



Nuts and Bolts:

Wisconsin's Supported Decision-Making Agreement Law

Today we will talk about:

- Challenges and fears families face when people with disabilities (physical, I/DD, mental health) transition into adult hood,
- Options including Supported decision-making (SDM), powers of attorney, and guardianship.
- Myths parents, and professionals have about guardianship
- Long-term consequences of overly restrictive guardianships.
- Wisconsin's Supported Decision-Making law & using SDM agreements
- Ways to presume competence and engage with people using SDM agreements and their Supporters.

Wisconsin law presumes all adults are competent to make decisions

- Decision-making is a learned skill.
- Everyone needs opportunity, experience, and support in order to learn how to make well-informed decisions.
- Ways people practice decision-making before age 18
 - Simple daily choices (what to wear, what to eat, asking preferences, allowing 'no' to be a choice)
 - Choosing interests, ways to spend free time, who to interact with and how
 - Practice with increasing responsibility, and “higher stakes” decisions

Cultural bias (Ableism) presumes people with disabilities are incompetent

What can that look like?

Professionals

- Visible disability, assume person has guardian.
- Invisible disability, presume ability/skills, fail to recognize stress, coping strategies/behavior.
- Assume whomever is with the person makes decisions for them
- See guardianship, POAs, SDMs as the same
- Policies, protocols assume there is a guardian
- Policies, protocols do not include space for Supporters, POAs, or informal attendees

Families

- Deference to family member over decisions made about the person
- Deference to family members in meetings, even when person with a disability is present
- Lack of involvement of person with a disability in decision-making
- Lack of practice with small/low stakes and larger/higher stakes decisions
- Actions driven by service system (medical, disability services/supports, schools etc.) needs/requirements not person with a disability.

What does that feel like/teach person with a disability?

“Learned helplessness”

I let others speak/decide for me

My preferences don’t matter

I can’t control my own life

I cannot say no

I must comply

If I can’t do everything perfectly, then I can’t do it at all

No practice or confidence making decisions

Consequences for not complying

People with greater self determination are

- Healthier
- More independent
- More well adjusted
- Better able to recognize and resist abuse (safer)

HIGHEST correlation to impact on people's lives.

People exercise rights

People are treated fairly

People are respected

People choose where and with whom to live

People choose services

Transitioning to adulthood is scary and hard

Families are also working, managing caregiving challenges, transportation, appts, other children etc. while taking on these added challenges

Challenges for Families

Navigating Social Security eligibility

Children's LTC system to adult LTC (functional screen, selecting program)

School 18-21 Transition program

Pediatric to new doctors

Navigating employment (DVR etc.)

Navigating other programs (housing, Foodshare, etc.)

Fears of Families

How can I advocate for my person for supports/services/medical care?

Will they be safe? How can I prevent abuse/neglect?

Are they ready to make decisions?

What if they make the "wrong" decisions?

Will people listen to my person if I'm not the guardian?

How can I keep them eligible for public programs? How will they navigate system without me?

All these decision points are occurring at the same time and are time sensitive. Families feel pressure and expectation they make final decisions quickly (crisis decision mode)

Current formal tools for people who need help with decisions



Release forms

- Person signs release forms authorizing a specific person(s) access to certain kinds of records (health, financial, etc.).
- Some release forms may allow a person to select certain records to be released while retaining privacy over others.
- Some release forms may provide one-time or time-limited access to records, others releases may remain in effect in perpetuity.



Supported Decision Making agreements (Wisconsin)

- Person makes all their own decisions. Person identifies area of the life in which they want support, identifies a Supporter(s) to help them gather information, compare options, and communicate their decisions to others.
- The Supported Decision-Making agreement outlines what types of decisions the Person wants support and the role of the Supporter.
- Agreement can be changed or stopped at any time by the Person or Supporter.



Representative payee

The Social Security Administration (SSA) appoints an individual/organization to receive SSI/SSDI benefits for a person who cannot manage or direct the management of their own benefits.

To change a Representative Payee, the Person must complete an application process with the SSA.



Power of Attorney, medical proxy

- Formal legal arrangements that permit others to act on the Person's behalf.
- Powers of Attorney (POA) designate another (a POA) individual to make certain decisions (generally health care or financial) on the Person's behalf. POAs can be set up in different ways. Some POAs are activated only when a person is incapacitated. Or a POA can be written so an individual other than the Person is always the designated decision maker in certain areas.
- Medical Proxy documents appoint a proxy/agent to express a person's wishes and make health care decisions for the person if the person cannot speak for themselves.



