



NCAPPS

How to Expand Supported Decision-Making and Increase Informed Choices

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A key feature of person-centered practices is respect and support for people's rights to make decisions about their own lives – both small and large. Having agency is important to feelings of self-worth, well-being, and unique identity, but for many people with disabilities and older adults who use long-term services and supports, the ability to shape the course of their lives is constrained by the appointment of a guardian as a substitute decision-maker. Recent National Core Indicators data (2018-2019) indicate that a majority (53.4%) of people with intellectual and developmental disabilities surveyed had a partial or full guardian. With respect to older adults, an estimated 1.3 million adults have guardians with potentially 85% of adults over 65 having guardians (Miller, 2018). While the numbers of people with mental illness who have guardians are not known, we can assume that some of them do have substituted decision-making arrangements.

To reduce the restrictions on choice and rights that are the outcomes of guardianship, a national movement is growing to advance supported decision-making (SDM) as an alternative to guardianship. The purpose of this publication is to introduce SDM and to suggest ways that more people can benefit by relying on supporters to help make decisions and to reduce reliance on guardianship. The strategies discussed are intended for use by a range of audiences, including public managers, advocacy organizations, people with disabilities, older adults, family groups, researchers, public interest lawyers, Developmental Disabilities Councils, and other state and local organizations interested in increasing people's ability to make informed decisions.

What Is Supported Decision-Making?

The importance of making life-affirming choices is stressed in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (Article 12, 2006). The CRPD asserts that everyone has the right to make decisions about their lives regardless of cognitive ability. Further, the Centers for Medicare & Medicaid Services (CMS) Settings Rule (2014) reinforces the importance of individual choice in waiver-funded services, including choice of home, roommates, staff, and daily schedule. Supported decision-making is a way to make these aspirations a reality.

The American Civil Liberties Union (ACLU) provides the following definition of supported decision-making:

Supported decision making (SDM) is a tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. A person using SDM selects trusted advisors, such as friends, family members, or professionals, to

serve as supporters. The supporters agree to help the person with a disability understand, consider, and communicate decisions, giving the person with a disability the tools to make her own, informed, decisions.

Why an Alternative to Guardianship?

The current efforts across the country and internationally to implement supported decision-making provide an historic opportunity to use less restrictive ways to help people navigate choices in their lives rather than using guardianship as a familiar default. Imposition of a substitute decision-maker can erode the ability of people with disabilities to develop the skills necessary to make decisions and can exclude them from their communities (e.g., by losing control over relationships, money, contracts, travel, voting, etc.). That may be why guardianship is often referred to by advocates as “civil death.” Once guardianship is ordered, it is very difficult to terminate.

The practice of supported decision-making gets people the support they need without losing their legal and human rights. In addition, other options can be combined with supported decision-making to help to avoid guardianship in the first place. These include partial, limited, and temporary guardianships, health care proxies or surrogates, durable powers of attorney, representative payees, joint or limited bank accounts, credit or bank cards with financial limits, and other informal or “natural supports” such as “circles of support.”

The following table shows the differences between supported decision-making and guardianship:

Guardianship	Supported Decision -Making
<ul style="list-style-type: none">• Decision -making rights are removed from the individual and given to another person.• Guardians make decisions <i>for</i> the individual – even if the guardian consults with the individual.• Guardianship is rarely removed or reduced.• Decisions are made by the guardian by “judging what is in the best interest of the person” standard	<ul style="list-style-type: none">• Individuals keep all decision -making rights.• Individuals make decisions <i>with help</i> from those people they select (even when extensive support to communicate and express decisions is necessary).• Allows change as individual’s preferences/needs change• The individual’s preferences are more important than best interest.

What Progress Has Been Made to Embed Supported Decision-Making in Public Policy?

According to the American Bar Association (2019), supported decision-making is gaining national recognition as an alternative to guardianship. As of this writing, there are 10 states that have passed laws that “define supported decision-making agreements as legally enforceable arrangements”: Texas, Delaware, the District of Columbia, Alaska, Wisconsin, Indiana, North Dakota, Nevada, Rhode Island, and Colorado. Several other states have SDM legislation pending. Additional states have passed or have legislation pending that would require state education and other agencies to provide information about supported decision-making as an alternative to guardianship.

The laws vary in terms of who can be a supporter, the role of third parties, and the scope of agreements. To implement these laws, a growing number of advocacy groups, social services organizations, and state agencies are formalizing the process with supported decision-making agreements. These agreements include the names and roles of supporters and details about the scope of their assistance, authority, and duties. Agreements may include whether the supporter has access to confidential information pertaining to the decision-maker or outline other important conditions. Agreements also typically outline the terms of revocation or termination.

