

Supported Decision-Making

Exciting New Legislation in Wisconsin



Your Presenters



Lisa Pugh, Executive Director
The Arc Wisconsin;
Co-Chair Survival Coalition



Tami Jackson, Public Policy
Analyst
Wisconsin Board for People
with Developmental Disabilities



Janet Zander, Advocacy and
Public Policy Coordinator
The Greater Wisconsin Agency
on Aging Resources, Inc.



Amy Devine, Public Policy
Coordinator
Disability Rights Wisconsin

Housekeeping

- You can send questions using the chat box.
- Technical Issues?
 - Call Amy at 608-308-2624 or
 - email amyd@drwi.org

What We Hope You Will Learn

- What is Supported Decision-Making?
- How does Supported Decision-Making differ from other options?
- Why make Supported Decision-Making a law?
- How you can help support a new Supported Decision-Making bill?
- Resources and next steps

Important to Keep in Mind...

- Under the law, all adults have the capacity for decision-making.
- Decision-making is a learned skill.
- Everyone, no matter their limitations, needs opportunity, experience, and support in order to learn how to make well-informed decisions.

Current decision making or support options



Informal Support

- Person asks for advice from friends, family, or others before making their own decision.



Supported Decision Making

- Person makes all their own decisions, and can identify Supporters to help them gather information, compare options, and communicate their decisions. Some states have a legally recognized role for supporters outlined in Supported Decision-Making agreements



Power of Attorney, representative payees, medical proxy

- Formal legal arrangements that permit others to act on the Person's behalf



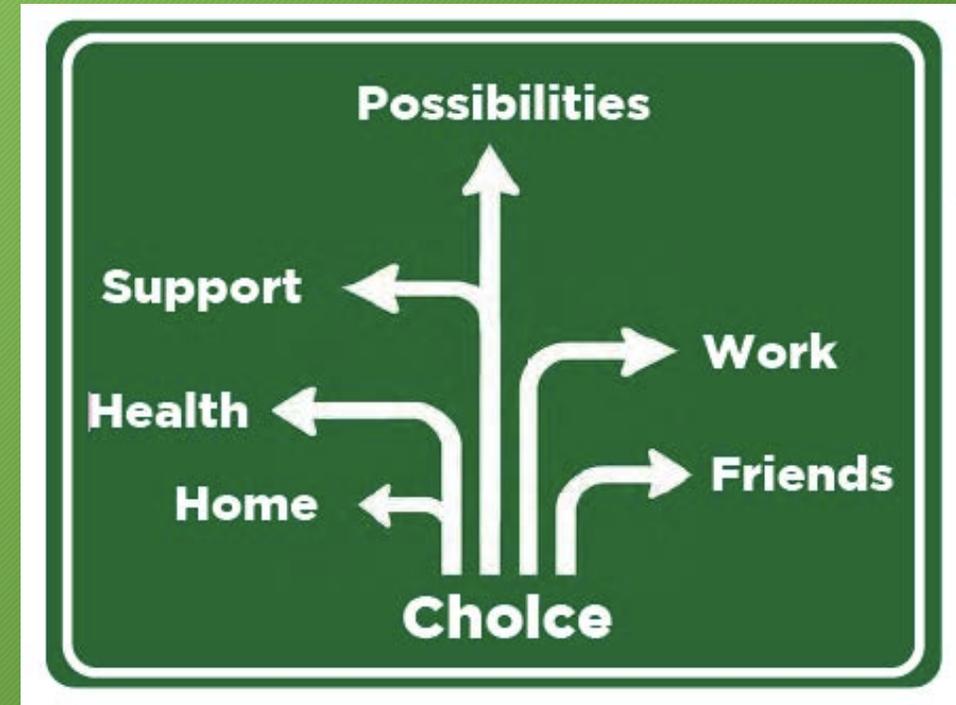
Limited or Full Guardianship

- Transfers some or all decision-making authority from the Person to a court-appointed Guardian, tends to be over recommended. A last resort.



What is Supported Decision-Making (SDM)?

