

Supporting Individuals to Live Full Lives



**Keeping
Individuals
with Disabilities
in Charge of Their Lives**



**Information for Idahoans
with Disabilities and
Their Families**

**SUPPORTED DECISION-MAKING
AND GUARDIANSHIP ALTERNATIVES**

This guide provides important information about empowering individuals with disabilities to make informed decisions about their life that protect both their rights while ensuring their safety and privacy.

Supported Decision-Making is a set of strategies that help individuals with disabilities have more control over their life and future. It involves family and friends' working together with individuals to support them in making complex decisions.

This guide is for: family members and friends who support individuals with disabilities; legal and education professionals; and service providers, including guardians or other supporters who work with people with disabilities.

Let's create better supports so people with disabilities can lead more independent lives!



“

Instead of guardianship of our daughter, we chose Powers of Attorney in the areas of medical and financial. These were much easier to obtain and didn't require going to court and having a judge tell her she would no longer make her own decisions. So far, these legal documents have been just as effective as having the guardianship.

—Parent

”

Self-Determination

Being able to make choices about your life is crucial for the independence and happiness of all people, including those with disabilities. Decision-making is a skill, and everyone needs practice. Just like all of us, people with disabilities continue to grow and gain experience throughout their lives. Regularly involving young people with disabilities in decision-making results in adults who are able to make informed decisions and direct their own lives.

Everyone has the right to make decisions about their own lives.

Did you know that being able to make your own decisions leads to a higher quality of life? Studies show that people with disabilities who have more control of their lives and are more self-determined are:

- Healthier
- More independent
- More likely to be employed at a higher-paying job
- Better able to avoid and resist abuse

When individual with disabilities are less able to make their own choices, they are more likely to feel helpless, hopeless, passive, and are at greater risk of abuse.



Khemka, Hickson & Reynolds, 2005; Wehmeyer, Kelchner & Reynolds, 1996; Wehmeyer & Schwartz, 1998. Deci. "Intrinsic Motivation," 208, 1975.

Choice

People with intellectual disabilities who have more opportunities to make choices make better decisions. The more someone makes their own decisions, the better they can learn new skills, including problem-solving, goal-setting, and taking more responsibility. According to the 2010 Department of Health Services Handbook, *Guardianship of Adults*, “We all learn by making mistakes. If a person is denied the right to take risks, he or she is also denied the opportunity to learn and grow.”

Making mistakes prepares us for future decision-making. There is dignity in being able to both succeed and fail, and to learn from our failures.

**We all make mistakes.
Mistakes help people learn.**

All people, including those with disabilities:

- Have the right to make decisions about things that affect their life.
- Can learn new skills to be more independent over time when they have the right supports.
- Have the right to choose:
 - Who will provide their decision-making support,
 - What types of decisions they want support to make, and
 - How this support will be provided.



Learning is a lifelong process and does not end at age 18. People with disabilities can learn new skills to increase their independence throughout their lives.

Supported Decision-Making

Supported Decision-Making recognizes a person's abilities as well as their limitations

Supported Decision-Making is an alternative to guardianship through which people with disabilities get help from trusted family members, friends and professionals to help them understand the situations and choices they face, so they can make their own decisions. Supported Decision-Making enables people with disabilities to ask for support where and when they need it. Powers of attorney, representative payees and simple release of information forms can also help families provide the needed supports and safeguards without going to court and imposing guardianship restrictions.

Supported Decision-Making helps individuals with disabilities learn how to make decisions about their lives. They choose the people they trust to help them understand complex information and make informed decisions about their medical, legal, financial, and other life matters. It's how most people make decisions.

When entering into a Supported Decision-Making agreement, those who can provide help in making decisions are called Supporters. Supporters agree to help explain information, answer questions, weigh options, and let others know about decisions that are made. They do not make decisions

The Role of a Supporter:

A Supporter is available to help when needed. The individual with a disability chooses who they would like to support them, and determines when and for what reason they would like the assistance of a Supporter.

A Supporter can:

- Help read complicated documents and explain their meaning.
- Attend meetings and help share questions or concerns.
- Help communicate the person's decisions and preferences to other.

Supported Decision-Making Agreements:

A Supported Decision-Making agreement includes a list of decisions the person with a disability wants assistance in making and identifies Supporters they trust to help them. Individuals and supporters can use existing sample Supported Decision-Making agreements or create a new one, making sure the following elements are included:

- Name and contact information,
- Why or what role the supporter plays,
 - Example: A supporter helps understand and figure out complex medical information
- Specific information about what the supporter will do,
 - Example: Education supporter: help decide what classes to take, etc...)
- Signature area for the individual and supporters.

**Sample documents can be found at
www.mychoicematters.idaho.gov**



Planning for the Future Using Supported Decision-Making

Supported Decision-Making does not require one individual to take on full Supporter responsibility. Multiple family members can be Supporters, increasing the breadth of the support network and making transitions easier as family members age and roles change.

Supported Decision-Making can be an important part of the person-centered planning process, which focuses on outcomes driven by the individual and implemented through the support of family, trusted allies and professionals of the individual's choosing to achieve those outcomes.