How Can SDM Be Expanded and Enhanced?

Establish coalitions to support legislation and SDM policies

While some states have adopted supported decision-making legislation as an alternative to guardianship, others have not. To successfully change state laws related to guardianship, interested parties will need to develop broad-based coalitions that include advocates for people with a variety of disabilities as well as older adults. Some successful amendments to existing guardianship statutes require that people explore less restrictive options rather than starting with the highly restrictive option of guardianship that takes away someone’s entire legal rights (“plenary guardianship”). For instance, the Texas legislature, in 2015, passed the Supported Decision-Making Agreement Act, which included the following language:

The purpose of this chapter is to recognize a less restrictive substitute [SDM] for guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are not considered

incapacitated persons for purposes of establishing a guardianship under this title. . .

An adult with a disability may voluntarily, without undue influence or coercion, enter into a supported decision-making agreement with a supporter.

Other changes could require that guardianship be independently evaluated or reviewed on a routine schedule to determine whether it is still needed or should be modified. Ongoing evaluation and review of SDM agreements may also support continued success and growth of guardianship alternatives.

Implement pilot/demonstration projects

A common strategy to turn concepts into practice is to create working examples of what the practice looks like. SDM pilots can provide an opportunity for everyone to learn about how decision supports work in the context of people's real lives, to test the validity of the concepts, to assess outcomes, and to improve the practice as it is scaled up. Evidence of pilot success and experience can be used to influence legislators and public managers to adopt SDM policies. Further, pilots and demonstrations can provide information on how SDM works with different target groups, what constellations of supporters works best, how the courts respond to SDM agreements, and the role and attitudes of family members and other supports. Pilots can also show how SDM works with diverse cultural or linguistic groups, and they can be regionally distributed to test the practice in rural as well as urban areas. They also provide the opportunity to collect data through empirical evaluations that can improve further implementation and enhance training content.

Develop and disseminate evaluations of the outcomes of SDM

To ensure the sustainability and expansion of SDM, it will be important to mount independent evaluations that assess the impact of the reform. Some evaluations have been completed (Pell & Mulkern, 2016; Martinis & Beadnell 2021; Costanzo & Krieger, 2021) but much more work needs to be done. Research is needed at the system level to determine whether statutory reforms have reduced the numbers of people who have guardians and at the individual level to determine whether decision support has increased people's ability to make informed choices about their lives. Evaluations can also yield information on best practices in SDM that can be used to enhance education and training. Finally, evaluations will be important to determine how SDM is experienced in different cultural, ethnic, language and racial groups.

Identify SDM “champions”

Adoption and expansion of SDM requires advocates for the SDM approach at the community and state levels—people to serve as champions for SDM, including people with disabilities and family members. There must be a conscious effort to recognize, develop, and mobilize needed leadership. Consequently, it is common to create and sustain a variety of leadership development initiatives linked to what is needed at a given point in time. As with any major reform effort, sustained advocacy from a cadre of leaders is necessary to keep the issue—in this case SDM—important to public managers, legislatures, the legal community, and the public. Leaders may come from a variety of sources including self-advocacy groups, the state Protection and Advocacy organization, the Arc, and other groups with an equity and rights mission. It will also be important to train potential leaders to grow and expand their movement to create alternatives to guardianship.

Support the leadership contributions of people with disabilities and others who may benefit from SDM

People with disabilities and members of other marginalized groups are increasingly demonstrating personal and collective leadership. This leadership should be supported and facilitated in the cause of SDM. People with disabilities can serve as trainers, peer supporters, and participants in evaluations, as well as other roles. A good example of this kind of leadership can be seen in the work of the ACL-funded Center for Youth Voice/Youth Choice, which includes recruiting “youth ambassadors” to pioneer SDM and work to reduce the use of guardianship.

Mobilize advocacy for SDM

Strong and sustained advocacy has been crucial to the passage of supported decision-making statutes around the country. Advocacy is also important to ensure that the implementation of SDM is carried out with the spirit of the law and best practice. To ensure there is a robust advocacy coalition in place, it is important to consider the following:

- Do we have engagement of all groups interested in SDM?
- Do we have adequate representation of communities that would benefit from SDM?
- Are there opponents? How are they organized? What is their primary objective? And what concerns have they raised?
- Do we have individual stories to present?
- Do we have research to back up our proposal?

The [Toolkit for Stakeholder Asset Mapping](#) can be useful for this review.

