



Maine Parent Federation Presents

Supported Decision-Making

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

Overview

- ▶ Pilot Program is in Response to:
 - ▶ Maine's new Probate Code for Guardianship, and
 - ▶ Feedback from families as their youth approach age of majority they were feeling pressured to gain full guardianship from schools and providers.
- ▶ Funding was provided by a grant from Maine's Developmental Disabilities Council:
 - ▶ Two year grant period, and,
 - ▶ Total of \$20,000 in funding which finances:
 - ▶ Stipends of \$100, mileage reimbursement, accommodations, and lunch at trainings for family participation,
 - ▶ Resources for trainings, and
 - ▶ Staff time.

Changes to Maine's Probate Code Effective July 1, 2019

- ▶ Maine Legislature repealed and replaced the entire probate code, which has been largely unchanged since the 1970's
- ▶ New Standard: Instead of "incapacitated individual" - The individual "lacks the ability to meet essential requirements for physical health, safety or self-care because" he/she:
 - ❖ "is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive service, technological assistance or **Supported Decision-Making;**"
 - ❖ "identified needs cannot be met by a protective arrangement instead of guardianship or **other less restrictive alternatives;**..."
- Less restrictive alternative is now defined as SDM, appropriate technological assistance, appointment of an agent by the individual, including appointment under a power of attorney for health care or power of attorney for finances, or appointment of a representative payee. Now all must be considered and ruled out during the three key stages of guardianship proceedings: petition, visitor's report, and court order.

First Year

- ▶ First Year has included;
 - ▶ Development and implementation of two full day family trainings,
 - ▶ Education about the changes to Maine's Probate Code,
 - ▶ All Guardianship options and other least restrictive options to guardianship available to families,
 - ▶ Assistance drafting a Supported Decision-Making (SDM) Plan, and
 - ▶ When appropriate assistance developing school IEP transition plans.

Second Year Will Include...

- ▶ Continuing our work with first year families and offering our full day workshops to new families,
- ▶ Implementation of SDM information into our Family Support Navigator program (MPF's peer to peer) which will include:
 - ▶ Education and access to SDM information and resources,
 - ▶ Development of SDM draft plan, and
 - ▶ When appropriate support with developing IEP transition plans.
- ▶ Development of a two hour training for parents and youth,
- ▶ Development of live and recorded online webinars,
- ▶ Development of written materials such as brochures and informational packets, and
- ▶ Outreach to schools and providers about our new programming for families.

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



Sample 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

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

Supported Decision-Making (SDM)

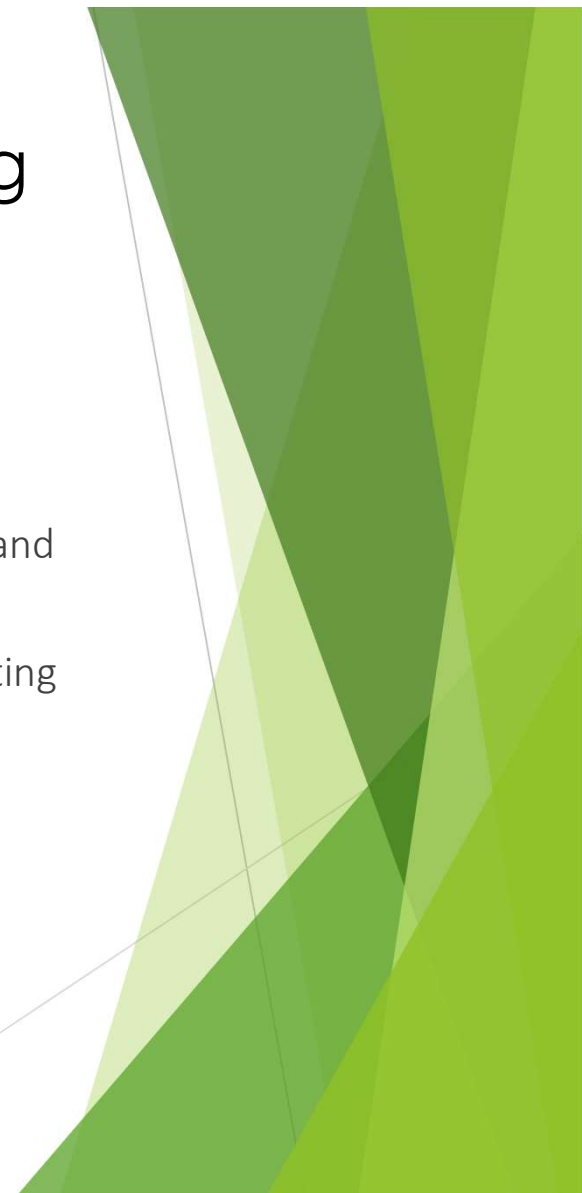
Throughout our lives, when faced with life choices, we have all used Supported Decision-Making by consulting a trusted friend, co-worker, family, neighbor, and professional. It is a natural human behavior to ask for help and everyone needs support when making decisions. So who can benefit from SDM?

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



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.



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

Adult Activity

In groups of 3 or 4 identify who will play the role of a young adult, a family member, a support person, and a financial agent/medical advisor.

Situation to discuss:

The young adult has decided to get a tattoo but has not followed through on this decision. They have come to their SDM team to determine what is needed to get a tattoo.

One support person will assume the position that a tattoo violates their values and beliefs. With this in mind proceed in having a discussion with the young adult as members of their SDM team.



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 they 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 may be 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.

Youth Breakout Agenda

- ▶ Morning Session is Self-Advocacy workshop with Youth Coordinator (included in handouts),
- ▶ Lunch with peers and parents,
- ▶ Afternoon Session includes;
 - ▶ Activity with Self-Advocate - which we will do in a few minutes,
 - ▶ Activities to identify (included in handouts):
 - ▶ Types of support,
 - ▶ Areas of support,
 - ▶ Who will provide support, and then we bring it together with
 - ▶ What type of support you would like for different situations and from whom.

Youth Activity

Clue game meeting in April to figure out the details.

Emphasize this activity first gives the youth a break and an opportunity to socialize, second that in doing this activity they are using each other as support to make decisions to solve the problems, it highlights the strengths of individuals to assist in making a decision where the strength exists, and emphasizes the need to use support even when playing a game and therefore asking for assistance is something that we all need to do to lead independent lives.



How Can SDM Work for You?

- ▶ 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 (provided in handouts)

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 (included in handouts)





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