



HEALTH MANAGEMENT ASSOCIATES

Sharon Lewis, Principal
August 2019

Supported Decision-Making, From Theory to Practice: Helping People Keep Their Power to Decide!



JENNY HATCH





What is Supported Decision Making?

A WAY FOR A PERSON (OFTEN A PERSON WITH A DISABILITY) TO MAKE THEIR OWN DECISIONS...

BY USING FRIENDS, FAMILY MEMBERS, PROFESSIONALS, AND OTHER PEOPLE THEY TRUST TO:

- + Help **understand** information, issues and choices;
- + **Ask questions**;
- + **Receive explanations** in language and ways they understand; and
- + **Communicate** their decisions and preferences to others.

(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

SUPPORTED DECISION MAKING – A WAY OF THINKING DIFFERENTLY



Supported decision making (SDM) starts with the assumption that ALL people -- including people with intellectual disabilities, people with mental health disorders, and older adults with cognitive impairment -- should **retain choice and control** over decisions in their lives.



It is not a program. It is not a specific set of rules or laws or forms. It is a **paradigm** – a way of implementing real self-determination, informed choice, and maintaining the humanity and dignity that comes with having our volition accepted and respected.



SDM is a **process** of working with the person to figure out when help in making decisions is needed and coming up with a way to provide that assistance.

■ UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

- **Sets out that people with disabilities:**

 - “have the right to recognition everywhere as persons before the law.”

 - “enjoy legal capacity on an equal basis with others in all aspects of life.”

- **Rejects the traditional legal structure of “best interest” or “substituted judgement” and honors the human rights of ALL people**

- **Proposes that states/countries shall:**

 - “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

 - “ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards that prevent abuse in accordance with international human rights law.”

MOVEMENT TOWARDS FORMALIZING SDM

2011 National Guardianship Summit, 2016 Position Statement

SDM should be considered first, and incorporated as part of the guardianship if needed

Social Security Advisory Board

Recommends SDM as an alternative to appointing a representative payee

American Bar Association

Adopted a resolution on SDM urging legislatures to require SDM be fully considered

2006

UN CRPD ARTICLE 12

New paradigm recognizes the rights and capacities of people with disabilities

2011
2016

2014

ACL establishes National Center on Supported Decision Making

Promote use of SDM, collect data, develop evidence, offer technical assistance

2016

2017

Uniform Law Commission

Model SDM is a less restrictive alternative to guardianship that must be explored before imposing a guardianship or conservatorship

2017

■ SUPPORTED DECISION MAKING: WHY?



Far too often, guardianship is the default option, which may assist with safety or health & well-being when implemented appropriately, but always inherently conflicts with self-determination, choice and control.



Guardianship, conservatorship, powers of attorney and other forms of legal decision-making authorities require attorneys, legal fees, and court involvement, making them expensive and less flexible.



Overbroad or undue guardianship can cause a “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being”

(Wright, 2010, p. 354)



**Zoe's Story:
High Expectations
Making Decisions
Independence.**

High Expectatic

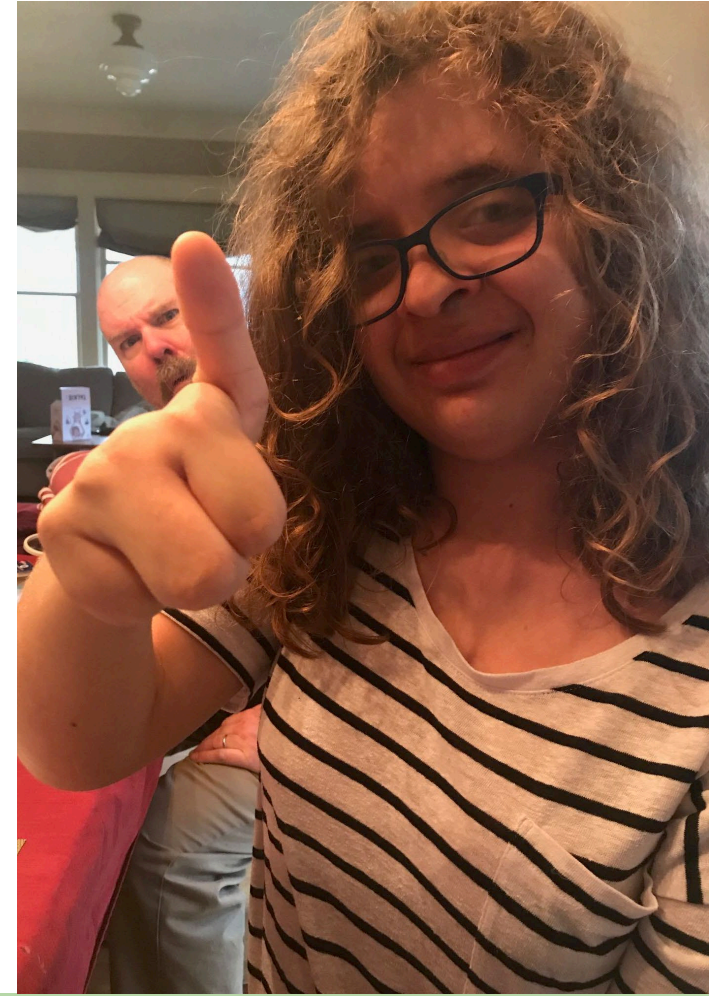
- My family always expects a lot of me for example, I do a lot of chores and help out
- My sisters and I are expected to understand the idea that fair does not always mean equal
- My teachers pushed me hard to be a good student just like my friends
- I expected that I would always be part of everything in my school and my community
- Sometimes people have low expectations of me and I like to prove them wrong!