Limited or Full Guardianship

- Transfers some or all decision-making authority from the Person to a court-appointed Guardian.
- Once guardianship is granted by the courts it is difficult (and costly) to modify or reverse the guardianship; any changes must be made through a formal court process.

Less Limiting

More Limiting

Administrative tasks required of guardians

Guardian of Estate	Guardian of the person
Duties (Ch 54.19) include management of real and personal property and money management including rep payee duties.	Duties (Ch 54.25) include securing necessary care and services for the ward and reporting.
Administrative requirements (Ch 54.19 and Ch 54.62) requires at least annual accounting of ward's assets, income, investments, receipts/expenditures of guardian, etc.	Administrative requirements include an annual report on the condition of the ward to the court and county. Counties develop reporting requirements and may require more than categories listed in statutes.
Courts may require more frequent accounting. Courts may set their own financial oversight requirements within a county. Some are onerous requiring court authorization before spending even low dollar amounts.	<i>The guardian of the estate and guardian of the person have separate and distinct duties and powers under the statute. Frequently the same person may be appointed both a guardian of the estate and person, but that is not always the case.</i>

Common Myths about Guardianship

Myths FAMILIES hear or believe	Myths PROFESSIONALS hear or believe
"I need to be a guardian to attend an IEP or other meeting" <i>(false)</i>	"All people with disabilities have a guardian to make decisions for them." <i>(false)</i>
"If you are the guardian, you make all the decisions" <i>(false)</i>	"I can't ask for the person who claims to be the guardian for documentation of their appointment" <i>(false)</i>
"I tell the court how we want the guardianship set up" <i>(false)</i>	"When a person has a guardian, the guardian makes all the decisions" <i>(false)</i>
"A guardianship can easily be changed later" <i>(false)</i>	"I must call and ask the guardian for permission for all decisions" <i>(false)</i>
"I can pick who will be the next guardian" <i>(false)</i>	"A person with a disability needs any help, they must have a legal guardian" <i>(false)</i>
"If I'm a guardian and my ward violates the law, they will not go to jail." <i>(false)</i>	"All guardians are acting in the best interest of their wards" <i>(false)</i>

Serious long-term consequences of guardianship

For families	
Petitioning for guardianship is rarely done in the context of long-term family future planning.	Once the Court has found someone incompetent and appointed a guardian, it is difficult (and costly) to reverse or change. The court approves or denies petitions.
Many petitioners do not know what rights they are taking away	Courts are charged with oversight of guardianship cases. They may appoint a new guardian at any time for cause.
Many petitioners are not aware limited guardianship is an option	When there is no willing or appropriate successor to a family guardian, courts will appoint another guardian. It may be a corporate guardian. Many corporate guardians have multiple wards
Courts are not always willing to grant limited guardianships.	Guardians have roles, responsibilities, and administrative duties required by state law.

Serious long-term consequences of guardianship

For individuals under guardianship (ward)

People with disabilities are rarely consulted about decision-making support needs or guardianship

Many Guardians maintain or assume increasing control over daily decision-making regardless of the terms of the guardianship

May not be aware someone is petitioning to become their guardian.

Many wards are unaware of what rights they have and what rights have been removed.

Most providers and third parties assume the guardian makes all decisions.

No training for wards about the rights they retain, ways to reduce the likelihood of abuse and neglect.

Third parties rarely check to confirm who is the guardian or what the terms of the guardianship are.

Many people with disabilities experience and describe an erosion of their rights.

Once imposed, a guardianship usually lasts a lifetime.

- **The gravity of a judicial declaration of legal incompetency cannot be understated.**
- Wis. Stats. Ch. 54 reflects the serious impact appointment of a guardian may have on an individual's life, freedom, and decision-making autonomy
- The ward loses their civil rights to make decisions about some or most things in his or her life.
- **The most restrictive option should not be the first option** *(but it often is the only option presented or considered).*

Even when full guardianship is granted...

Guardians of the person shall do the following (Wis. Stats. Ch 54.25(2)(d)3.a and b)

- Place the *least possible restriction* on the individual's personal liberty and exercise of constitutional and statutory rights, and *promote the greatest possible integration* of the individual into his or her community.
- Make *diligent efforts to identify and honor the individual's preferences* with respect to choice of place of living, personal liberty and mobility, choice of associates, communication with others, personal privacy, and choices related to sexual expression and procreation. In making a decision to act contrary to the individual's expressed wishes, the guardian shall take into account the individual's understanding of the nature and consequences of the decision, the level of risk involved, the value of the opportunity for the individual to develop decision-making skills, and the need of the individual for wider experience.