- With Supported Decision-Making, older adults and people with disabilities (the Person) remain fully in charge of their decisions.
- SDM can be used for any decisions the Person feels they need additional support—such as housing, health care, financial affairs, employment, or other areas the Person identifies.
- The Person chooses trusted relatives, friends, and people with expertise in an area (a Supporter) to help them gather information, understand and evaluate options, and communicate their decisions to others.
- The Person is the decision-maker (not the Supporter).



What is Supported Decision-Making (SDM)?

- Supported Decision-Making is flexible and can be updated easily as the Person's ability and capacity to make decisions changes over time.
 - People with Intellectual/Developmental Disabilities (I/DD) continue to gain experience throughout their lives that can increase decision-making skills. SDM can provide support as the person practices making decisions.
 - Changes in functional impairments (more or less) through a rehabilitation process or progressive conditions can change the kinds of decisions with which a Person wants support.



What is Supported Decision-Making (SDM)?

- For many older adults and people with disabilities, Supported Decision-Making agreements may be the only tool they need to have trusted people provide support as they make their life decisions.



What is Supported Decision-Making (SDM)?

- SDM can also be used in combination with other legal arrangements (including Power of Attorney or limited guardianship).
- These options are not mutually exclusive and can be used to complement each other.
 - For example, a SDM agreement can ensure the Person's independence in certain areas of life where they have retained their decision-making authority, even when authority to make other decisions has been given to a Power of Attorney or Guardian.



Benefits of Supported Decision-Making

- Supported Decision-Making is a fundamental part of Self-Determination.
- People with greater self-determination are:
 - Healthier
 - More independent
 - More well adjusted
 - Better able to recognize and resist abuse (safer)

(Wehmeyer, Palmer, Rifenbark, & Little 2014; Powers et al., 2012; Khemka, Hickson & Reynolds 2005; Wehmeyer & Palmer, 2003; Shogren, Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer, Kelchner, & Reynolds 1996)



Benefits of Supported Decision-Making

- A [2016 survey on Supported Decision Making](#) in practice found Non-guardian Supporters reported that supported decision-making has made their child's/client's/friend's life better in the following ways:
 - They have more confidence.
 - They can do more things in their life.
 - They are happier.
 - They want to try more things.
 - They get to do what they want.



Supported Decision making should be a legally recognized option no matter where you live

- On August 14, 2017, the American Bar Association's (ABA) adopted [Resolution 113](#), urging states to:
 - (1) amend their guardianship statutes to require that supported decision making be identified and fully considered as a less restrictive alternative, before guardianship is imposed, and
 - (2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights.

How SDM can work for People with Disabilities

- Many schools are encouraging parents to obtain guardianship when their child turns 18 so parents don't need to ask permission from their adult child to attend IEP meetings.
 - Guardianship has serious and often lifelong implications for the Person and their family and can impact many or all areas of the Person's life, far beyond whether a parent can attend a meeting.
- Supported Decision-Making can enable parents to participate in their child's IEP meetings without taking away their child's legal right to make decisions.



How SDM can work for People with Disabilities

- Currently, some state agencies/providers/private entities have policies, informal protocols, and common practices that restrict any interactions to the person or someone who has been given legal authority to make decisions for the person (Power of Attorney, Guardian).
- This makes it unnecessarily difficult for people with cognitive/functional impairments to use or access trusted friends or family members when requiring a person to make a decision.
- Supported Decision-Making would give Supporters authority to interact with agencies on behalf of the person, except the Person would be making their own decision (not the Supporter).



How SDM can work for People with Disabilities

- Facilitate clear communication of Person's wishes
 - Supporters can help ensure the Person is clearly understood by others.
 - People who have challenges with speech, use sign language or communication devices, and/or who are non-verbal communicators might use a Supporter to ensure the other party understands them.



How SDM can work for older adults

- Identifies friends and other non-family members who have been selected to assist with decision-making.
 - Increasing percentage of women who remain childless and over 37% of Wisconsin women age 65 and older, live alone.
- Informed consent is key to self-determination in medical care
 - Three Key Parts:
 1. Information to the person
 2. Understanding by the person
 3. Choice by the person



How SDM can work for older adults

- Supported decision-making can address areas in addition to those covered by a traditional Power-of-Attorney.
 - Housing/living arrangements
 - Choosing a service provider (Examples - internet, cellphone, cleaning service)
 - Filing taxes



How SDM can work for older adults

- Supported Decision-Making provides a powerful tool for empowering older adults who are experiencing changes in memory and cognition.
 - Older adults in early stages of degenerative disease (like Alzheimer's) may have many years where they want help, but do not need guardianship.
 - Alternative to premature guardianship (allows for a transition to more support when needed)



Why make Supported Decision-Making a law?