Our Decision Making Agreement

- Acknowledge reaching age of Majority
- Talks about making decisions with support
- Discusses informed consent and need for understanding
- Requests that agencies and organizations seek cooperation
- Lists types of decisions (Legal Agreements related to healthcare, finances, contracts, services, public benefits)
- Expires and has to be renewed every 5 years (but can be changed anytime)

“Adulting” college, independence, work



“It’s MLife. I get to Cho

SUPPORTED DECISION-MAKING: FROM THEORY TO PRACTICE

Jonathan Martinis

Senior Director for Law and Policy

The Burton Blatt Institute at Syracuse University

IT IS HAPPENING

- Laws in Texas, Delaware, Nevada, Tennessee, Alaska, Maine, Missouri, Wisconsin, Washington DC, and others recognizing and encouraging Supported Decision-Making
- National Resource Center for Supported Decision-Making – www.SupportedDecisionMaking.Org
- Projects in South Carolina, Tennessee, New York, DC, Kentucky, California, Nevada, North Carolina, Maine, Massachusetts, Florida, Georgia, and others focused on increasing access to Supported Decision-Making

BUT IT'S NOT "JUST" ABOUT GUARDIANSHIP

People with disabilities who exercise greater self-determination have a **better quality of life**, more independence, and more community integration.

- Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003

SUPPORTED DECISION-MAKING AND SELF DETERMINATION

“Supported Decision-Making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration”

- Blanck & Martinis, 2015

OPPORTUNITIES FOR SDM ARE ALL AROUND US

- **Education:** “Student Led” IEPs
- **Employment:** “Informed Choice” in Vocational Rehabilitation
- **Medical Care:** Person Centered Planning for Medicaid and Waivers
- **Adult Services:** Centers for Independent Living PASS plans, ABLE Accounts

SDM Opportunity in Special Education: The Student Led IEP

THE STUDENT actually engages in self-determination

THE STUDENT can practice different decision-making methods in a “safe environment”

THE STUDENT leads meeting

THE STUDENT Identifies goals and objectives with assistance from professionals and people **THE STUDENT** invites

THE STUDENT LED IEP IS CONSISTENT WITH RESEARCH

- Students who led their IEP meetings “gained increased self-confidence and were able to advocate for themselves, interacted more positively with adults, assumed more responsibility for themselves, [and] were more aware of their limitations and the resources available to them.” - Mason, C. Y., McGahee-Kovac, M., & Johnson, L., 2004

SDM OPPORTUNITY IN VOCATIONAL REHABILITATION: “INFORMED CHOICE”

VR Agencies must ensure that the person can exercise “informed choice”

“Informing each applicant and eligible individual . . . through appropriate modes of communication, about the availability of and opportunities to exercise informed choice, including the availability of support services for individuals with cognitive or other disabilities who require assistance in exercising informed choice throughout the vocational rehabilitation process”

- 34 C.F.R. 361.52

SDM OPPORTUNITY: PERSON CENTERED PLANNING

PCP Focuses on what is:

- Important TO the Person
- Important FOR the Person
- Where the Person is and where the Person wants to be
- What needs to change and what needs to stay the same to get there

IT IS HAPPENING

PICKAWAY COUNTY AND PERRY COUNTY, OHIO AND RUTLAND VERMONT

- “Successful Transitions Project”
- Collaboration between School, VR, and Providers
- Identifying students at risk of guardianship and putting supports in place to help them live independently
- Using SDM to create IEPs, IPE, and ISPs with common goals and consistent objectives
- Identifying “gaps in the system” and helping agencies work together to provide more effective, cost-efficient supports.

