National Center for Family Professional Partnerships

a project of FAMILY VOICES®



Building Partnerships and Educating Families and Professionals about Supported Decision-Making

February 21, 2019

Sponsored by Quality Trust and Family Voices' NCFPP

Welcome! We will begin shortly. <u>Phone lines are muted</u>, and will be opened for Q&A near the end of the webinar.

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AGENDA AND SPEAKERS

Welcome—Melissa Vickers, Family Voices Project Director

Introduction—Morgan Whitlatch, Legal Director for Quality Trust for Individuals with Disabilities and Lead Project Director of the National Resource Center for Supported Decision-Making

Experience from the Family Voices Network:

- **Carrie Woodcock** is the Executive Director, Maine Parent Federation, and Project Director for their Supported Decision-Making program
- Janna Murrell, Assistant Executive Director of Raising Special Kids
- Elizabeth Hecht who serves as Outreach Specialist for Public Policy, Waismann Center, University Center for Excellence in Developmental Disabilities at the University of Wisconsin Questions and Answers



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WEBINAR OBJECTIVES

At the end of this webinar, participants will be able to:

- 1. Describe educational approaches to help families and professionals understand Supported Decision-Making as an alternative option to guardianship for transition-age youth.
- 2. Describe potential partners and stakeholders in getting the word out about Supported Decision-Making.

Here's the link to our first webinar: <u>http://familyvoices.org/resources/?sq=&f%5B%5D=supported-decision-making</u>.



Quality Trust for Individuals with Disabilities

- Independent advocacy and monitoring
- Dignity, respect, and autonomy
- Rights protection and decision-making supports
- Partnering with families
- Jenny Hatch Justice Project (2013 to present) <u>www.JennyHatchJusticeProject.org</u>
- National Resource Center for Supported Decision-Making (2014 to present)

www.SupportedDecisionMaking.org



New Resource: 2019 Self-Directed Care Calendar

The calendar focuses on personal medicine, a type of self-directed care that allows a person with a serious mental illness to obtain the resources they believe will best support them in achieving their recovery or treatment goals. These resources can include traditional mental health services and medications, or goods and services that focus on reducing stress and increasing engagement in personally meaningful activities. Each month in the Self-Directed Care Calendar features a goal to help users



Community Living and Participation of People with Serious Mental Illness (TU Collaborative) at Temple University has published the Maine Parent Federation Presents

Supported Decision-Making

In Collaboration with; Developmental Disability Council of Maine (DDC) Disability Rights Maine (DRM)

Agenda

- 10:00 AM Welcome & Introductions
- 10:30 AM Overview of the Pilot Program
 - Preworkshop survey, 1099 form, mileage form
- 10:45 AM Parent & Youth Breakout Sessions
 - ▶ 10:45 AM 12:00 PM
 - Parent Session Margaret Cardoza Self-Advocate
 - Youth Session Self-Advocacy Workshop Dylan Campbell MPF
- 12:00 PM 12:30 PM Lunch
- 12:30 PM 1:30 PM
 - Parent Session MPF & DRM Workshop w/activity
 - Youth Session MPF, DRM, Self-Advocates workshop w/activity
- 1:30 PM 1:45 PM Break
- 1:45 PM 2:45 PM Parent & Youth Reconvene SDM Agreement Work
- Next steps

Supported Decision-Making Understanding How it Works and Your Role as the Supporter



Important Terms to Understand

- Power of Attorney A person knowingly and voluntarily signs a legal document that identifies someone they trust to act for them.
- Representative Payee The Social Security Administration appoints someone to manage a person's Social Security benefit.
- Advanced Health Care Directives— A person has a family member or natural support who can make health care decisions that the person cannot make, even with support,
- **Guardianship** A legal process by which a court takes away the right and power of an individual to make decisions and enter into a legal relationship because they are deemed incapacitated.
- Supported Decision-Making A person with a disability makes their own decisions by using support networks to help understand the issues and choices, ask questions and receives answers in language they understand, and communicate their own decision to others.

"A series of relationships, practices, arrangements and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to other decisions about the individual's life." –Robert Dinerstein

This is what the actual slide looks like following this slide we provide a more detailed description of the service as well as how to obtain each service. We break out Full, Limited, and Temporary Guardianship. We have our Disability Rights Office give a detailed description of the complete Guardianship process and the new Probate Code.

Supported Decision-Making (SDM)

Throughout our lives, when faced with life choices, we have all used Supported Decision-Making by consulting a trusted friend, co-worker, family, neighbor, and professional. It is a natural human behavior to ask for help and everyone needs support when making decisions. So who can benefit from SDM?

- Anyone & Everyone!
- Individuals who want to be independent but need some formal assistance.

Very similar slide in the Youth Workshop.



3 Principles to Supported Decision-Making

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

This slide is included in both the parent and youth workshop.

Guardianship vs Supported Decision-Making

Guardianship	Supported Decision-Making
Protective Device	Presumes Capacity
Restrictive by Design – An individual's powers, rights, and authority are transferred to a surrogate- a process which "unpersons" an individual	Acknowledges other practical and legal options that can address challenges and needs
Should be used only as a last resort	Asks: what does an individual need to be supported in making decisions?
Most restrictive	Least restrictive alternative

What Does SDM Look Like?