- Professionals required to recognize a SDM agreement as a legal expression of the Person's wishes.
- Adding SDM in the statutes establishes a legal framework for Supporters to document their role in helping the Person to others (bankers, state agencies, other professionals, etc.).
- A SDM agreement would mean a Supporter can participate in the meetings, conversations, etc. in which decisions are made (to the extent the Person wants the Supporter involved in those decisions).



Why make Supported Decision-Making a law?

- Statutory language is also needed so that professionals know the Person has given the Supporter consent to hear, receive, and discuss information, and that the SDM agreement satisfies statutory privacy or other requirements to release records to the Supporter (if applicable).



Why make Supported Decision-Making a law?

“When I am no longer able to support my son that role will fall to others. Those others do not need to be guardians. Nor would many folks in our lives currently want that role. The supports will likely need to be split out. Those “bit” supporters need something that is recognized and accepted to have an uncontested seat at the table.

In my attempts to use SDM I have had to use the “I am an attorney” too many times with the entities my son interacts with. There needs to be something formal sitting between full guardianship and no support.”

--A Parent

Wisconsin's Supported Decision-Making legislation

- Bill (LRB 4637 in the Assembly) and LRB 2053 in the Senate has bi-partisan support
- Introduced for co-sponsorship by Representatives Kathy Bernier, Todd Novak, Beth Meyers, and Debra Kolste and Senator Sheila Harsdorf on October 25th
- Next Steps: Public Hearings

Wisconsin's Supported Decision-Making legislation

Key components of the bill:

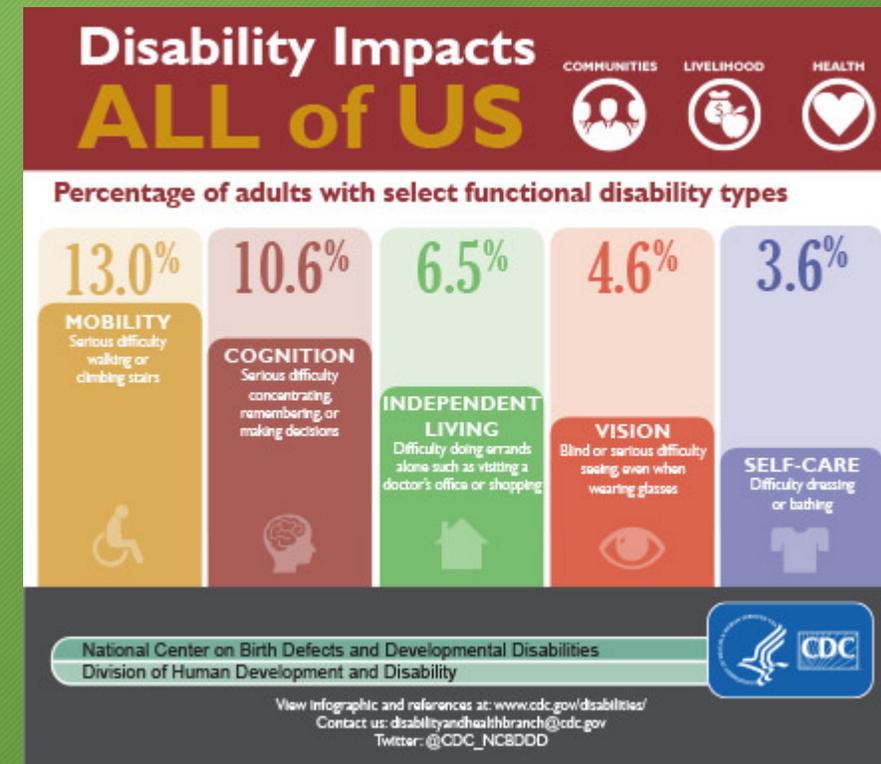
- Definitions.
- What is a supported decision-making agreement.
- Protections from liability; how to report abuse.
- How agreements are terminated.
- Role of others in ensuring SDM is considered.

