

Legal Basics: Supported Decision-Making

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American Bar Association Commission on Law and Aging

The American Bar Association Commission on Law and Aging (ABA COLA) is a collaborative and interdisciplinary leader of the Association's work to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of aging persons.

The Commission accomplishes its work through research, policy development, advocacy, education, training, and through assistance to lawyers, bar associations, and other groups working on issues of aging.

Key Lessons

1. Supported Decision-Making (SDM) is a person-driven decision-making model that, with advice and guidance from trusted advisors, empowers a person with limited or declining capacity to make choices.
2. SDM starts with the principles that all individuals, as long as they are able to communicate, have a fundamental ability and right to make choices, that adults normally engage advisors to assist with life's decisions and that choices of the individual should be honored.¹ The ultimate outcome of SDM is to protect the fundamental human and constitutional rights of persons with disabilities including persons who are experiencing a decline in memory and cognition.
3. An assessment guide and tool kit (the "PRACTICAL Tool") helps lawyers and other professionals evaluate SDM as an alternative to guardianship or conservatorship, or as a guide to alternatives that may lead to restoration of rights by terminating or modifying guardianship.²
4. The advisors in SDM should be legally empowered as agents to assist the person as needed with carrying out the decisions of the person. Instructions on utilizing SDM principles should be drafted into advance care planning documents.
5. States are increasingly recognizing formal SDM agreements, which formalize the relationship between the person, the advisors and agents.

What is Supported Decision-Making?

Supported Decision-Making (SDM) is a person-driven decision-making model based on the assumption that all persons seek advice and guidance with making decisions; that all persons, as long as they have the ability to communicate, have the ability and right to make choices; and that the choices of the individual should be honored.³ By applying these principles to decision-making for individuals across the spectrum of capacity, we empower persons with disabilities including those experiencing changes in memory and cognition.

SDM gained traction in advocacy for adults with disabilities⁴ and is expanding as a model for helping older adults experiencing a decline in memory and cognition. SDM can be a viable alternative to guardianship or conservatorship.⁵

We all engage in SDM. When we seek assistance from a doctor, lawyer or accountant, we are asking that person to serve as an advisor, helping us to understand the issue, asking the advisor to offer us choices and explain the risks and benefits of the options, to answer our questions, and ultimately to support us, while

allowing us to make choices.⁶ The spectrum of issues where SDM will provide benefit will vary based on the person's life experience and ability. A person with less experience or ability will need advice and guidance with a broader range of issues than a person more life experience and greater ability.

The concepts behind SDM are nothing new. What is new is utilizing the principles to help persons with disabilities, including changes in memory and cognition, maintain control of their lives by working with supporters to understand issues and options, receive guidance and help to make choices and decisions about simple and complex issues.

In SDM, persons with a disability select individuals whom they trust to support their decision-making.⁷ The supporters may be known as supporters, advisors, partners, or agents. Their role is to help the person understand the issue and the options, offer advice, allow the person to make a choice, and help carry out that choice.⁸

SDM is a balancing point⁹

Everyone needs help with making decisions, but adults with disabilities need more help and are particularly vulnerable if left unassisted. The paternalistic model of someone making decisions for a person with a disability takes away the fundamental human and constitutional right of choice. The right to make personal choices was confirmed in 1965 by the Supreme Court in *Griswold v. Connecticut* as part of a "penumbra of rights" in the bill of rights, which the court described as predating the Constitution.¹⁰

SDM seeks a balancing point that empowers the person to make choices, with advice and guidance.

A PRACTICAL Guide for SDM

The PRACTICAL Tool, developed by the ABA Commission on Law and Aging with other partners, is designed to help professionals review decision-making options and overcome obstacles to implement a plan for SDM for a person with disabilities. The Tool is available at: americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.authcheckdam.pdf.

The steps in the PRACTICAL Tool are:

Presume that guardianship is not needed. For too long the default answer for assisting a person with a disability was to file for guardianship or conservatorship. Guardianship or conservatorship should be the last resort, only if all reasonable alternatives fail.

Reason. Clearly identify the reasons for concerns. This section of the guide contains a detailed checklist of issues the person with a disability may or may not need help with. Understanding the true needs of the individual is essential to tailoring solutions that are least restrictive.

Ask if the concern is caused by a temporary or reversible condition. Illness or injury where recovery is likely can create a temporary disability. Permanent action should be delayed and time should be allowed for recovery and healing.

Community. The vast majority of care is provided by family, friends, and community based services. These resources are essential in building the supports needed for SDM. SDM should include a full exploration of available community based resources to help each person.

Team. Ask an individual trusted by the person to provide help in making decisions. Many people already have in place an informal circle of family and friends that can fill the role of advisors/agents for SDM.

Identify the abilities and needs of the person. SDM assistance should be limited to areas the person needs help with.

Challenges presented by potential SDM advisors or agents. It is important to carefully review and address concerns about challenges presented by the advisors or agents selected to support the person in decision-making.

Appoint advisors and empower them as legal agents to carry out the choices of the person. Giving the advisors legal authority makes it possible for the SDM choices to be implemented when third parties question the capacity of the person with a disability to make choices, or when the person with disabilities needs help carrying out those choices.