- Way for individuals with disabilities retain independence but to get assistance making decisions,
- Assistance they receive will often times improve decision-making skills,
- Flexible and can change with the needs of the individual,
- Promotes independence,
- Improves quality of life,
- Can be used in many decision-making situations or arrangements.

For many individuals SDM may be the only tool they need to have trusted people provide support as the make their life decisions. It can be provided by one support person or with a team of support people. The supporters assist in making decisions but the individual with the disability always makes the final decision. The relationship between the individual and their supporters can be written in a Supported Decision-Making Agreement, it does not have to be a legal document.

Role of the Supporter

As the supporter it is important to understand and respect your role. You can provide information and resources but you are not the decision maker. The individual you are supporting is the decision maker and captain of their ship. A good supporter will;

- Be someone who agrees to **support** the individual.
- Be somebody the individual trusts and supports their independent living goals.
- Be someone who accepts and supports the individual, their family, and other SDM team members.
- Be someone who has knowledge of the specific areas you are providing support in.
- Although changes to the team can occur it is best if the supporter can support the individual for a long period of time.
- Be flexible in providing your support and suggestions.
- Be someone who understands that the individual is the decider and supports their decisions despite your own feelings.
- You do **NOT** have to be a family member, it can be anybody that meets the above guidelines.
- You do **NOT** have to be they only supporter, it can be a team of people.

Areas to Provide Support

It will be important for you as the supporter and the individual being provided support to have conversations around the areas where support is wanted. There maybe many different areas they may need support and they may request different support from different individuals. These will be very specific to each individual. Some examples are:

- Finances
- Physical Health
- Mental Health
- Legal Matters
- Services & Supports
- Work
- Independent and Community Living
- Independent and Community Housing
- Education
- Social & Recreational Activities
- Self-Care

Supported Decision-Making

How to create a supportive network and become empowered to make your own choices. Supported Decision-Making or SDM is a way you get help to make your own choices. You can choose family, friends, or staff who you want to help you make your choice.

Supporters are the people who will **help** you make your choice and you are the **decider** which means you make the final decision.

You can choose who will be your supporter, how many supporters you have, and what each supporter will assist you with. You are always able to change your mind and change your supporters.

Types of Support

- Plain-language information Providing you with written information in a way in which you can understand.
- Information Provided to Suit Your Needs Receiving information in the best way you are able to receive it including but not limited to; verbal communication or with pictures.
- Knowing Your Options Knowing all you're available choices for the specific situation you are navigating.
- Visits and Trials Trying out your different choices to see what fits best, talking to experts who know a lot about your choice before making a decision, and participating in classes about your choice.
- Reminders Setting up a reminder system in order to enable you to be the most successful with your choices.
- Pros versus Cons Making lists of the good, challenging, and even bad things which may come with the different choices you are considering.
- Meetings & Appointments A person who can provide assistance in preparing for meetings & appointments and to attend with you in person if you wish for that to occur.
- Extra Time Thinking about the timeline in which you have to make a decision and if it is appropriate, necessary, and allowed requesting additional time.
- Consider Values Remembering what is most important to you and how these values may affect your decision.
- Technology Using phones, I-pads, computers etc... to assist you with your choices and even after making your choice enabling you to carry out your choice such as reminders.
- Supporters Individuals who are able to assist you with decision making BUT you are always the decider.
- Communicating Choice After you have made a choice you may need assistance from individual to make sure your choice is communicated, understood, and respected.

The Supporter

- Someone who agrees to support you.
- Someone you trust and who is willing to support you in your independent living goals.
- Someone who accepts and supports you and your family.
- Someone who has knowledge of the specific area you are asking them to support you in.
- Someone who can support you for a long period of time. Although changes to the team can occur it is best if the supporter is long term.
- Someone who can be flexible in providing support and suggestions.
- Someone who understands that you are the decider, supports you in your decisions despite their own feelings.
- > They do **NOT** have to be a family member, it can be anybody that meets the above guidelines.
- > They do **NOT** have to be just one person, it can be a team of people.

Who Are My Supporters activity

When to be Supported

- It will be important for you to explore and consider many different areas you may or may not need support with. This will be very specific to individual. Some examples are:
 - ▶ Finances
 - Physical Health
 - Mental Health
 - Legal Matters
 - Services & Supports
 - Work
 - Independent and Community Living
 - Independent and Community Housing
 - Education
 - Social & Recreational Activities
 - Self-Care

When Do I Want Support Activity

484 Maine Ave.
Farmingdale Maine 04344
P – 207-588-1933
E – parentconnect@mpf.org
f https://www.facebook.com/maineparentfederation/

Maine Parent Federation Since 1984... because every family matters



Raising Special Kids Families Helping Families



Raising Special Kids Janna Murrell Assistant Executive Director

Mission

Strengthening families and systems of care to improve outcomes for children with disabilities.





