



Supported Decision-Making in the US: History and Legal Background

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What is Supported Decision-Making (SDM)?

Supported decision-making (SDM) is a significant and growing alternative to guardianship. SDM has been defined as a tool under which an individual with a disability selects advisors or supporters, such as friends, family, or professionals, to help the individual gather and evaluate information as well as to help make and communicate decisions. SDM arrangements may be either informal or made pursuant to a signed agreement between the individual and supporters.

Whether informal or formal, SDM arrangements should contain three characteristics:

- Recognition that individuals with a disability have their right to make their own decisions.
- Acknowledgment that individuals can enter into SDM arrangements without surrendering their right to make decisions; and
- Understanding that the individual with a disability may need assistance in making or communicating decisions.

Assisting someone to make a decision is not a new concept. Providing such assistance is a traditional function of attorneys, accountants, social workers, and other counseling professionals. What is distinctive about SDM is that such assistance is provided to an individual with a disability, in many cases as an alternative to guardianship; and such assistance is provided in an organized manner, often pursuant to a written supported decision-making agreement that identifies the parties and their respective roles.

SDM vs. Other Types of Decisions

It is useful to distinguish SDM from other types of decisions involving individuals with disabilities:

- *Supportive decision-making* presumes that the individual has the ability to make decisions but requires assistance in making those decisions. It is the least restrictive option for those who wish some form of assistance.
- *Shared decision-making* involves decisions made jointly by the individual and another person.
- *Delegated decision-making* involves the voluntary transfer of decision-making responsibility to another through a planning tool such as a power of attorney or advance health-care directive.
- *Surrogate decision-making* occurs when the government vests another person, such as a guardian or conservator, with substitute decision-making authority.

Early History of SDM

SDM had its origins in Sweden and in several of the Canadian provinces. In 1988, Sweden abolished full guardianship and substituted a two-tier system. For an individual whose needs could not be met by a less restrictive means, such as a power of attorney, a “*god man*” [good person] could be appointed. The *god man* could only make decisions with the consent of the individual with a disability. The appointment of a *god man* does not affect the ability of the individual to make their own decisions.

For individuals with more serious disabilities for whom there are grave concerns about decision-making ability and whose needs cannot be met by the appointment of a *god man*, the court may appoint an administrator but with specific powers tailored or limited to the indicated need.

The Canadian legislation takes a variety of forms depending on the province in question. The best known is the Representation Act enacted in British Columbia in 1993, but other forms of supported or shared decision-making models exist in several other provinces. In all these cases, supported or shared decision-making is a substitute for guardianship in a particular case, not a total replacement for guardianship.

The UN Convention

Although the Swedish and Canadian legislation helped pave the way, SDM did not come into prominence until the 2006 approval of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD has to date been ratified by or acceded to by 185 countries. The key provision of the CRPD relevant to guardianship is Article 12(2)-(3), which provides that disability may not be used as the basis for diminishing an individual’s legal capacity. Rather, Article 12(3) mandates that SDM or other equivalent supports be provided. The official text states:

- “(2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- (3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

While advocates of SDM have understandably focused on Article 12(3) and its requirement that supports be provided, as important is Article 12(2) and its prohibition on the restriction of legal rights on account of disability.

Traditionally, the appointment of a full guardian removed *all* of the individual’s legal rights, including the right to marry or divorce, vote, agree to contracts, consent to medical treatment, sue and defend lawsuits, apply for government benefits, manage money or property, and to decide where to live and with whom to associate or be friends. Further, there is a stigma associated with guardianship as a person is determined by a court to be “incompetent” or “legally incapacitated.” This type of labeling has a serious negative effect on an individual’s self-esteem and personal dignity.

SDM in the US

Despite extensive efforts, including support from such prominent figures as the late Senator Bob Dole, the US has not ratified the CRPD and is unlikely to do so anytime soon. Yet, the CRPD has had a major impact in the US. Much of the impetus for reform of guardianship in the US has arisen from a series of national conferences, held approximately once each decade, at which experts meet and make recommendations. The first conference, known as Wingspread, was held in 1988. At the Third National Guardianship Summit held in 2011, much of the meeting was devoted to a discussion of person-centered planning (PCP). PCP is a tool in which the preferences of the person with a disability are at the center of the planning process and be given considerable weight when making decisions, which fits well with the concept of SDM.

A second impetus for growing interest in SDM was the 2014 World Congress on Adult Guardianship, held in Washington, D.C., which included representatives from twenty-two countries. At the Congress, numerous programs were presented on various countries’ efforts to implement the language of Article 12(3) of the United Nations’ resolution to provide support to assist people in exercising their legal capacity.