Limit any guardianship or conservator appointments to only the issues absolutely needed. Limited appointments preserve the human and constitutional rights of the person with a disability.¹¹

SDM Agreements and Advance Care Planning

An SDM agreement is a contract between the person with a disability and the person or persons agreeing to serve as advisors.¹² An SDM agreement describes the issues the person wishes to receive help with, and other terms or limitations.¹³ Currently laws in Texas and Delaware recognize SDM agreements, with adoption of similar laws expected in other states.¹⁴ The Texas statute includes a core statutory form; the Delaware law directs the state cabinet to develop a standard form agreement.¹⁵ These statutes urge courts to consider SDM before guardianship and to consider the SDM agreement as a valid alternative to guardianship. If health care is within the scope of SDM, the SDM agreement should include language addressing HIPAA concerns.¹⁶ Additional terms can be drafted into SDM agreements such as limitations on spending by the person, limitations on certain business transactions without express mutual agreements, agreements to provide spending money to the person with a disability without need for accounting, and terms and conditions for termination by either party to the agreement.

SDM should be included in powers of attorney and advance care planning documents. The advance care planning documents should instruct the agent to engage in SDM on all health care decisions. The agent or surrogate should be asked to always explain the health care issue, options and recommendations and seek input from the person, even if the person appears unable to understand. It is important to remember that sometimes the person who has lost the ability communicate has not lost the ability to understand.

Is SDM Always the Answer?

SDM should always be considered before guardianship or conservatorship.¹⁷ SDM will not work if it is truly impossible for the person with a disability to communicate a choice, decision, or preference. Every effort should be made to communicate with the person. Communication can be time consuming, often it is necessary to break complex issues down into small sub-issues and ask for many minor preferences that add up to the ultimate choice.¹⁸ For persons who are experiencing a decline in memory or cognition,¹⁹ the advisor will be better prepared to make decisions based on the person's known goals and values if SDM is started early in the illness before significant assistance is necessary.

If the person with a disability is being abused or neglected, SDM may be difficult. For SDM to succeed, the advisors or agents must be trustworthy.

Conclusion

SDM allows persons with a disability, including those experiencing changes in memory or cognition, to make decisions or choices, with advice, assistance and guidance from supporters of their choice. The role of the supporter is to help the person understand the issues, options and choices, to offer advice, but ultimately to allow the person to make a decision, choice or preference and to help as needed to carry out the choice of the person. SDM is a viable alternative to guardianship or conservatorship in many cases. SDM is a person centered planning process and a person driven decision-making model that should be incorporated into advance planning and health care planning. SDM protects the human and constitutional rights of persons with disabilities.

Additional Resources

- David Godfrey, david.godfrey@americanbar.org
- Administration for Community Living—Supported Decision-Making:
 - » acl.gov/programs/consumer-control/supported-decision-making-program
- American Bar Association—Resources on Supported Decision-Making:
 - » americanbar.org/groups/law_aging/resources/guardianship_law_practice.html#sdm
- American Bar Association—PRACTICAL Tool home page:
 - » americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
- National Resource Center on Supported Decision-Making:
 - » supporteddecisionmaking.org

Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at ConsultNCLER@acl.hhs.gov.

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Endnotes

- 1 Jonathan G. Martinis, *Supported Decision-Making: Protecting Rights, Ensuring Choices*, 36 BIFOCAL 107 (May-June 2015).
- 2 A PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making (Amer. Bar Assn. 2016), available at americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html.
- 3 Peter Blanck and Jonathan G. Martinis, *The Right to Make Choices The National Resource Center for Supported Decision-Making*, 3 INCLUSION 24 (2015), available at bbi.syr.edu/publications/2015/SDM_Overview.pdf.
- 4 See National Resource Center for Supported Decision-Making website at supporteddecisionmaking.org.
- 5 See *Id.* for examples.
- 6 *Id.*
- 7 Nina A. Kohn, et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 177 Penn. St. L. Rev. 1111 (2013).
- 8 Blanck and Martinis, *supra* note 3.
- 9 Brainstorming Guide: How Are We Already Using Supported Decision-Making, available at supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf.
- 10 *Griswold v. Connecticut*, 381 U.S. 479 (1965).
- 11 PRACTICAL Tool, *supra* note 2.
- 12 Kohn, et al., *supra* note 7.
- 13 The National Resource Center for Supported Decision-Making provides model agreements at supporteddecisionmaking.org/legal-resource/supported-decision-making-model-agreements.
- 14 The Texas Supported Decision-Making Agreement Act, Tex. Estates Code § 1357.001 et seq.; Delaware Supported Decision-Making 80 Del. Laws, c. 427, § 1.
- 15 The Texas Supported Decision-Making Agreement Act, Tex. Estates Code § 1357.001 et seq.; Delaware Supported Decision-Making, 80 Del. Laws, c. 427, § 1.
- 16 See model agreements, *supra* note 14.
- 17 Kohn, et al., *supra* note 7.
- 18 Victoria State Gov't, *Communication for people with disabilities*, available at dhs.vic.gov.au/for-business-and-community/community-involvement/people-with-a-disability-in-the-community/communicate-and-consult-with-people-with-a-disability/communication-with-people-with-disabilities. See also Dep't Homeland Sec., *A Guide to Interacting with People who have Disabilities*, available at dhs.gov/sites/default/files/publications/guide-interacting-with-people-who-have-disabilities_09-26-13.pdf.
- 19 Alzheimer's Assn., *Communication and Alzheimer's*, available at alz.org/care/dementia-communication-tips.asp; see also Nat'l Health Serv., *Communicating with someone with dementia*, available at nhs.uk/Conditions/dementia-guide/Pages/dementia-and-communication.aspx.