An example of successful advocacy is the Missouri Working Interdisciplinary Network of Guardianship Stakeholders (MO-WING) that was established to review and reform the state guardianship statute (Bradley et al., 2019). Members of MO-WING included representatives of the Missouri Developmental Disabilities Council and the UMKC Institute for Human Development, and prominent members of the Missouri Bar, as well as people with disabilities, parents, family members, representatives of older adults, NAMI, and other key advocacy and provider organizations. After working for five years, the group was successful in supporting the passage of reform legislation Senate Bill 806, in 2018. The law stresses the consideration of less restrictive options and supported decision-making.

Create education and training opportunities

To ensure that SDM becomes a more frequently used alternative to guardianship, it will be important to invest in education and training. This will help build understanding and assist people to learn and master new habits and practices. This may extend beyond an initial orientation to various forms of ongoing learning. For instance, Colorado has recently developed and implemented the Speak Up curriculum for self-advocates, which incorporates training and knowledge on supported decision-making.

Education and training regarding the tenets of SDM should be directed at a variety of groups, including people with a range of disabilities, their families, older adults, service providers, guardians, advocates, government officials, politicians, members of community organizations, religious organizations interested in social issues, educators, attorneys, judges and other court personnel. Trainings should take place in a variety of venues including at conferences at the state and national level, in local school communities, sponsored online by advocacy organizations, in courses at the National Judicial College, through family and caretaker organizations, and in meetings attended by people with lived experience.

Develop publications, videos, reports, websites

To improve the adoption of SDM, it is important to generate information about the practice in a variety of formats that are culturally and linguistically accessible. For instance, [Disability Rights Texas](#) has many helpful SDM guides, videos, definitions, forms, user-friendly overviews, and other resources as part of their SDM “toolkit.”

There are currently several supported decision-making videos that have been developed for various educational purposes and directed to specific potential audiences. The Georgia Advocacy Office has created standout examples of such

videos and made them available on YouTube, including a [series featuring John McCarty](#), an active self-advocate, and a [video that includes a compilation of interviews](#) that shine a spotlight on SDM. The NPR station in Wisconsin also aired an [interview](#) with a person who had been successful in terminating his guardianship. Other materials are listed in the Resources section of this paper.

There are also important resources that have been developed by national organizations including the American Bar Association, the National Guardianship Organization, and the National Council on Disabilities. Resources can also be drawn from several different websites including two of the better known sites that solely address supported decision-making: [supporteddecisions.org](#), operated by the Center for Public Representation, and [www.supporteddecisionmaking.org](#) of the National Resource Center for Supported-Decision Making of the Quality Trust for People With Disabilities.

Identify “best practice” networks

Another way to expand the practice of supported decision-making is to ensure that SDM is embraced by local, regional, state and national advocacy and other values-based networks that emphasize autonomy and rights. Various national organizations such as the National ARC, the National Disability Rights Network, and the ACLU are examples of such networks that have adopted supported decision-making as a component of their overall work. Other groups could include federally funded state protection and advocacy organizations, progressive service providers organizations, family support entities, self-advocacy organizations, local Bar Associations, supportive state government officials, and faith-based organizations.

Conclusion

Supported decision-making offers people with disabilities and older adults the possibility of gaining agency in their lives with the assistance of a circle of friends. However, guardianship often remains the default when people’s ability to make informed decisions is questioned. To reduce the use of guardianship it will be important to ensure that the concept of SDM is widely shared and that coalitions be developed to lobby for statutory and policy change. The preceding discussion includes concrete steps that can be taken at the state and local level to give more people with disabilities and older adults the ability to be actors in their own lives.

References

- American Civil Liberties Union (n.d.). Supported decision-making: Frequently asked questions.
https://www.aclu.org/sites/default/files/field_document/faq_about_supported_decision_making.pdf
- Bradley, V.J., Hiersteiner, D., St. John, J. & M.L. Bourne (2019). What do NCI data reveal about the guardianship status of people with intellectual and developmental disabilities. Human Services Research Institute.
https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf
- Centers for Medicaid and Medicare Services (2014). Home and Community-Based Services Settings Rule.
<https://www.medicaid.gov/medicaid/hcbs/guidance/hcbs-final-regulation/index.html>
- Costanzo, C. & Kreigel, G. (in press). Supported decision-making: Lessons from pilot projects. Syracuse Law Review
<http://law.syr.edu/uploads/docs/academics/costanzo-glen-krieger.pdf>
- Martinis, J. & Beadnell, L. (2021) *"I learned that I have a voice in my future"* Summary, Findings, and Recommendations of The Virginia Supported Decision-Making Pilot Project retrieved from
http://www.supporteddecisionmaking.org/sites/default/files/2021_virginia_SDM_pilot_project.pdf
- Miller, K. (2018). What happens when a guardianship gets contentious. *AARP Magazine*. <https://www.aarp.org/caregiving/financial-legal/info-2018/court-ordered-guardianship-separates-family.html>
- Missouri Senate Bill No. 806. 99th General Assembly.
<https://www.senate.mo.gov/18info/pdf-bill/intro/SB806.pdf>
- National Core Indicators (2018-2019). In-Person Survey National Report. [IPS Chapter Contents \(nationalcoreindicators.org\)](https://www.nationalcoreindicators.org/IPS_Chapter_Contents)
- National Center for Advancing Person-Centered Practices and Systems (2020). Toolkit for stakeholder asset mapping. Human Services Research Institute.
https://ncapps.acl.gov/docs/AssetMappingToolkit_200827_linked.pdf