Wisconsin's Supported Decision-Making legislation

- The bill lets older adults and people with disabilities retain all or some of their own decision-making authority over their life decisions and have trusted people provide support as they make their decisions.
- Supported Decision-Making does not replace Wisconsin's existing guardianship system; rather it provides an additional option for individuals and families seeking assistance with some or many life decisions.

Who can use a SDM agreement?

- The legislation defines who can use a SDM agreement as a “person with a functional impairment:”
 - People with physical, developmental, or mental conditions that substantially limit one or more of an individual’s major life activities as specified in the bill.
 - People experiencing degenerative diseases.
 - Conditions incurred at any age that substantially interfere with the Person’s ability to provide self-care.
- Functional impairment does not need to be determined or “certified” by health care professionals.



What does an SDM agreement look like?

- The bill includes standard elements that must be included in all SDM agreements.
 - Types of decisions the Person wants Support with;
 - The roles the Person elects to allow the Supporter to do:
 - Access, collect, or obtain information relevant to a decision area the Person has chosen;
 - Understand options so Person can make an informed decision;
 - Communicating decision to others; and
 - Access personal records that may require a release.



What is the role of the Supporter?

- The Person is always in control of their decisions.
- The Supporter has no authority to make the person's decisions—their role is defined by the older adult or person with a disability through the SDM agreement.
- The SDM agreement identifies what types of decisions a Supporter may assist with.
- The possible roles of the Supporter are limited to assisting the person with the gathering of information, helping the person understand their options/responsibilities/consequences of the decision, and communicating the Person's decisions to others.



How does the bill protect information?

- The bill limits access to personal information. Only information that is relevant to the decision with which a Supporter has been asked to assist is accessible by the Supporter.
- The bill establishes clear parameters on how records protected by confidentiality can be accessed by a Supporter with the permission of the Person.
- The bill requires Supporters to ensure all personal information they access in the course of fulfilling a SDM agreement is kept privileged and confidential and is not subject to unauthorized access, use, or disclosure.



Does the bill protect people from exploitation?

- The Person is always in control of their own decisions and their Supported Decision-Making agreement.
- Either the Person or the Supporter can revoke a SDM agreement at any time.
- SDM agreements are automatically revoked if the Supporter has a substantiated allegation of neglect or abuse of the person, the Supporter has been found criminally liable for abuse or neglect, or there is a restraining order against the Supporter.
- Anyone who suspects that a Supporter is abusing, neglecting, or financially exploiting an older adult or person with a disability can report their concerns to the elder or adult at risk agency, or appropriate law enforcement agency.



What you can do to expand Supported Decision-making in Wisconsin

- Tell your legislator to support the Supported Decision-Making bill; be ready to testify at a committee hearing.
- Educate yourself and others (schools, Family Care, IRIS, ADRCs, healthcare and other providers).
- Use speakers from The Arc, BPDD, GWAAR, DRW.
- Think about whether SDM is the right option for people you know; guardianship can be revisited.

Supported Decision-Making Resources

- BPDD's Supported Decision Making Toolkit: <http://wi-bpdd.org/index.php/SupportedDecision-Making/>
- New video from The Arc on SDM: https://youtu.be/rBNL_R4sJPo
- American Bar Association resolution on supported decision-making: https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.authcheckdam.pdf
- Supported Decision-Making Basics for older adults (Justice in Aging) <http://www.justiceinaging.org/wp-content/uploads/2017/07/Supported-Decision-Making-Basics.pdf>
- AARP Guide for Supporters (specific to financial support - TX): <http://protecttheirmoneytx.org/guide/help-supporters-under-supported-decision-making-agreement>
- Webinar on supported decision-making in healthcare: <https://futureplanning.thearc.org/pages/learn/where-to-start/webinars/archived-webinars>
- More information on promoting autonomy: <http://www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship>
- Additional resources related to supported decision-making: <http://supporteddecisionmaking.org/>

Questions?