Wisconsin's Supported Decision-Making law

Three principles of Supported Decision-Making

1. Everyone has the right to make choices
2. People can get help making choices without giving up that right
3. People will often need help in understanding, making, and communicating their choices



Who in Wisconsin can use Supported Decision-Making agreements?

- While all of us use Supported Decision-Making as strategy in our daily lives, only certain people in Wisconsin can use formal Supported Decision-Making agreements.
- People who can use Supported Decision-Making agreements are defined within Wisconsin's law as people with "functional impairments" and include:
 - People of any age with degenerative diseases
 - People of any age with conditions that substantially interfere with the ability to provide self care
 - People with physical disabilities or conditions that substantially limits one or more of their major life activities
 - People with Intellectual/Developmental Disabilities
 - People with mental health conditions

What Supported Decision-Making agreements do NOT do.

They do not restrict a Person's rights to make any decisions.

- Having a supported decision-making agreement does not preclude the Person from acting independently of the agreement or making decisions that the Supporter does not agree with.
- The Person is always in control of their own decisions.

It does not give Supporters any new rights

- The Supporter has no authority to make the person's decisions. The Person makes all their own decisions.
- Supporters cannot sign legal documents for the Person or bind a Person to a legal agreement
- Supporters have only the authority/role granted by the Person under the terms of the supported decision-making agreement.

What is the role of the Supporter?

The possible roles of the Supporter are limited to:

1. Access, collect, or obtain information relevant to a decision area the Person has chosen
2. Helping the person understand that information;
3. Helping the Person understand their options, responsibilities, and consequences of that person's life decisions, without making those decisions on behalf of that person
4. Assisting with communicating the Person's decision to others



What is the role of the Supporter?

- The law 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.
 - *Note: A Supporter is allowed to access records that require a release only if the Person has signed a release allowing the Supporter to see the information*
- Supporters are required to ensure all personal information they access when fulfilling a Supported Decision-Making agreement is kept privileged and confidential and is not subject to unauthorized access, use, or disclosure.



Can a Person have more than one Supporter or agreement?

- A Person may have multiple Supported Decision-Making agreements.
- The Person can choose different Supporters for different decision types.
- The Person can identify more than one Supporter in the same Supported Decision-Making agreement.



How are Supported Decision-Making agreements changed or terminated?

- The Person is always in control of their own decisions and their Supported Decision-Making agreement.
- The Person can include a specific date when the agreement ends.
- Either the Person or the Supporter can revoke a Supported Decision-Making agreement at any time.
- 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.