Inviting Supporters to person-centered planning can help the discussion focused on the individual's talents, gifts, and dreams for the future.

**We all want to improve our lives,
not just maintain them.**

Person-centered planning and Supported Decision-Making can:

- Help an individual with a disability share their hopes and dreams for the future and identify goals to improve quality of life
- Identify strategies and opportunities to help achieve a goal.

“

We wanted our son to have the chance to grow and learn to make decisions that affect his life. As his parents, we won't always be around to guide him, and we didn't want to restrict his life and future happiness. So, we chose not to pursue guardianship and instead to develop a circle of supporters to help him make those big decisions in life.

—Parent

”

Facts about Guardianship

While guardianship is often considered to be a way to keep people safe, it is the most restrictive option a family can choose. It can strip away all or most civil rights and has not been proven to make people safer.

Guardianship can take away the ultimate decision-making rights from both the individual with disabilities and their family members. While most courts do follow the wishes of the individual petitioning for guardianship, ultimately the judge presiding over the hearing makes the final decisions.

Limited and full guardianships restrict or remove entirely the person's right to make decisions and give the guardian responsibility for making decisions on the person's behalf. Overly restrictive guardianships can limit the individual's independence, cost families and the court system, are difficult to change, and can result in over reliance on paid supports.

Important Considerations about Guardianship

- Establishing and declaring in court that a person is “incompetent” is painful for all involved because it emphasizes the person's limitations, rather than his or her strengths.
- Being found incompetent means losing many basic, day-to-day rights, and the loss of dignity and respect because the person subject to guardianship must now seek the consent of the guardian for many activities that other people take for granted.
- Taking away an individual's decision-making power reduces the ability to learn to make choices and develop decision-making skills.
- Not knowing his or her basic rights and of how to assert them, the person subject to guardianship is at greater risk of abuse and exploitation by others.
- Having decisions made by someone else reduces self-confidence and the ability to develop decision-making skills.
- Imposing Guardianship and decision-making on a family member when it is not necessary creates potential for unnecessary conflict.
Guardianship should not be imposed to protect the person from some risk of harm that may not exist.

Guardianship does NOT protect a person from abuse or neglect.
Guardianship does NOT guarantee safety.

“

Family members and others involved in the person’s life often overestimate the security that guardianship can provide, fail to look to other forms of support that may provide better protection of both safety and rights, and fail to consider the benefits of risk-taking, in terms of the learning opportunity for the person in setting goals, trying new things, and learning from failures.

”

The Judge has the ultimate decision-making power.

1. The judge may decide to grant full guardianship even if only partial guardianship is requested.

Example: A parent requesting guardianship may ask that their son or daughter be allowed to retain the right to vote or to marry. The judge may decide that since the individual is incompetent, then he or she should not be given those rights.

2. Guardianship is not easy to change or reverse. Anyone wanting to reverse a guardianship must file a formal petition with an attorney and fill out multiple forms, then appear in court. There must be evidence and documentation that the guardian is unfit. Any change in the terms of a guardianship also requires going back to court and is costly.

“I would rather be exposed to the inconveniences of too much liberty than to those attending too small a degree of it.” - Thomas Jefferson

Getting Started with Supported Decision-Making

Supported Decision-Making can help people with disabilities stay in control of their own lives. Each person with a disability decides the amount and type of support he or she wants and needs. People with disabilities need people they trust to support them in reaching their goals.

STEP 1: START THE CONVERSATION

Talk about goals and needed supports to achieve them. Think about an individual's current abilities and areas where growth can occur.

STEP 2: IDENTIFY PEOPLE WHO ARE WILLING AND ABLE TO ASSIST

A support person should know the individual well and be able to understand and communicate with her or him.

STEP 3: PLAN AND COMMUNICATE

Bring the support team together to determine how team members will communicate.

STEP 4: SET UP AN AGREEMENT

Supported Decision-Making agreements are as individual as the people using them. See sample resources.

STEP 5: LET EVERYONE KNOW

Once the Supported Decision-Making agreement is signed, share copies with doctors, financial institutions, schools, and others who are involved.



Idaho Law

How does Idaho law include Supported Decision-Making?

While Idaho does not currently have a legally binding Supported Decision-Making Agreement in state statute, it requires a court to consider whether lesser restrictive alternatives to guardianship are available and appropriate and ensure that persons are able to participate as fully as possible in all decisions that affect them.

Guardians can use Supported Decision-Making as a tool to:

- Provide a person under guardianship with the greatest amount of independence and self-determination.
- Place the least possible restriction on the individual's personal liberty and promote the greatest possible integration of the individual into his or her community.
- Make diligent efforts to identify and honor the individual's preferences with respect to choice of place of living, personal liberty and mobility, choice of associates, communication with others, personal privacy, and choices related to sexual expression and procreation

Advantages to a Supported Decision-Making Agreement:

- Considers the individual's wishes first,
- Provides the least restrictive form of support,
- Allows for growth and maturity as a person experiences and practices new skills,
- Encourages Supporters to help the individual learn to make decisions,
- Eliminates the need to go to court,
- Can be changed at any time,
- Can be set up for free, using easily available forms.

