done to develop appropriate safeguards (e.g., Pilcher, Greenfield and Huber, 2019a).

Yet most of the primary benefits of SDM can be achieved without legal rights for supporters. Given the research on the positive effects of engagement in decision-making, informal SDM might be encouraged in all settings, even in combination with other options. Although implementation difficulties exist, modern statutory guidelines and the National Guardianship Association's [Standards of Practice](#) (2013) state that guardians should act in accordance to the individual's preferences and encourage the individual to participate. Following this principle, guardians can apply SDM even in cases where guardianship cannot be avoided. Additionally, in a limited guardianship where the individual does not lose all legal rights and decision-making powers, SDM can supplement the tailored guardianship in areas not covered by the guardianship.

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