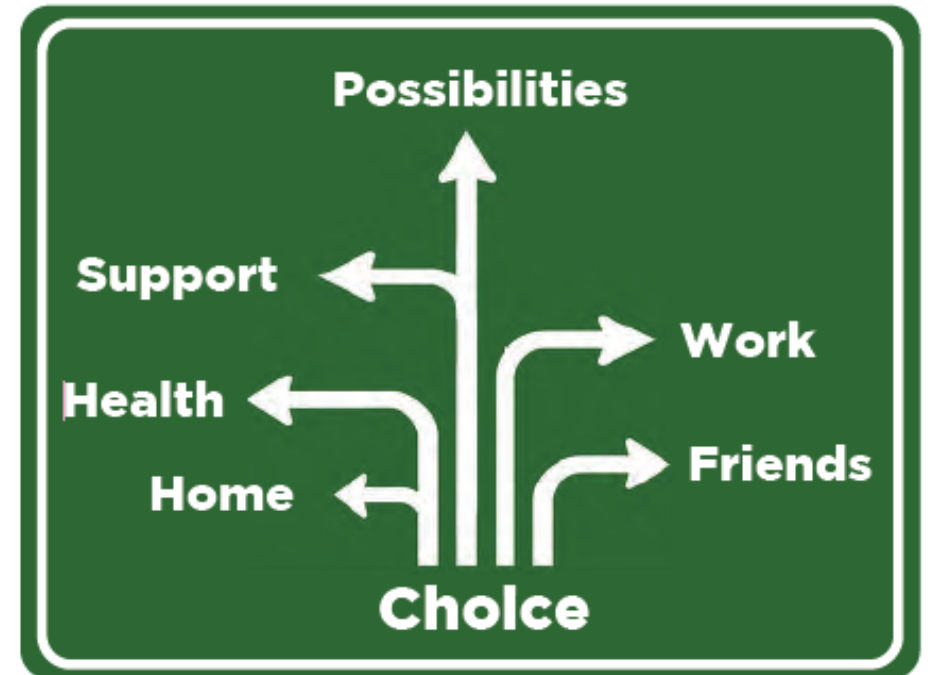
More features of Wisconsin's SDM law

Liability Protections for Professionals	Protections against fraud, abuse, neglect
Professionals who receive a Supported Decision-Making agreement are required to rely on that agreement as a legal expression of the Person's wishes.	Anyone who suspects that a Supporter is abusing, neglecting, or financially exploiting a person with a functional impairment may report their concerns to the elder or adult at risk agency, or appropriate law enforcement agency.
Liability protections for professionals and Supporters are included for actions done in the context of a valid Supported Decision-Making agreement	Those who are required by law to report abuse, neglect, or financial exploitation (i.e. mandated reporters) must still follow those requirements.
Other changes made by SDM legislation	
A supported decision-making agreement may not be used as evidence of incapacity or incompetency of the Person.	In guardianship proceedings judges are now required to consider
Schools are now required to provide students and parents with information on supported decision-making and other alternatives to guardianship.	1. Whether any alternatives to guardianship, including Supported Decision -Making, have been tried, and 2. Whether less restrictive means, including Supported Decision-Making, could be used.

Using Supported Decision-Making Agreements

Supported Decision-Making agreements

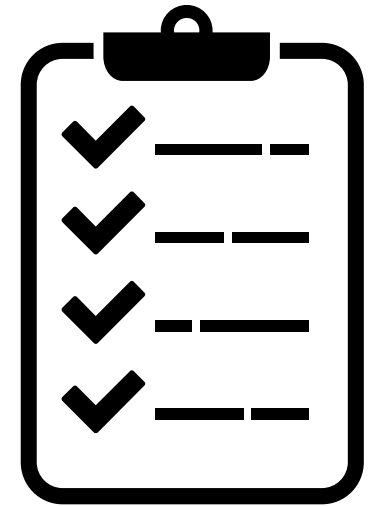
- Agreements can be used for any decisions the Person feels they need additional support—such as housing, health care, financial affairs, employment, etc.
- Supported Decision-Making agreements are flexible and can be updated easily as the Person's ability and capacity to make decisions changes over time.



What is included in a supported decision-making agreement?

The law includes standard elements that must be included in all Supported Decision-Making agreements.

- The name and contact information of the Supporter(s)
- Type(s) of decisions the Person wants Support with;
- The role(s) the Person elects to allow the Supporter to do
- The effective date of the agreement and any end date the Person chooses to specify
- The signatures of the Supporter(s), two witnesses or a notary public



What is included in a supported decision-making agreement?

Types of decisions included on the form:

- Obtaining food, clothing, and shelter
- Taking care of my physical health
- Managing my financial affairs
- Taking care of my mental health
- Applying for public benefits
- Assistance with seeking vocational rehabilitation services and other vocational supports
- other decisions I have specifically identified that I would like assistance with



What is included in a supported decision-making agreement?

- Check either Yes or No to give permission for a Supporter to help
- You can also list other kinds of decisions not on the form that you want a Supporter to help with
- The law presumes if you do not check Yes or No (i.e. leave both options unchecked) that you do not want the Supporter to help with that kind of decision.

Practical Examples

Using Supported Decision-Making agreements

Ensure friends, non-family, or extended family can act as Supporters

- Sometimes the closest relationships are with extended family.
- Family members are not always geographically close, and some people do not have family.
- Many people with functional impairments do have close relationships and social networks with non-family members who want to help.
- Supported Decision-Making agreements ensure that non-family members are recognized as carrying out roles and responsibilities specified by the Person.



Can adjust based on person's support needs

- Can help people experiencing changes in memory and cognition, and other abilities that may decline over a long period of time.
- Many people need a little help for a long time.
- Allows for a transition to more support when needed.



Places people use SDM agreements

- IEP meetings.
- DVR meetings
- Care plan meetings
- Medical appointments
- Financial planning
- housing/living arrangements,
- choosing a service provider (Examples - internet, cellphone, cleaning service),
- filing taxes etc.



Better communication person to professional

- Helps ensure the Person is clearly understood by medical or other staff.
- 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.



Better communication professional to person

- Supporters can help people understand information and their options in ways that make sense to them.
- A Supporter can help professionals more effectively communicate complex information and understand the person's questions/concerns.