Pell, E., & Mulkern, V. (2016). Supported decision making pilot: Pilot program evaluation year 2 report. Human Services Research Institute.
https://www.hsri.org/files/uploads/publications/SDM_Pilot_Evaluation_Year_2_Report_HSRI_2016_FINAL.pdf

Supported Decision-Making Agreement Act, Title 3. Estates Code, Section 1357 (September 2015).
<https://statutes.capitol.texas.gov/Docs/ES/htm/ES.1357.htm>

UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106. <https://www.refworld.org/docid/45f973632.html>

Resources

Alford, B., Fracht, A., Hennessy, M., & Smith, H. (2021). How to Strengthen the Americans with Disabilities Act after 30 Years: Promoting Supported Decision-Making for Persons with Intellectual and Developmental Disabilities. Harvard Law Review Blog.
<https://blog.harvardlawreview.org/how-to-strengthen-the-americans-with-disabilities-act-after-30-years-promoting-supported-decision-making-for-persons-with-intellectual-and-developmental-disabilities/>

Easy read version: <https://blog.harvardlawreview.org/supported-decision-making-for-persons-with-intellectual-and-developmental-disabilities/>

American Bar Association. (2016). The PRACTICAL tool for lawyers: Steps in supporting decision-making. (“PRACTICAL” is an acronym for nine steps for lawyers to identify alternatives to guardianship). Chicago, IL.
www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool/

Center for Public Representation. Supported Decision-Making Gives People with Disabilities a Voice. <https://supporteddecisions.org/>

Disability and Health Information Center (n.d.). Missouri Guardianship: Understanding Your Options & Alternatives.
<https://health.mo.gov/shcn-secure/docs/GuardianshipInfoPack.pdf>

Georgia Advocacy Office. Supported Decision-Making Resources. [Supported Decision-Making Resources – The Georgia Advocacy Office \(thegeo.net\)](http://thegeo.net)

National Council on Disability. (2018). Beyond guardianship: Toward alternatives that promote greater self-determination, Washington, D.C. https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf

National Guardianship Association. (2013). Standards of practice. Bellefonte, PA. <https://www.guardianship.org/standards/>

National Guardianship Association. (2017). Position Statement on Guardianship, Surrogate Decision Making, And Supported Decision Making. https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision_Making_PositionStatement.pdf

National Resource Center for Supported Decision-Making. <http://www.supporteddecisionmaking.org/>

Speak Up Colorado: <https://speakupcolorado.com/curriculum>

UMKC Institute for Human Development. (n.d.). Missouri Guardianship Project. <https://ihd.umkc.edu/missouri-guardianship-project/>

Videos

Disability Rights Texas. Supported Decision-Making in Action series: <https://www.disabilityrightstx.org/en/asl-videos/supported-decision-making/>

Georgia Advocacy Office. John McCarty (2020). https://www.youtube.com/channel/UCXPkGt_cyYyPPWFxWYB7NTQ

Georgia Advocacy Office. Shining a Light on the Inner Workings of Supported Decision-Making. <https://www.youtube.com/watch?v=UXFMNguab1A>

Guardianship requests decline as knowledge of alternative legal option grows. (Aug. 9, 2021). WSAW-TV. <https://www.wsaw.com/2021/08/10/guardianship-requests-decline-knowledge-alternative-legal-option-grows/>

About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services to help States, Tribes, and Territories to implement person-centered practices. It is administered by the Human Services Research Institute (HSRI) and overseen by a group of national experts with lived experience (people with personal, first-hand experience of using long-term services and supports).

NCAPPS partners with a host of national associations to deliver knowledgeable and targeted technical assistance.

You can find us at <https://ncapps.acl.gov>