IT IS HAPPENING: POSITIVE OUTCOMES

■ In Vermont:

- 86% Agreed that the Program helped prepare students for life after high school;
 - 100% Agreed that the Program improved the supports provided to students;
 - 93% Agreed that the Program increased the amount of supports students received;
 - 100% Agreed that the Program helped identify student needs
 - 100% Agreed that the Program provided better supports to meet student needs
 - 73% Agreed that the Program was an easy process
- Martinis, Cassidy, Gustin, Nadeau, and Robinson (in press)

CHANGE THE CULTURE, CHANGE THE WORLD!

“Long after the schools, Vocational Rehabilitation, early interventionist, behavioral consultants, and para-educators have gone. the students will be adults. . . We [are] ethically, morally, and fiscally responsible for supporting their lives of success and meaning. . . . We have the tools, we have the means . . . we have the vision.”

Gustin, 2015

SUPPORTED DECISION MAKING

Wisconsin Statute Chapter 52 specifies:

- Who can use supported decision-making agreements.
- Who can be a supporter.
- Roles and responsibilities of the individual and the supporter.
- Terms of the agreement.
- Specifies what must be included in a supported decision-making agreement.

PERSON-CENTERED

Supported decision making supports the person-centered approach to developing services and supports plan in long-term care services and supports (LTSS) by:

- Allowing full control of decision making.
- Not impeding self-determination.
- Assuring access to desired support from family members and non-family members.

CURRENT AND FUTURE CONSIDERATIONS

To fully recognize supported decision making in long-term care programs, changes must be considered:

- Contracts (managed LTSS and self-direction waivers)
- Forms
- Systems
- Policies and processes



The Arc[®]
Wisconsin

Supported Decision-Making, From Theory to Practice: Helping People Keep Their Power to Decide!

Lisa Pugh, Executive Director &
Parent

Achieve with us.[®]

Advocating for SDM in Wisconsin

- No statewide tracking of guardianships; limited data
- County Court data: almost 34,000 people under guardianship (2015).
- Number of guardianship petitions filed each year increasing since 2011. Many young people.



Overuse of Guardianship in WI

- Wisconsin National Core Indicators (NCI) data indicate limited self-determination in the long-term care system.
- Wisconsin ranks below average in all NCI Choice and Decision-Making questions except two.
- Respondents in Wisconsin have less input into where they live and work, their staff, and their finances than the national average.

Schools are Major Referral Source for Guardianship

- Focus groups found that family members most often learned about guardianship from schools.
- Parents felt guardianship was expected even if they did not feel their children were legally incompetent.
- Half of education professionals said they received no guidance to provide information to families but 67% advised families to seek full guardianship.
- If supported decision-making agreements had been presented, many families would have tried it first.

Wisconsin's Law

<http://docs.legis.wisconsin.gov/statutes/statutes/52.pdf>

- Passed law in spring 2018 - recognizing supported decision-making agreements as an alternative to guardianship.
- Lead advocates: The Arc Wisconsin, DD Council, P&A, Older Americans Act grantee/guardianship support center.
- The law includes standard elements that must be in all SDM agreements: Dates, names, witnesses, notary signature.
- Includes types of decisions a supporter can help with.
- Includes types of information a supporter may access.



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

DEPARTMENT OF HEALTH SERVICES
F-02377 (08/2018)

STATE OF WISCONSIN
Wisconsin Stat. § 52.20(1)

SUPPORTED DECISION-MAKING AGREEMENT

Appointment of Supporter

I, _____, make this agreement
(insert name of person designating a supporter)

voluntarily and of my own free will. I agree and designate that

Name of supporter (Print)

Address of supporter

Email address of supporter (if applicable)

Phone number(s) of supporter

is my supporter. For the following everyday life decisions, if I have checked "Yes," my supporter may help me with that type of decision, but if I have checked "No," my supporter may not help me with that type of decision:

- | | | |
|------------------------------|-----------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Obtaining food, clothing, and shelter. |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Taking care of my physical health. |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Managing my financial affairs. |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Taking care of my mental health. |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Applying for public benefits. |
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | Assistance with seeking vocational rehabilitation services and other vocational supports. |

The following are **other decisions** I have specifically identified that I would like assistance with:

If I have not checked "Yes" or "No," or specifically identified and listed a decision immediately above, my supporter may not help me with that type of decision.



