

Supporting Individuals with Disabilities to Take Charge of Their Lives



Self-Determination and Supported Decision-Making

ADVOCACY • INCLUSION • SYSTEMS CHANGE

This guide provides important information about empowering individuals with disabilities to be in control of their lives, make their own choices, and have better life outcomes including safety and privacy.

Supported Decision-making is a natural process that many people use when making important decisions. It is “what really good family and friends do. It’s having conversations with each other about needs and wants and coming to a decision with their help when needed. Supported Decision-making is a set of strategies that can help individuals with disabilities have more control over their lives and their futures. It involves family and friends working together with individuals to support them in making complex decisions.” (Source: <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>)

“Supported Decision-making...retains the individual as the primary decision maker, while recognizing that the individual with a disability may need some assistance – and perhaps a great deal of it – in making and communicating a decision.”

(Source: http://supporteddecisionmaking.org/sites/default/files/implementing_legal_capacity_article_12_un_convention.pdf)

This guide is for people living with disabilities; family members and friends; legal and educational professionals; service providers; guardians, or other supporters.

It is the person’s will and preference, plus support, plus accommodations, that equals legal capacity.



“ Instead of guardianship of our mother, 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. ”

– Daughter

Self-Determination

Being able to make choices about their own lives is crucial for the independence and happiness of all people, including those living with disabilities. Decision-making is a skill that everyone needs to practice, including people with

disabilities, so they can 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.

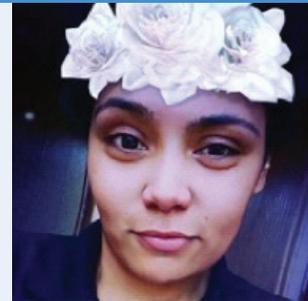
Did you know that being able to make your own decisions leads to a higher quality of life? Studies show that people living with disabilities who have more control of their lives and are more self-determined are:

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

When individuals living 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.

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

(Source: <https://www.nationalcoreindicators.org/>)



I think getting out of guardianship has changed me in many ways. Now I'm able to pay my own bills (with no assistance). I'm able to live in my apartment and as well cook my own meals. And also hold down a job.

When I was under guardianship of the state they wouldn't have let me do any of that.

But when I got out of the guardianship and Trudi started helping me, she taught me to cook and manage my money. I now need minimum to no help/assistance, but when I need help I can get it from Trudi and my friends.

– Caroline Glenn

Choice

People with intellectual and developmental 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 Wisconsin 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."

(Source: <https://www.dhs.wisconsin.gov/publications/p2/p20460.pdf>)

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

All people, including those with disabilities:

- Have the right to make decisions about things that impact their lives,
- Can learn new skills to be more independent over time when they have the right supports.

And...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.

We all make mistakes. Mistakes help people learn.

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 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.

Supported decision-making enables people with disabilities to ask for support where and when they need it from family members, friends, and professionals. Alternatives to guardianship that support individual choice can include release of information forms, powers of attorney, special needs trusts, and representative payees. These options can help families, friends, and professionals provide the needed supports and safeguards without imposing guardianship restrictions.

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 the 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 the Supporter.

A Supporter can:

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



Supported Decision-Making Agreements:

A supported decision-making agreement can be developed to clarify the type of support a person needs and identifies who will provide it. A supported decision-making agreement is not a legally-binding document; it is more like a person-centered plan. It 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 may use existing sample agreements or create one of their own. The following items should be included in an agreement:

- 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 helps decide what classes to take, who to invite to an Individualized Education Program meeting*); and
- Signature area for the individual and Supporters.



Samples of supported decision-making resource documents can be found at: www.supporteddecisionmaking.org/content/resource-library

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 and friends 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 meetings can help keep the discussion focused on the individual's talents, gifts, and dreams for the future.

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 the quality of their life.
- Identify strategies and opportunities to help achieve a goal.

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

“ 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

The decision to seek guardianship is an intensely personal one that only the people involved can make, after carefully reviewing all of the facts and alternatives. Guardianship can be a necessary support for some people under some circumstances; however, it can strip away **most or all** 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. Most courts follow the wishes of the individual petitioning for guardianship, but the judge presiding over the hearing makes the final decisions.

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 limited or full guardianships can limit the individual's independence, are difficult to change, can result in over-reliance on paid supports, and can be time-consuming and costly for families.

Guardianships and other forms of substitute decision-making tend to be overused because:

It can be more complicated and time-consuming to help a person who needs decision-making support to understand and make a decision for themselves, than it is to simply have someone else make the decision for the person.

(Source: <https://www.dhs.wisconsin.gov/publications/p2/p20460.pdf>)

You don't need a guardian just because:

- You are a certain age;
- You have a certain IQ;
- You need support; or
- Because things have always been done a certain way.

