

SUPPORTED DECISION-MAKING

WEST VIRGINIA

EMPOWERED & ABLE!

TOOLKIT

A Project of Astrive Advocacy, Inc. Funded by the WV Developmental Disabilities Council

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What Is Supported Decision-Making?

Supported decision making (SDM) is a tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. A person using Supported Decision-Making selects trusted advisors, such as friends, family members, or professionals, to serve as supporters. The supporters agree to help the person with a disability understand, consider, and communicate decisions, giving the person with a disability the tools to make her own, informed, decisions.¹

SUPPORTED DECISION-MAKING CAN HELP PEOPLE²

- Understand information, issues, and choices;
- Focus attention in decision-making;
- Weigh options;
- Ensure that decisions are based on their own preferences
- Interpret and/or communicate decisions to other parties.

“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”³

Supported decision making is an alternative to guardianship through which people use friends, family members and professionals to help them understand situations and choices they face, so they may make their own decisions without the “need” for guardianship. It is an emerging approach to providing decision-making assistance without imposing any long-term legal limitations on rights or personal liberties.⁴

Supported Decision-Making, as an approach to guardianship, has its foundation in the *United Nations Convention on the Rights of Persons with Disabilities*. Its core principles are that:

- ⊙ **Every person can express their will and preference**
- ⊙ **A person with disability has the right to make decisions**
- ⊙ **A person with disability can expect to have access to appropriate support to make decisions**



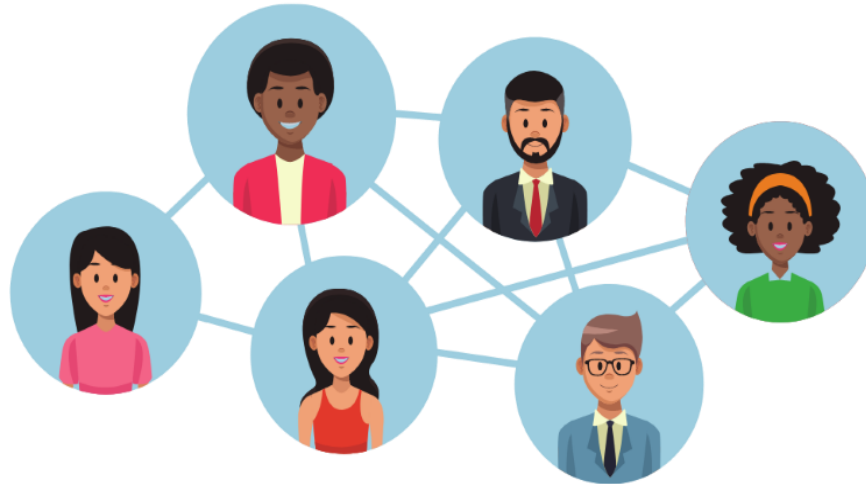
¹ SA Health, Policy and Commissioning Division, Department for Health and Ageing, Government of South Australia. FIS: 14062.4K June 2014.

² Salzmann, 2011

³ Blanck & Martinis, 2015

⁴ Blanck & Martinis, 2015

Why Is Supported Decision-Making Important?



SUPPORTED DECISION-MAKING IS EMPOWERING ⁵:

- By using Supported Decision-Making, the individual retains his or her legal rights
- Supported Decision-Making increases self-esteem, self-worth
- Supported Decision-Making allows for personal growth and experiences
- Supported Decision-Making reduces stigma
- Using Supported Decision-Making means that individuals with disabilities are viewed as more capable of contributing to society because they are in charge of their own lives

- ⊙ **People with disabilities face long-standing biases about perceived abilities**, including decision-making; but most people can make at least some decisions about their lives.⁶
- ⊙ **Decision-making is a learned skill that requires encouragement and practice.** Let's give a person a chance to learn how to make decisions before taking rights away.⁷

- ⊙ **Research shows us that maximizing choice and control (self-determination) in a person's life increases positive outcomes in health, happiness, and safety** through stronger relationships and better ability to recognize and resist abuse. Having more than one supporter provides a check against abuse or manipulation by any one supporter.⁸

PEOPLE WITH AN INTELLECTUAL DISABILITY SAY

- ▶ We want to have our voice heard and acknowledged
- ▶ We want to be accepted for who we are
- ▶ We want to make our own decisions
- ▶ We want to be asked for our view and opinion on things
- ▶ We want to be treated the same as other people
- ▶ We want to have the same rights and opportunity to do things, with support only when needed

Independent But Not Alone, 2014

⁵ www.supporteddecisions.org/about-supported-decision-making/frequently-asked-questions/