The Arc[®]
Wisconsin

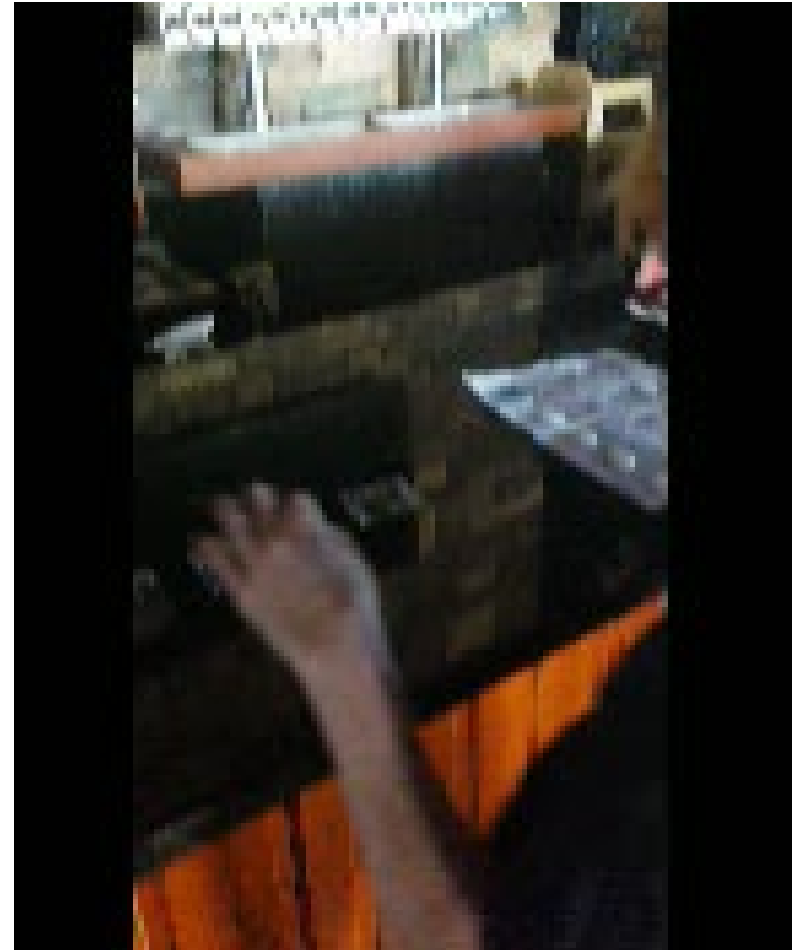
Who in WI can use Supported Decision-Making agreements?

- 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

Honoring the Ability to Make Choices



Honoring the Ability to Make Choices



Opportunities with Implementation in WI?

- Many families are interested in using this alternative but find they are pioneers as they interact with medical, financial, and other systems.
- Traditional referral sources to guardianship (schools, long-term care programs, courts) have been slow to integrate supported decision-making into their policies and practices.
- Wisconsin has a limited guardianship system with defined roles for guardians; often guardians do not act within this role; Guardian training is necessary.



The Arc[®]
Wisconsin

WI Supported Decision-Making Resources

- Toolkit and webinar: <https://wi-bpdd.org/index.php/supporteddecision-making/>
- Other resources for self-advocates: <https://arcwi.org/2018/04/13/supported-decision-making/>

Wisconsin

Betsy Genz, Director

Bureau of Adult Programs and Policy

Division of Medicaid Services

Department of Health Services

Supported Decision Making

Wisconsin Statute Chapter 52 specifies:

- Who can use supported decision-making agreements.
- Who can be a supporter.
- Roles and responsibilities of the individual and the supporter.
- Terms of the agreement.
- Specifies what must be included in a supported decision-making agreement.

Person-Centered

Supported decision making supports the person-centered approach to developing services and supports plan in long-term care services and supports (LTSS) by:

- Allowing full control of decision making.
- Not impeding self-determination.
- Assuring access to desired support from family members and non-family members.

Current and Future Considerations

To fully recognize supported decision making in long-term care programs, changes must be considered:

- Contracts (managed LTSS and self-direction waivers)
- Forms
- Systems
- Policies and processes

■ SUPPORTED DECISION MAKING RESOURCES

- + National Center for Supported Decision Making:
www.supporteddecisionmaking.org
- + Uniform Law Commission:
<https://my.uniformlaws.org/committees/community-home?CommunityKey=2eba8654-8871-4905-ad38-aabbd573911c>
- + American Bar Association information on guardianship and SDM:
https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/
- + Burton-Blatt Institute Research Project on SDM:
http://bbi.syr.edu/projects/Community_Living_DRRP/index.html