Find the right supports for individuals with disabilities to live full lives.

Many families feel pressured into pursuing guardianship to retain access to medical or school records and to try to reduce the risk of victimization.

To provide support at meetings:

As adults, individuals with disabilities have the right to choose who is invited to meetings with service providers. Access to information can be as simple as a signed release to attend an IEP, employment services, or a medical appointment.

- Ask the school, Vocational Rehabilitation Counselor, medical professional for a release
- A release gives those named on the form permission to attend meetings and speak to professionals involved.

To provide support for healthcare decisions:

POWER OF ATTORNEY (POA) FOR HEALTHCARE

Allows the friend or family member to help make health care decisions for the individual and provides access to the individual's medical records.

Free forms are available on-line.

LIVING WILL

Allows the friend or family member to make end of life decisions when the individual is incapacitated.

Free forms are available on line or from a health care provider.



To provide support for financial decisions:

POWER OF ATTORNEY FOR FINANCES

Allows the friend or family member to help make financial decisions.
Free forms are available on-line.

ABLE ACCOUNTS

Allows eligible individuals with disabilities to save money in a tax-exempt account that may be used for qualified disability expenses.

Individuals with disabilities can save money while keeping their eligibility for federal public benefits.

<https://silc.idaho.gov/able-accounts/>

SPECIAL NEEDS TRUST

Managed by a trustee. Funds must be used to benefit the individual.

Can be set up through a bank.

REPRESENTATIVE PAYEE

A Representative Payee helps manage a bank account: sign checks and receive information from the bank. The “rep payee” makes reports and is accountable for all funds in the account. Form is available from the Social Security office - <https://www.ssa.gov/payee/>



DUAL SIGNATURE BANK ACCOUNTS

Requires 2 signatures for each check. Form is available at the bank.

**Links to information about alternatives to
guardianship and supported decision-making
can be found at
www.mychoicematters.idaho.gov**

Resources

Where to go for more information:

My Choice Matters is Idaho Medicaid's website dedicated to listen to what adults with intellectual and developmental disabilities have to say and improving the service system for adults so they can be the boss of their own lives. **www.mychoicematters.idaho.gov**

DisAbility Rights Idaho gives people with disabilities a voice to assert and defend their own rights through information, education and individual assistance. **<https://disabilityrightsidaho.org>**

Idaho Council on Developmental Disabilities is the state's Developmental Disabilities Council. For more information on the Supported Decision-Making project, visit **www.icdd.idaho.gov**

Crisis Prevention and Court Services provides assistance to individuals with intellectual/developmental disabilities and their families in a variety of areas and oversees the evaluation of persons seeking guardianship/conservatorship for people with I/DD. **www.CPCS.dhw.idaho.gov**

The National Resource Center for Supported Decision-Making has resources, publications, and a state-by-state guide to information on Supported Decision-Making. **www.supporteddecisionmaking.org**

Autistic Self-Advocacy Network (ASAN) is a nonprofit organization run by and for autistic people. It is a disability rights organization for the autistic community, advocating for systems change and providing a voice for autistic people. **www.autisticadvocacy.org**

American Bar Association offers **The PRACTICAL Tool**, which aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship. **https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html**

Ginger's Story

Ginger's foster parents taught her how to make responsible decisions and how to ask for help if needed. At age 18, Ginger's Mom became her representative payee, but not her guardian, to help her manage her Social Security benefits.



Her parents have both passed away, but every day Ginger uses the skills they taught her to make decisions at work and at home in her own apartment. She has become a skilled self-advocate, supporting others to make both big and small decisions in their lives. When Ginger needs health care advice, she consults her siblings. For financial questions, she asks her boss, and for social networking and other everyday decisions, she turns to her friends in her local People First chapter.

Josh's Story: His Circle of Support



Josh's Mom is his guardian, and they use Supported Decision-Making to gather all the information Josh needs to make important financial and healthcare decisions. For the everyday decisions that Josh makes, he turns to his support broker, his roommate and friends, and family members to help him look at his options, set priorities, and make the decision that is best for him.

Josh works in the community at a Nursing and Rehabilitation Facility and attends movies and Packer games with friends. He also has support from his friends in his local People First Chapter.

A special thanks to:

Jonathan Martinis, Esq., J.D., Senior Director for Law and Policy at the Burton Blatt Institute at Syracuse University

Kate Schilling and Grace Knutson, Attorneys, GWAAR Elder Law & Advocacy Center

Photos courtesy Nicolet Area Technical College and the Idaho Council on Developmental Disabilities



We believe that people with disabilities can be self-determined and make choices about their lives with the right support at the right time.

The Idaho Council on Developmental Disabilities and its partners: DisAbility Rights Idaho, the Idaho Department of Health & Welfare, and the Office of the Idaho Attorney General, are working to help more families use Supported Decision-Making tools and resources to decrease the number of unnecessary guardianships, while addressing concerns around safety and access to information.

This publication was adapted for Idaho with permission from the original creator:



Find out more at
www.mychoicematters.idaho.gov