



Maine Parent Federation Presents

Supported Decision-Making

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

Disability Rights Maine (DRM)

WIFI Connection: Cohen Guest Password: SpecGen01

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

Overview

- Pilot Program is in Response to:
 - New Probate Code for Guardianship, and
 - Feedback from families as youth approach age of majority and feeling pressure to gain full guardianship.
- What to expect
 - Education about Probate Code,
 - Options available to your family,
 - Two trainings,
 - One to one Peer Support,
 - Draft Supported Decision-Making Plan, and
 - Financial stipend and mileage.
- Questions?

Rules

- No idea is a bad idea,
- Be creative,
- Take risks,
- Ask questions, and
- No criticism allowed.

Parental Morning Breakout Session

Margaret Cardoza Self-Advocate
Supported Decision-Making Model



Supported Decision-Making

Understanding How it Works
and Your Role as the Supporter



Educational Purposes

This material is presented for educational purposes only. It is not and does not take the place of legal advice in any specific situation nor is it offered as such by the author and speaker. The material is intended to be timely as of the date written and/or originally presented. Due to the rapidly changing nature of the law, information contained in these materials or presented by the speaker may become outdated. It is the responsibility of any individual using or relying on these materials to confirm their timelines.

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

Power of Attorney



Signing a Power of Attorney does not mean the individual is giving up their rights to make financial, property, health, or any other of their own decisions. As long as they are willing and able they can make their own decisions. Power of Attorney means that someone else **can** make a decision if they are asked by the individual or if the individual is unable to.

If the individual identified as a Power of Attorney (agent) does start handling the individuals affairs, they must do so in the way the individual wants. As long as they are capable of making decisions, the agent must follow their directions. The law says that the agent must do what is in the individuals best interests.

A Power of Attorney can be revoked at any time if the individual becomes unhappy with what the agent is doing so long as they still have capacity, meaning they understand what they are doing.

Power of Attorney cont...

It is recommended an attorney assists in drafting a Power of Attorney. It is not recommended to use a pre-printed form from an office supply store, a library, or the internet. Some of these forms are not legal in Maine and even if the form is legal, it may not give the best legal protections.

Most pre-printed forms give agents the broadest possible authority with few limits. Using an attorney to draft a Power of Attorney will assure that protections are included to avoid or reduce this risk.

It can be used during an interim period while waiting for other arrangements to become legal, such as guardianship.

Representative Payee



A Representative Payee is a person or an organization who must be appointed by the Social Security Administration to use the Social Security benefits to pay for the current and future needs of the beneficiary, and properly save any benefits not needed to meet current needs.

Being an authorized representative, having power of attorney, or a joint bank account with the beneficiary is not the same as a representative payee and does not give legal authority to negotiate or manage Social Security benefits. Even if you are appointed full guardian you will need to have an appointed representative payee through the Social Security office.

You can apply to be a Representative Payee at your nearest Social Security office. The application you must fill out is called a SSA-11 form (request to be selected as payee), you usually need to fill it out in person, and you need to bring documents to prove your identity as well as your Social Security number.

Duties of a Representative Payee

- Determine the beneficiary's needs and use his or her payments to meet those needs;
- Save any money left after meeting the beneficiary's current needs in an interest bearing account or savings bonds for the beneficiary's future needs;
- Report any changes or events which could affect the beneficiary's eligibility for payments;
- Keep records of all payments received and how you spent and saved them;
- Provide all records of how payments are spent or saved to SSA upon request;
- Report to SSA any changes that would affect your performance or your continuing as payee;
- Complete written reports accounting for your use of payments, as required;
- Return to SSA any payments to which the beneficiary is not entitled; and
- Return to SSA any payments saved when you are no longer the representative payee for the beneficiary.

Advance Healthcare Directive

An advance healthcare directive, also known as living will, personal directive, advance directive, medical directive or advance decision, is a legal document in which a person specifies what actions are to be taken if they are no longer able to make decisions for themselves because of illness or incapacity.

In Maine it is referred to as Life Sustaining Treatment Choices and in order to obtain a Maine Directive you need to fill out the Maine Advance Directive Form.

https://www.everplans.com/sites/default/files/Maine_Advance_Directive_Form.pdf

The Advance Directive form must be signed and dated by yourself as well as two witnesses at the same time you sign it. Tell others about your decisions and give copies to your physician, other health care providers, family and hospital.



Guardianship

Under the current law, the 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 and appoints this power to another person, the Guardian. This decision can be made at the age of majority, 18, when a youth becomes an adult or anytime after.

Obtaining guardianship is a very serious step to take as it significantly restricts a person's individual rights and freedoms. It should be considered only after all other alternatives have been explored. The decision as to whether a guardian is necessary will be made by a Probate Court.



Types of Guardianship

Full Guardianship – The most restrictive form of Guardianship which removes all legal rights. Under current law, a full guardianship takes away the right to make decisions about health, money, education, work, where to live, **with whom to associate**, marriage, and making contracts of any kind.

Limited Guardianship - Some people are able to make responsible decisions in some but not all areas of their lives. In such situations, a guardianship will/can be limited by the Probate Court to only those areas in which the person does not have the capacity to make responsible decisions.

For example: A guardianship could be limited to providing consent for medical treatment.