⁶ Lauren Pearcy, TN Council on Developmental Disabilities

⁷ Lauren Pearcy, TN Council on Developmental Disabilities

⁸ Lauren Pearcy, TN Council on Developmental Disabilities

Supported Decision-Making vs. Guardianship

Guardianship is a legal process to determine if a person is “incapacitated.” The court decides if, due to a physical or mental condition, the individual is substantially unable to manage their financial affairs or personal affairs (to provide food, clothing, or shelter for themselves, and to care for their physical health). Under a guardianship, someone is appointed to make decisions on behalf of the incapacitated person, referred to as the “ward.”⁹ There are two main types of guardianships:

1. Guardian of the Person: Responsible for the physical well-being of the ward, including making medical decisions and choosing residence
2. Guardian of the Estate: Responsible for the ward’s assets

SUPPORTED DECISION-MAKING ¹⁰	GUARDIANSHIP ¹¹
<ul style="list-style-type: none"> ⊙ Identify, support individual competencies ⊙ Person keeps rights ⊙ Identify person’s choices and preferences ⊙ Rely on committed, trustworthy relationship ⊙ Person chooses who provides support 	<ul style="list-style-type: none"> ⊙ Label person as “incompetent” ⊙ Strip away rights ⊙ Substitute guardian’s “best interest” decision ⊙ Often a professional paid to provide service ⊙ Court chooses the Guardian

Under a full guardianship of the person, an individual loses many rights, including the right to drive, choose where to live and work, vote, get married, consent to medical treatment, and more. All people need and use support to make important life decisions. Even if a person with a disability needs extra help to make significant life decisions, their right to make their own choices should not automatically be taken away.

Guardianship is not the only option if someone needs help making life decisions. There are many other options available that vary in how formal and how involved others need to be. Each person’s abilities and needs should determine the option(s) that are the most appropriate to provide the maximum opportunity for self-determination.¹²

Should a substitute decision-maker be needed, decision-making authority should only be granted to someone trustworthy, as exploitation is always a possibility when an individual is given authority to make decisions on behalf of someone else.



⁹ *Alternatives to Guardianship*, 2016, The Arc of Texas

¹⁰ *Contrasting Approaches*, David Lord, Disability Rights Washington; Diana Zottman, Washington State Developmental Disabilities Council

¹¹ *Contrasting Approaches*, David Lord, Disability Rights Washington; Diana Zottman, Washington State Developmental Disabilities Council

¹² *Options for Supporting Decision-Making and Independence* - Indiana Disability Rights.org

Decision-Making Skills

The National Guardianship Association, "Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making" (2015) States:

"Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings."



KEY DECISION-MAKING CONSIDERATIONS¹³

- Decision-making is not a one size fits all model. We all make decisions differently because we are all individuals with specific desires and goals.
- We all require outside support at some point during the decision-making process. (Ex: consulting a mechanic about a car repair, consulting friends about choosing a school, consulting with your family about where to live, etc.)
- Much like any other skill, decision-making can be practiced and learned.
- If your disability makes it difficult to access certain parts of decision-making, you have the right to be accommodated.
- Guardianship strips people of their civil rights and removes them from their own decision-making process.
- Overbroad and undue guardianships are linked with decreased physical and mental health, longevity, ability to function, and reports of subjective well-being.

A person's decision making capacity must be assumed unless there is evidence to the contrary.

The factors that should be taken into account when considering if a person has decision making capacity include whether or not a person can:

- Understanding any information that may be relevant to the decision, including the consequences retaining such information, even for a short time
- Using information to make decisions
- Communicating the decision (in any way)

¹³ Supported Decision-Making Fact Sheet, Disability Rights Maine

Supported Decision-Making: How To Do It

People often question how to actually “do” Supported Decision-Making and ask for step by step guides to explain to them how supported decision-making is done. Understanding and agreeing with the ideas behind supported decision-making is one thing, but actually following the steps is really not as complicated as it may sound.

- ① **Start the Conversation**
- ② **Identify and Select Supporters**
- ③ **Determine the Plan**
- ④ **Write and Sign Agreement**
- ⑤ **Let Others Know the Plan**

Many families, support staff, other advocates, and professionals are already engaged in supported decision-making without realizing that they are by helping a person make his or her own choices by providing help and guidance.

However, although many families and support workers are already using supported decision-making, formalizing Supported Decision-Making agreements can help ensure that the choices of people with disabilities are heard and respected.

People with disabilities may find that doctors, nurses, bankers, teachers, or lawyers do not believe that the person with a disability is “capable” of making their own decisions and will tell families that they must get a conservatorship or guardianship before procedures, participation in meetings, or entering into contracts or purchases.

Supported Decision-Making agreements would allow a person with a disability to present their agreement in a situation like this to serve as documentation that the person is able to make his own choices and that they are informed and supported, even if there are consequences to the action.¹⁴

DIGNITY OF RISK:

Even if someone receives decision-making assistance, that person must have the final say over the decisions that are made, and he or she must ultimately be allowed to face the consequences of his/her decisions.