A third impetus was the founding in 2014 of the [National Resource Center for Supported Decision-Making](#). The Center has acted as a major catalyst for the promotion of SDM in the individual states. Administered under contract by two universities and a public advocacy group, the work of the Center is funded by the Administration on Community Living (ACL), an agency of the US Department of Health and Human Services.

Finally, continuing the trend in favor of SDM, a fourth impetus was the approval in 2017 of the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act (UGCOPAA). This project, which was chaired by this author, implemented many of the recommendations of the Third National Guardianship Summit, including a focus on person-centered planning. Furthermore, under the model Act, before appointing a guardian, a court must specifically determine whether SDM is an appropriate less restrictive alternative. Unlike some of the more detailed statutes discussed below, the UGCOPAA does not otherwise regulate SDM.

State Legislation on SDM

Perhaps the most significant trend to date is enactment of SDM in the states. Currently close to 20 states have enacted statutes recognizing SDM. The first statute was enacted in Texas in 2015. The Texas statute addresses SDM in detail and contains a statutory form of agreement. Numerous states have followed the lead of Texas, dealing with SDM in detail and including a form of SDM agreement either in the statute or by regulation, but these statutes otherwise vary in numerous details.

A second statutory approach is to follow the lead of the UGCOPAA and require consideration of SDM as a less restrictive alternative before appointing a guardian, but these statutes do not otherwise add forms of SDM agreements and other regulatory details.

A third statutory approach attacks a root cause of guardianship, the assumption by schools that a child with a developmental or intellectual disability who is turning age 18 must have a court-appointed guardian. Oregon recently enacted a statute requiring school districts to provide the young adult and the young adult's parents with information and training resources on supported decision-making and other alternatives to guardianship.

Despite the numerous, recent, and often detailed SDM enactments, there is not yet a consensus on whether detailed SDM statutes are desirable or whether a less detailed approach such as that taken by the UGCOPAA is better. On the positive side, a detailed SDM statute can:

- Specify the duties of supporters in detail, including prohibiting a supporter from making decisions on behalf of the individual with disabilities that directly benefits the supporter;
- Encourage the acceptance of SDM agreements by relieving third parties such as a bank or healthcare facility from possible liability for accepting the agreement; and,
- Provide overall structure and accountability.

On the negative side, a detailed statute might formalize something that works better as an informal arrangement. There is also concern about the potential misapplication of SDM in situations where it may not be appropriate, such as instances of undue influence and exploitation. One solution is to impose a fiduciary duty of good faith on the supporter, the individual who is helping the person with a disability make decisions. The supporter or advisor should always be answerable to the person with a disability and accountable for the supporter's actions and process.

Those designing legislation would benefit greatly if they knew how well SDM actually worked. But unfortunately, there is a lack of empirical evidence on the effectiveness of SDM due, in part, to its relative newness in the US. Fortunately, numerous pilot projects are in process. As of May 2019, pilot projects were in process in nine states, and we await the information that the studies may provide on the effectiveness of SDM.

Supported decision-making can be used in conjunction with a financial or health care power of attorney or proxy to provide a comprehensive framework of assistance for individuals with disabilities without resorting to guardianship or conservatorship, legal proceedings that always carry a negative stigma for the person labeled incapacitated, and that involve often expensive and time-consuming legal procedures and court supervision that may or may not be effective in protecting the individual.

Conclusion

SDM holds great promise as a tool for reducing the number of unnecessary guardianships. But work remains to be done in determining the effectiveness of and best methods for providing SDM. Work also remains to be done in training those who will use SDM, especially the supporters or advisors. This training should include not only education on how SDM works but also education for those providing the support, and those who may be asked to carry out decisions made by and through the process. SDM holds great promise for enhancing the self-determination and preserving the dignity of individuals with disabilities.

Despite the recent flurry of SDM statutes, there is a debate on whether such statutes are needed or useful and a lack of consensus on what features the statutes should contain. But there is no need to wait for a statute to implement SDM in a specific case. SDM arrangements can be implemented today in all 50 states, statute or no statute, by creating formal, written SDM agreements or well-understood informal arrangements. A good legal advisor can help create an agreement appropriate to an individual's unique situation.

Additional Resources:

- A follow up to this article, *Legal Document Inventory for Individuals Engaged in Supported Decision-Making Arrangements*, will be published and distributed in the next installment of *The Voice*®.
- Readers may also benefit from this previous issue of *The Voice*® on this topic: [Finding a Balance of Autonomy, Support and Assistance: Using Supported Decision-Making Agreements and Powers of Attorney](#).

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