Training Developed

In collaboration with Arizona's state DD agency, Raising Special Kids developed a training for parents, caregivers and professionals. These are the learning objectives that include exploring SDM.

- Define adult guardianship
- Explore less restrictive options to guardianship
- Support for families
- Provide resource information

Family Experience

- Many parents struggle with the gravity of these issues.
 - Balance between independence and protection
 - Concerns about continuity of care throughout their child's life span
- Difficult terminology
- Families make their own determination as to what is right for them.

Alternatives to Guardianship

• Families are encouraged to choose the least restrictive option(s) regarding guardianship and managing an individual's rights to their life decisions.



Power of Attorney

Power of Attorney must be given by **informed consent.**

- Durable General(Financial) Power of Attorney
- Durable Health Care Power of Attorney
- Mental Healthcare Power of Attorney



What is Supported Decision Making?

- Supported Decision-Making (SDM) where older adults and people with disabilities use trusted friends, family members, or professionals to help them understand the situations and choices they face so they can make their own decisions and direct their own lives.
- http://www.supporteddecisionmaking.org/

Supported Decision Making Advisory Committee – Arizona

- Year One Supported Decision-Making Grant Activities
- Identify issues people with IDD and families face
- Survey stakeholders about guardianship and supported decision-making
 - survey for people with IDD, families, and caretakers
 - survey for service providers, legal and medical stakeholders
- Write white paper on results of survey and advisory committee identified issues.
- Create Project Strategic Plan
- Create Curriculum training for people with IDD, families, and supports and evaluations
- Create continued legal education curriculum and evaluation
- Create curriculum for social service providers and medical stakeholders and evaluation
- Draft proposed legislation on supported decision-making



Home Resource Library Learn Engage News About Us

Each Family Has a Voice

Together, our voices will be heard

JOIN GIVE



Considerations for Supported Decision Making: A Multi-Level Approach

LIZ HECHT

FAMILY VOICES OF WISCONSIN

IN COLLABORATION WITH UW - WAISMAN CENTER, UCEDD





Family Voices of Wisconsin

- Professional Education
- Family Education
- Systems Change Partnerships
- State Law





Professional Education

- General Pediatrics and Adolescent Health
- Specialty clinics
- Family Medicine medical resident community rotation
- Vocational Rehabilitation Counselors-PROMISE grant





Family Education

 Training - <u>When Young Adults Turn 18 –</u> <u>Considerations for Supported Decision</u> <u>Making</u>

- Decision-making is a learned skill
- What is supported decision-making?
- Decision-making tools
- Guardianship





Resources

- Family Voices of Wisconsin fact sheet: Supported Decision Making for Transition Age Youth
- National Resource Center for Supported Decision Making
- <u>Got Transition-Guardianship and Alternatives for Decision</u> <u>Making Support</u>
- Wisconsin Guardianship Support Center
- WI DHS <u>Advance Directives Forms</u>
- WI DHS <u>Supported Decision-Making Agreements Form</u>





Systems Change Partnerships

WINGS –Wisconsin Interdisciplinary
 Network of Guardianship Stakeholders 2015
 Seed money from the National Guardianship Network for state courts to partner with community stakeholders

 Community of Practice on Supported
 Decision-Making established with aging and disability advocates





Supported Decision-Making Agreements Law

<u>Supported Decision-Making Agreements law</u> passed in 2018

Wisconsin Law formally recognizes <u>Supported Decision-Making Agreements</u> as legal arrangements that allow persons to retain their right to make their own decisions, while also choosing trusted people (called Supporters) to help them gather and understand information, compare options, and communicate their decisions to others.

Board for People with DD Resources





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From our June 2018 Webinar: More resources shared by individuals in the Family Voices Network *Note that Family Voices and Quality Trust will be creating a database of SDM materials in the near future. Look for more information to follow!*

Recommended by Family Voices Indiana by Jennifer Akers:

- Guardianship Rights, Risks & Responsibilities (VIDEO)
- <u>Supported Decision Making Family Fact Sheet from</u> <u>WINGS</u>
- Supported Decision Making: An Introduction to an Alternative Guardianship PowerPoint
- <u>Supported Decision Making Support Table</u> Recommended by Missouri Family to Family:
- <u>Alternatives to Guardianship</u>
- <u>Charting the LifeCourse</u>
- <u>Charting the LifeCourse Integrated Supports Cheat</u> <u>Sheets</u>
- Missouri F2F's Resource Page

Recommended, shared by Tamara Bakewell:

ACLU Supported Decision Making Library

Recommended by Wisconsin's Waisman Center, Liz Hecht:

- Factsheet on Supported Decision Making from Wisconsin F2F
- Supported Decision Making Presentation from the Waisman Center
- Supported Decision Making Webinar
 - <u>Recording</u>
 - <u>Slides</u>
 - Supported Decision Making Agreement
- <u>2017 Wisconsin Act 345</u>



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Thank You!

Before you go.... Please fill out the short one minute survey below!

https://www.surveymonkey.com/r/WebinarFeedbackSDMBuildingPartnershipsandEducatingFamiliesandProfessionals