The law requires that guardian help the person subject to guardianship stay as independent and self-reliant as possible, limited guardianship is preferable to full guardianship.

Types of Guardianship cont...

Temporary Guardianship - A temporary guardian may be appointed without a hearing by the Probate Court for the following reasons:

In emergencies to prevent serious, immediate and irreparable harm to the health or financial interests of the incapacitated adult when there is no other person who appears to have the authority to act in the circumstances.

The Probate Court may act as the guardian or may appoint a temporary guardian immediately to deal with the emergency;

or

When the already appointed guardian is not effectively performing his or her duties and immediate action is necessary.

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

How Did We Get Here?

Internationally as a Consequence of WWII and the Holocaust

- Creation of the United Nations (1946)
- Universal Declaration of Human Rights (1948)
- Human rights are defined as: inalienable, indivisible, interrelated, intra-dependent, they exist by virtue of being born human
- Human rights are based on equality, non-discrimination, and *dignity*

How Did We Get Here cont...

In ME

- 1880's to 1970's institutionalization, Pineland, Augusta Mental Health Institution, Bangor Mental Health Institution 1970's to present, guardianship
- 1970's to present, guardianship
- 2015 Maine Supported Decision-Making Coalition Formed to Bring SDM to Maine and DRM receives grant from the National Supported Decision-Making Technical Resource Center
- 2016 OCFS includes SDM in its Guide to Transition Services in Maine and Supportmydecision.org launched
- Maine's First SDM Pilot Project (2016/2017)
- 2017 Maine Probate Trust Law Commission recommends inclusion of SDM in the Probate Code

Maine's Current Probate Code

- All laws involving Guardianship are part of the probate code and all appointments are made by a probate judge which can be found within every county in Maine,
- Currently (this standard will change July, 2019) to be appointed guardian the individual needs to be deemed "incapacitated",
- An "incapacitated person" lacks sufficient understanding or capacity to make or communicate responsible decisions concerning their person.



Maine's New 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: 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 decision, 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**;"

New Emphasis on Less Restrictive Alternatives to Guardianship

- "'Less restrictive alternative' means an approach to meeting an individual's needs that restricts fewer rights than would the appointment of a guardian or conservator. 'Less restrictive alternative' includes supported decision making, 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.
- Must be considered and ruled out during three key stages of guardianship proceeding: petition, visitor's report, and court order

1. Petition

A brief written description providing the reasoning a guardian is necessary which includes;

- a) Nature and extent of individual's need,
- b) Any less restrictive arrangements and/or alternatives (such as Supported Decision-Making) instead of guardianship which have been considered or implemented,
- c) If no less restrictive arrangements and or alternatives have been implemented or considered reasoning as to why, and
- d) The reason why less restrictive arrangements or alternatives would be insufficient to meet the individual's need.

2. Visitor's Report

Once guardianship paperwork has been filed the court will appoint an individual to visit with the individual's filing to be guardian and the individual with whom they are filing on behalf of and write a report which must include;

- Recommendations regarding the appropriateness of guardianship,
- Whether a protective order or other less restrictive alternatives are available to meet the individual's needs,
- If guardianship is recommended whether it should be full or limited and if limited what powers would be granted to the guardian.

3. Court Order

The basis for guardianship appointment is made through a court order and includes;

1. Choosing a guardian/conservator for the individual who is an adult if it has clear and convincing evidence that the individual lacks the ability to meet essential requirements for physical health, safety or self-care because;
 - a) Even with appropriate supportive services, technological assistance, or Supported Decision-Making the individual is unable to receive, evaluate, make, and/or communicate decisions,
 - b) The individual's needs cannot be met with a protective arrangement or other less restrictive alternatives, and,
 - c) The appointment is necessary or desirable in order to enable the individual to meet needs for physical health, safety, or self-care.
2. Choose a protective arrangement or less restrictive alternative instead of guardianship or dismiss the proceeding.

3. Court Order cont...

3. Establish only those powers to the guardian which are deemed necessary to address the demonstrated limitations and needs of the individual.

This will also encourage the development of the individual's maximum self-determination and independence.

A full guardianship may not be established if a limited guardianship, protective arrangement instead of guardianship, or other less restrictive alternatives would meet the needs of the individual.

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.

Self-Determination

Supported Decision-Making is a fundamental part of Self-Determination which allows individuals to assume greater responsibility and control. Individuals who are self-determined are better able to:

- Appreciate strengths while acknowledging their limitations
- Set challenging yet realistic goals for themselves,
- Create plans to achieve their goals,
- Make appropriate choices and decisions,
- Accept responsibility for their choices,
- Develop problem solving skills,
- Advocate for themselves,
- Achieve their goals



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

Questions to Explore

1. What types of support does the Individual need to make the best decision for themselves?
2. Where/with whom can the Individual get those supports?

Activity

Adapted Activity "When do I want Support Worksheet" ACLU SDM guide

Youth Re-join

Family work youth present "When do I want Support Worksheet"

Families review SDM templates and begin a foundation.

End of day survey.

Next Steps

- 1) Families assigned to MPF staff member for peer to peer support.
 - Work will include continued SDM draft plan.
 - Support with transition IEP meetings to inform the school about SDM and how they may support the individual.
- 2) Second full day workshop.



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