Professionals

What I want you to know about my Supported Decision-Making Agreement

Wisconsin law (Wis. Stats. Ch 52) formally recognizes Supported Decision-Making (SDM) agreements. People who difficulty taking care of major life activities themselves or communicating – including certain people with disabilities, older adults and people with chronic conditions–qualify to use SDM agreements.

SDM agreements allow individuals to retain their civil rights to make their own decisions while allowing friends, family and trusted allies (Supporters) to support them as they make their own decisions.

Please remember these things when interacting with me:

- Sometimes I need help making decisions, but that doesn't mean I can't make my own decisions.
- Sometimes my Supporter will come to my appointment with me. Please talk to me, not to my Supporter.
- My Supported Decision-Making agreement tells you the role of my Supporter.
- Sometimes my service provider will bring me to my appointment. My Provider is someone from an agency that provides me services for my disability.
- Please talk to me, not my service provider. They don't make decisions for me.
- Explain things in a way that I can understand.
- Check to make sure that I understand what you are saying; Ask me if I have any questions.
- Give me important information in writing. Make sure it is written in a way that I can understand.
- Give me time to think about what you are saying.
- When I am upset, worried, or confused, it may take me longer to make decisions. Get to know me; ask me how I might react when I am upset worried or confused, and what might calm me.
- Ask me if I would like to talk with my Supporter; Give me time to talk to my Supporter, if I want to.
- My Supporter may ask questions to help me understand my options.
- My Supporter may help me tell you what my decision is. The decision is mine.
- Please respect my decision.

Engaging with people using SDM agreements and their Supporters

1. Make sure your agency's forms and technology systems include ways to denote Supporters and Supported Decision-Making agreements.
2. Include SDM agreements in client files/records, just as you include POAs, Letters of Guardianship, or release forms (if applicable).
3. Review and revise policies to reflect Supporters (not just guardians or Powers of Attorney) may be present in meetings or other procedures to fulfil their duties under the SDM agreement.

Engaging with people using SDM agreements and their Supporters

Communication tips

- | | | |
|--|--|--|
| • Talk to the person, not their Supporter. | • Explain things in a way the person can understand (plain language) | • Read the SDM agreement so you know the role of the Supporter. |
| • Check to make sure the person understands what you are saying; Ask if they have questions. | • Give the person time to think about what you are saying. | • Give important information in writing. Make sure it is written in a way the person understands (plain language). |
| • Some people take longer to make decisions. Allow time for this. | • Ask the person how they react when upset worried or confused, and what calms them. | • Ask the person if they want to talk with their Supporter and give them time to do so. |
| • The Supporter may ask questions to the person to help them understand their options. | • The Supporter may help the person tell you their decision. The decision is theirs. | • Please respect the person's decision. |

Resources

Official Wisconsin Supported Decision-Making Agreement form

- <https://www.dhs.wisconsin.gov/forms/f02377.pdf>



State of Wisconsin
Department of Health Services

To Whom It May Concern:

Enclosed is the Supported Decision-Making Agreement form you requested. The Supported Decision-Making Agreement makes it possible for persons to choose trusted people (called supporters) to help them gather and understand information, compare options, and communicate their decisions to others. Supported decision-making agreements DO NOT restrict the person's rights to make decisions; the person makes all their own decisions.

Supported decision-making is a way for people with disabilities to get help from trusted family members, friends, and professionals, to help them understand the situations and choices they face so they can make their own decisions. Supported decision-making enables people with disabilities to ask for support where and when they need it. Supported Decision-Making is NOT a form of guardianship or a power of attorney.

When entering into a supported decision-making agreement, those who can provide help in making decisions are called supporters. Supported decision-making agreements DO NOT take away any rights from the person asking for support. Supporters agree to help explain information, answer questions, weigh options, and let others know about decisions that are made. Supporters DO NOT make the decisions.

The form includes a list of decisions the person with a disability wants assistance in making and identifies supporters they trust to help them with those decisions. Be sure to read all four pages of the form carefully and understand it before you complete and sign it. The agreement must be signed with two witnesses who are at least 18 years of age OR by a notary public.

More information is available to assist you in filling out this form. The Board for People with Developmental Disabilities has additional information on supported decision-making available on its website:

<http://wi-bpdd.org/index.php/SupportedDecision-Making/>

Supported Decision-Making Resources

- Supported Decision Making toolkit: <https://wi-bpdd.org/wp-content/uploads/2019/12/SDMToolkit.pdf>
- Supported Decision Making statute (Wis. Stats. Ch 52, <http://docs.legis.wisconsin.gov/statutes/statutes/52>)

Questions?