Important considerations about guardianship:

- 1** 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.
- 2** Being found "incompetent" means losing many basic, day-to-day rights, and the loss of dignity and respect because the ward must now seek the consent of the guardian for many activities that other people take for granted.
- 3** Taking away an individual's decision-making power reduces the ability to learn to make choices and develop decision-making skills.
- 4** Not knowing their basic rights and how to assert them, could put the person at greater risk of abuse and exploitation by others.
- 5** Having decisions made by someone else reduces self-confidence and the ability to develop decision-making skills.
- 6** 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.

(Source: <https://www.dhs.wisconsin.gov/publications/p2/p20460.pdf>)

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

The Judge has the Ultimate Decision-making Power

1 In guardianship proceedings, the judge has ultimate decision-making power and may grant more restrictions than are even sought. (Example: A parent requesting guardianship may ask that their son or daughter be allowed to retain the right 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 reverse or change. Anyone wanting to reverse a guardianship must file a formal petition with an attorney, fill out multiple forms, and appear in court. Evidence and documentation that the protected person has re-gained capacity or that the guardian is unfit must be presented. Any changes in the terms of a guardianship also require going back to court. Reversing or changing a guardianship can take time and may be costly if an attorney is involved.

3 Capacity determinations often lack sufficient scientific or evidentiary basis.

4 People with disabilities often feel they are denied due process rights in guardianship proceedings.

5 Although most state laws require consideration of less-restrictive alternatives, courts typically do little to enforce those requirements.



[When I was under guardianship] I was not allowed to go to my job... I wasn't allowed to have my friends or co-workers visit or even call me. I wasn't allowed to have my cell phone or computer. I felt like a prisoner but I didn't do anything wrong.

I was told I had rights...but that wasn't true. [My guardian] took them away. It was like I didn't matter. Like I didn't exist. [My guardian] took away my rights, my choices, my independence. A guardian is supposed to help me reach my goals.

Instead, I was kept away from my community, my church, and my friends. I kept telling everyone I was unhappy but no one listened to me.

– Jenny Hatch

(Source: https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html)

(Source: <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>)

“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.”

(Source: Autistic Self-Advocacy Network (ASAN))

Colorado Law About Guardianship (CRS 15.14.311)

While Colorado does not currently have a legally-binding supported-decision making agreement in state statute, it does promote supported-decision making. Colorado's State Statute on Guardianship gives the court permission to appoint a limited or unlimited guardianship only if it finds by clear and convincing evidence that the person is an incapacitated person; and his or her needs cannot be met by less restrictive means, including use of appropriate and reasonably available technological assistance. It also states that the Court, whenever feasible, shall grant to the guardian only those powers necessitated by the ward's limitations and demonstrated needs and make appointive and other orders that will encourage the development of the ward's maximum self-reliance and independence.

(Source: <https://leg.colorado.gov/sites/default/files/images/olls/crs2019-title-15.pdf> (page 360 of 600))

The key question for a Court or anyone seeking guardianship is: "How do you know if the person is **incapable** or **unable**?" How can you know if you haven't tried something else, first, in an attempt to empower the person to be capable and able?

Supported decision-making can be used as a tool for guardians to:

- Provide a ward 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 her or his 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.

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

– National Guardianship Association

Advantages to the supported decision-making process:

- 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 to learn to make decisions.
- Eliminates the need to go to court.
- Can be changed at any time, and
- The type of decision-making supports and Supporters can be easily changed.

Getting Started with Supported Decision-Making

Supported decision-making can help people with disabilities stay in control of their own lives. Each person decides the amount and type of support they want and need from 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 him or her.

STEP 3: PLAN AND COMMUNICATE

Bring the supporting individuals together to determine how the group will communicate.

STEP 4: SET UP AN AGREEMENT

Supported decision-making agreements are as individual as the people using them. See sample resources from the National Resource Center for Supported Decision-Making. However, they are not legally-binding documents.

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.

Find the Right Supports for Individuals with Disabilities to Live Full Lives.

Many families feel pressured into pursuing guardianships to retain access to medical or school records and to try to reduce the risk of victimization. Family members should include the individual with a disability in the exploration of and deciding upon which of the following supports would be beneficial for him/her/they.



To provide support at meetings:

Release of Information

Once they reach the age of majority (18 in most instances and 21 for school services in Colorado), individuals with disabilities have the right to choose who is invited to meetings with service providers. Access to information can be as simple as verbal permission or using a signed release form to communicate with a community service provider, or governmental entity, like the Social Security Administration, employment services, or a medical appointment.

- Ask the community service provider, governmental entity, or medical professional for a release of information form.
- This release form gives those named on the form permission to attend meetings and to speak to professionals involved.

