



WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON
University Center for Excellence in Developmental Disabilities

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Making the Case for Supported Decision-Making



What is Supported Decision-Making?

Supported Decision-Making (SDM) is a way to help individuals with intellectual and developmental disabilities (IDD) make decisions with the assistance of friends, family and trusted allies. Supported Decision-Making can be used by someone who makes their own decisions as well as by those who may have legal structures such as guardianship that identifies someone else to make decisions.

The Waisman Center along with the Wisconsin Board for People with Developmental Disabilities and Disability Rights Wisconsin have been working together to explore and advance the understanding of supported decision-making for people with intellectual and developmental disabilities in Wisconsin. Following an invitational meeting convened by the Wisconsin Supreme Court Justice Shirley Abrahamson, work began on a Wisconsin law to create supported decision-making agreements. The law was passed in 2018. This brief offers an overview on supported-decision-making and ideas to support the practice.

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Issue Statement

Individuals with IDD are considered equal under the law, which includes the right to choose where to live, agree to medical treatment, vote, enter into contracts, marry, manage finances, and exercise legal rights just like any other adult. Some individuals with IDD may need support exercising these rights. SDM is one way of supporting an individual with a disability by using friends, family members, and professionals to help the person with IDD understand the situations and choices they face.¹

The belief that individuals with IDD are capable of making their own decisions is relatively new. Historically, most individuals with IDD have been subject to a restriction of their civil rights in the courts known as guardianship. While guardianship may be appropriate for some individuals, assumptions about the capabilities of people with IDD have resulted in guardianship being commonly used as the first and only option.

Nationally the number of adults under guardianship has tripled since 1995 with approximately 90% of guardianships being the most restrictive form.² Many families report that physicians, school personnel or human service professionals recommend they seek guardianship when their young adults turn 18.



The Americans with Disabilities Act of 1990 was seminal civil rights legislation reflecting the changing perceptions of people with IDD. Together the self-advocacy and self-determination movements, families, providers, communities, and individuals are rethinking assumptions about the ability of individuals with IDD to make decisions.

Background

As more people with IDD live in the community instead of institutional settings we have the opportunity to think about new ways to support people to make decisions about their day to day lives. Additionally, research on brain development and functioning indicates that the brain continues to mature well into a person's 20's potentially impacting decision-making. Furthermore, learning and life experience can improve decision making.

Historically, guardianship has been the way to provide decision-making supports. Guardianship is a legal process resulting in a decision by the court finding the individual with IDD incompetent.

A person, institution or agency is given authority to make decisions on behalf of the individual. Current Wisconsin law requires that decisions should be made with input from the individual with IDD, but there is no guidance, criteria or enforcement of this requirement.

While the loss of decision-making control is supposed to guarantee the safety of the person with IDD, there is growing concern that the opposite may actually be true. Evidence suggests that using formal systems of substituted decision-making can reduce inclusion, self-determination and community integration, in violation of the ADA and other federal laws.³ Studies increasingly link self-determination, the right to make choices and decisions about important parts of one's life, to a better quality of life.⁴ For example, students who were more

self-determined did better across multiple life categories, including employment and access to health and other benefits, financial independence, and independent living.⁵ Increases in self-determination leads to better health, greater independence, better employment, and the ability to avoid and resist abuse.

While guardianship has been the typical way to support individuals with IDD, there are risks with guardianship. These include:

- Being found incompetent can be painful, emphasizing what the person can't do rather than their strengths. The person may feel labeled as second-class and feel a loss of dignity and respect. They may be viewed by others as not worth

listening to.

- People labeled incompetent and placed in guardianships are often deprived of self-determination and the opportunity to direct their own lives. People

can experience low self-esteem, and feelings of inadequacy and incompetency, decreasing their ability to function.

- In addition to the social impact of guardianship, individuals who are considered incompetent can be at greater risk for abuse and exploitation by others. This is because they either are not allowed to "say no" or may see themselves as incapable of making decisions.
- Similarly, a person who has decisions made by someone else will have fewer opportunities to learn and practice decision-making skills.

The use of SDM does not eliminate the need for guardianship for some individuals. Even in situations where guardianship is needed, it is still possible and in

"The United Nations Convention on the Rights of Persons with Disabilities calls out the need for supported decision-making in Article 12 stating: "States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." CRPD 2006

- Wisconsin law requires the use of “the least restrictive option” when considering guardianship. Educate judges, attorneys and guardians ad litem about the range of decision-making tools available.
- Include skill-building opportunities in school and health education that allow students with IDD to explore and practice decision-making.
- Develop and disseminate educational resources to families and young adults to help them as they make decisions at age 18.
- Access to and the use of technology can mitigate some of the decision-making needs of an individual. Disseminate information about the use of technology to support decision-making.
- Disseminate information about community resources available to everyone that can support various aspects of life skills management.

Resources

- [Keeping Individuals with Disabilities and Aging Adults in Charge of Their Lives Supported Decision-Making and Other Alternatives to Guardianship](#) - BPDD
- [Let’s Talk About Supported Decision-Making](#) - BPDD
- [Supported Decision Making Agreement Form](#) - Wisconsin DHS
- [Advance Directives and POA Forms](#) - Wisconsin DHS
- [National Resource Center for Supported Decision Making](#)
- [Guardianship and Alternatives for Decision Making Support](#) - Got Transition
- [PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making](#) - American Bar Association
- [Supported Decision-Making for Transition Age Youth](#) - Family Voices of Wisconsin

References

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- ² Jameson, M., Riesen, T., Polycronis, S., Trader, B., Mizner, S., Martins, J., Hoyle, D. (2015). *Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities*. *Research and Practice for Persons with Severe Disabilities Research and Practice for Persons with Severe Disabilities*, 40(1) 36–51
- ³ Salzman, L. *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*. (2010) *University Of Colorado Law Review*, 81, 157-245.
- ⁴ Khemka, I., Hickson, L., & Reynolds, G. (2005). *Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse*. *American Journal on Mental Retardation*, 110, 193–204.
- ⁵ Wehmeyer, M. L., & Palmer, S. (2003). *Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination*. *Education and Training in Developmental Disabilities*, 38(2), 131–144.
- ⁶ 2017 WISCONSIN ACT 345 – Wisconsin Chapter 53 <https://docs.legis.wisconsin.gov/2017/related/acts/345>