“To deny the right to make choices in an effort to protect the person with disabilities from risk is to diminish their human dignity.”

-Robert Perske

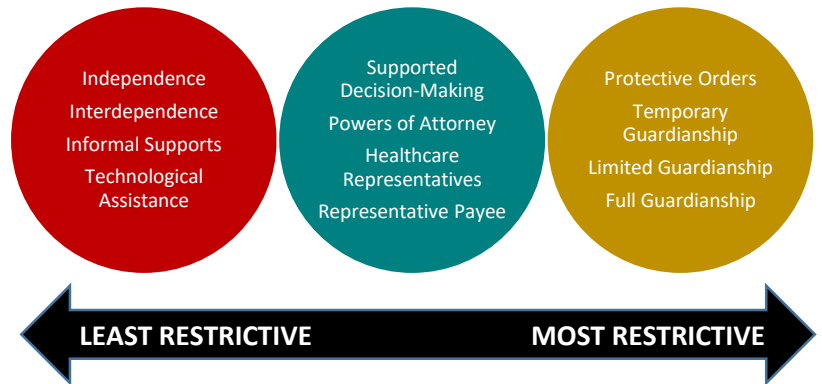


¹⁴ “The Dignity of Risk”, Robert Perske, 1972

Supporting A Person To Make Decisions

In today's society, individuals with disabilities are supported in different ways with varying levels of involvement from supporters. It should always be the goal of anyone who is identified as a supporter in the person's life, to strive for the least restrictive option and to always utilize informal supports and person-centered planning to the maximum degree possible.

Person-centered planning is an ongoing process where a person and a group of people who care about the person come together. This team meets to focus on the person's vision for the future and helps identify ways for the person to develop relationships, participate in the community, increase control over their life, and develop the skills and abilities needed to achieve these goals. The team takes action to make sure that the strategies are implemented.¹⁵



Under a supported decision-making agreement, the person-centered model is formalized through an agreement, with the supporter only being allowed to assist the individual with whatever is specified in the agreement. The supporter:

- ⊙ helps the individual gather and obtain information relevant to the options and their decisions
- ⊙ helps the individual understand the options, responsibilities, and consequences of their decisions so that information can be used to make an informed decision, and
- ⊙ assists the person with a disability in communicating the decision to the necessary third parties.

WHO SELECTS THE SUPPORTER?

In Supported Decision-Making, persons with a disability, including those with limited or declining capacity, select individuals whom they trust to support their decision-making. The supporters may be known as supporters, advisors, partners, or agents.

The person chooses their own Supporter(s). Supporters can be friends, family members, co-workers, colleagues, people with professional expertise, or others within the person's trusted network of support.



¹⁵ Decision-Making: Planning & Supports, DC Quality Trust, www.dcqualitytrust.org

Supported Decision-Making Tools/Alternatives

The supporter merely assists the individual with a disability in a decision and **cannot** make a decision for a person with a disability. Assistance may require the supporter to find tools and supports to help a person with a disability understand, make, and communicate their own choices. Examples of these tools might be:

- ⊙ developing or accessing plain language materials or information in visual or audio form
- ⊙ allowing extra time to discuss choices
- ⊙ creating lists of pros and cons
- ⊙ role-playing activities to help the person understand choices
- ⊙ using assistive, accessible, and reliable technology
- ⊙ attending important appointments to take notes and help the person remember and discuss her options
- ⊙ utilizing visits and trials to determine best choice

Supports, Tools, Assistance Available To All Through Community, Governmental, or Personal Resources

INFORMAL:

- Family and Friends
- Circles of Support
- Advocacy Agencies
- Faith-Based Entities
- Non-Profit Organizations

Additionally, before planning to establish one of these options, it is strongly recommended to seek input from trusted individuals that are familiar with the needs and abilities of the person. This can include current or former teachers, medical providers, support team members, friends and family, and others.

The person should be supported and encouraged to have as much self-determination as possible and to use the least restrictive options available to provide support.

MEDICAL/HEALTHCARE:

- Pill timers, alarms, or other reminders
- Transportation to medical / other appointments
- Prescription drug deliveries
- Medical Power of Attorney
- Release of information agreements
- Advance Directives/Living Will
- Surrogate decision making
- Healthcare Proxy

FINANCES:

- Joint bank accounts or two-signature checks
- Authorization of a specific banking transaction
- Trusts (Supplemental/Special Needs)
- Representative Payee (SSI/SSDI benefits)
- ABLE Account
- Bill Pay services
- Personal Banker
- Credit Card Opt-Out Services
- Release of Information Agreements

HOME:

- Food deliveries services
- Meals on Wheels
- Home visitors and "Pets on Wheels"
- Service animals
- Home sharing/roommate
- Home and Community-based Services/Waivers
- Community-based volunteer programs
- Protective Orders
- Case management/supports coordination
- Respite care programs

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