To provide support for healthcare decisions:

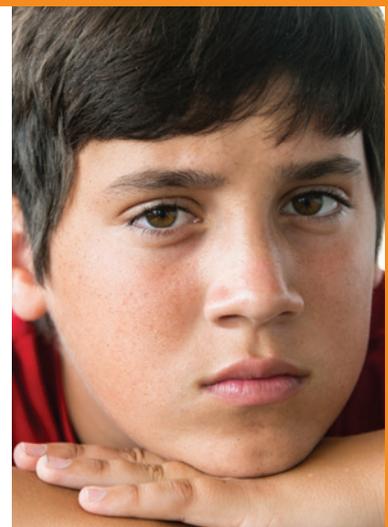
Power of Attorney (POA) for Healthcare

- Provides access to the individual's medical records,
- Free forms available online,
- Must be notarized.

Living Will

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

- Free forms are available online or from a health care provider.



To provide support for financial decisions:

Power of Attorney for Finances

- Allows a friend or family member to make financial decisions,
- Free forms are available on line,
- Must be notarized.



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://www.coloradoable.org>



Supplemental or Special Needs Trust

- Managed by a trustee. Funds must be used to benefit the individual.
- Should be set up by an attorney who specializes in this area of law.

Representative Payee

- A Representative Payee may help manage a bank or credit union account, sign checks, and receive information from a bank. They may also provide financial management for people who are receiving Social Security payments, who are not able to manage it themselves.
- Forms are available from a bank or credit union. For Social Security, forms are available at a local Social Security Office or online at <https://www.ssa.gov/payee/form>

Dual Signature Bank Accounts

- Requires two signatures for each.
- Form is available at the bank or credit union.

In Conclusion

Supported decision-making embraces personal strengths and capacities, provides an alternative to guardianship and can strengthen ties to the community for a person living with a disability without reducing their civil rights and ability to make choices.

The following table summarizes some misconceptions about the need for guardianships and provides alternatives that support self-determination and personal choice.

When guardianship is believed to be needed	Alternatives that embrace self-determination
Attend the Individualized Education Program after the student's 18th birthday	Student can invite whomever they wish to their IEP meetings
Talk with social security	Use a release of information form
Have surgery	Use a medical power of attorney for the time period needed for surgery and recovery
Checking account	Set up a representative payee
Signing contracts	Use a double signature
Purchasing and closing on a home	Set up a financial power of attorney for one day
Service provider denies services unless guardianship is in place	Use the service provider's appeal process; Work with an advocate; Find a different service provider
For provider convenience in communication with divorced parents	Find communication options that work for all parties



Resources

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 guardianships. https://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.authcheckdam.pdf

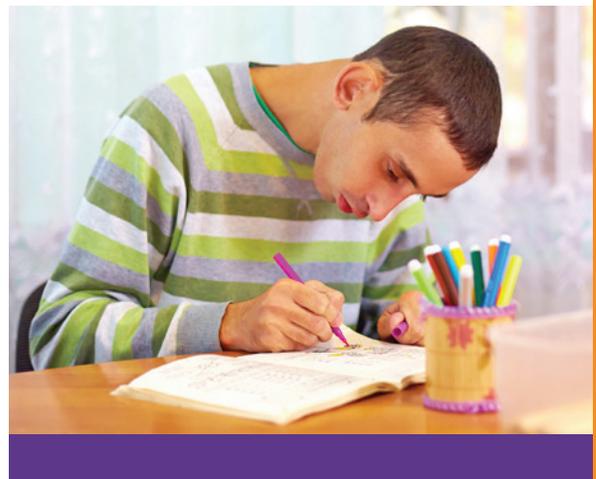
The Autistic Self-advocacy Network (ASAN) describes itself as a disability rights organization for the autistic community, advocating for systems change and providing a voice for autistic people. <http://www.autisticadvocacy.org>

Disability Law Colorado, the State Protection and Advocacy Organization for people living with disabilities and seniors. <https://www.disabilitylawco.org>

The National Resource Center for Supported Decision-Making has resources, publications, and a state-by-state guide to information on supported decision-making. <http://www.supporteddecisionmaking.org>

Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination for People with Disabilities <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>

The Colorado Developmental Disabilities Council is 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.



The Council is pleased to be working collaboratively with the following organizations:



The Council would like to thank the Wisconsin and Missouri DD Councils and Jonathan Martinis, Esq., J.D., for the generous use of their Supported Decision-making resources. We would also like to thank Caroline Glenn and Jenny Hatch for sharing their stories.

There are approximately 12,000 people
in Colorado currently living under
a guardianship



The mission of the CDDC is to advocate for system change by promoting meaningful person-centered participation, self-determination, and inclusion for all individuals with developmental disabilities.



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