



Supported Decision-Making and Guardianship

Is Guardianship the ONLY Choice?

Every day, parents across Nebraska ask this question. Because, every day, people and professionals tell them they have to get guardianship of their children with disabilities. They're told they have to get guardianship or they can't go to Individualized Education Program (IEP) meetings. Or they have to get guardianship to manage health care and finances or to keep their children safe.

Every day, parents follow this advice and spend time and money on lawyers, doctors, and court costs because they think guardianship is their only choice.

Sometimes it is. A lot of times it isn't.

Answering the Question

Guardianship is a legal process where a judge takes away one person's right to make some or all decisions – like where to live, who to spend time with, what to spend money on, and what kind of medical care to get – and gives that power to someone else. So, if you think your child can or may be able to make some or all of those decisions, guardianship isn't your only choice.

That doesn't mean guardianship is always wrong. If people truly can't make decisions or direct their lives, guardianship can be a good thing. But, if people can make decisions, by themselves or when they get help, putting them in guardianship can hurt them.

That's because guardianship takes away people's right to make choices and control their lives – their "self-determination." Decades of research shows that when people lose self-determination their lives can get worse; it can have a "significant negative impact on their physical and mental health, longevity, ability to function, and reports of subjective well-being."¹

Studies show that in almost all guardianships, the judge takes away all of the person's rights, even if they are able to make at least some decisions.² In these "full" or "plenary" guardianships, the guardian has the power to make the most basic and intimate health, personal, and financial decisions instead of the person.³ In a legal sense, it's like the person doesn't exist.



So, guardianship isn't and shouldn't be the only choice if your child can make decisions (or can learn to make decisions) by themselves or with help. There are other options that can empower them to direct their own lives and be as independent as possible.

This brochure will tell you about an option called Supported Decision-Making.

Supported Decision-Making: What Is It?

Supported Decision-Making is getting help when you need it, from people you trust, so you can make your own decisions.⁴

Isn't that how we all make decisions? When you have to make a tough choice, or a decision about something you're not familiar with, or just want to "talk it out," what do you do?

You get help, don't you? We all do. Think about all the clichés about decision-making like "get a second opinion," "don't make a snap judgment," and "make an informed choice." They all mean the same thing: When you need help making a decision, get it!

Everyone does! You may ask a friend for advice or a professional for information, or you may have “go-to” people to talk about specific subjects. They help you “think through” the issues, discuss the “pros and cons” to clear up your choices, and identify solutions. That way, you can understand your options and choose the one that’s best for you.

When you do that, you’re using Supported Decision-Making. People you trust give you support, so you can decide. That’s it.

Answering the Question with Supported Decision-Making

If your child can use (or learn to use) Supported Decision-Making, guardianship isn’t the only choice.

Research shows that “many, if not most” people with disabilities, even those with the most significant disabilities, can use Supported Decision-Making to make at least some decisions in their lives.⁵ When they do, they can have more control over their lives and more

self-determination.⁶ That’s important because studies show that when people with disabilities have more self-determination, they can have better lives; they are more likely to work, live independently, be more involved in their community, and be safer.⁷

For example, a study showed that people with disabilities who did not have guardians were more likely to work, live in their community, and have friends than people with similar abilities and limitations who did have guardians.⁸ Another study found that people with disabilities who used Supported Decision-Making were more independent and self-confident, were better at making decisions, and made better decisions.⁹

Of course, people with disabilities may need different types of support or more support. But the principle is the same: they make decisions with support, just like you. And if they can make decisions just like you, then, just like you, they don’t need guardians.

Most of the time, there’s no way to know if people can use Supported Decision-Making unless they try. That’s why you may want to at least try Supported Decision-Making before seeking guardianship, except in extreme situations. If it works, your child can live as independently as possible, have more self-determination, and may have a better life. If it doesn’t, then guardianship may be a good option.

We’re not the only ones recommending Supported Decision-Making. It’s also the official position of the National Guardianship Association, a group made up of guardians, by guardians, and for guardians. They say, “Alternatives to guardianship, including supported decision-making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”¹⁰

Supported Decision-Making: Making It Work

As we said, except in extreme examples, everyone uses Supported Decision-Making to make at least some decisions. However, the things people need support to do, the type of support they use, and the ways they use it are unique to them because everyone makes decisions differently and has different ways they like to be supported. Therefore, the practice of Supported Decision-Making will be different for each person.



When you're starting Supported Decision-Making, the first and most important thing to do is explore and identify when the person wants support, who the person wants support from, and how the person wants to be supported. That's the Golden Rule of Supported Decision-Making: Support people the way they want to be supported.

While the details will be different for each person, here are steps you can take to help people explore and identify when, where, how, and from whom they want support.¹¹

Listen and Think

Supported Decision-Making should always be based on the person's strengths, needs, and interests. Therefore, you should start by encouraging the person to think about the types of decisions they would like support to make. The Missouri Stoplight Tool can help people explore and identify life areas and decisions where they want support, what they do well, and where they want help.

Identify Opportunities and Challenges

Next, explore how the person would like to be supported. One way to do that is by exploring how the person uses support now and how the person has been supported in the past. If there is a type of support that works well or has worked well before, consider trying it in other life areas. The Supported Decision-Making Brainstorming Guide can help people identify ways they have been supported and how they'd like to be supported.

Find Supporters

Next, connect with people, professionals, agencies, and organizations that can provide the support the person wants. Don't forget to consider support you may be able to receive from agencies or programs like Special Education, Vocational Rehabilitation, Medicaid Waivers, and Centers for Independent Living.

In other brochures, we'll show you how you can use Supported Decision-Making in these and other programs. There are also videos that can help you identify ways to use Supported Decision-Making and organizations that can provide support.



Coordinate Support

Next, work with the person and their supporters to develop a Supported Decision-Making plan. The Setting the Wheels in Motion guide includes tips and worksheets that can help people identify areas where they want support, the types of support they want, people, professionals, and agencies that can provide support, and ways they can work together.

Put it in Writing

Although it's not required, we recommend that you create written Supported Decision-Making Agreements describing the life areas where the person wants support, the support they want, who will provide support, and how and when that support will be provided. Written agreements are helpful because Nebraska law says that judges can only put someone in guardianship if it is "the least restrictive alternative available."¹² Therefore, Supported Decision-Making Agreements can protect people if someone tries to put them in a guardianship because they show that there is a less-restrictive alternative that the person can use.



People can then show their Supported Decision-Making Agreements to friends, family members, and professionals like doctors and attorneys to demonstrate how they make decisions and want to be treated. They should review their agreement from time to time to make sure things are working well and to make changes if they're not.

There are model forms you can review and adapt from the National Resource Center for Supported Decision-Making. You can also work with advocates or attorneys to help you write your own form.

We Can Help!

While some people may need guardians, unless you're 100% sure that your child can't make any decisions, even with support, we think the National Guardianship Association's position makes sense: You should at least try Supported Decision-Making.

Wherever you are on your Supported Decision-Making journey, whether you're just gathering information or you're ready to write a Supported Decision-Making Agreement, we can answer your questions or connect you with people and organizations that may be able to help. Contact us at:

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Brad Meurrens, Public Policy Director, brad@drne.org

Nebraska Council on Developmental Disabilities

301 Centennial Mall South
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www.dhhs.ne.gov/pages/DD-Planning-Council.aspx

Nebraska University Center for Excellence in Developmental Disabilities

Munroe-Meyer Institute for Genetics and Rehabilitation
985450 Nebraska Medical Center
Omaha, NE 68198
402-559-6483
www.unmc.edu/mmi

**Scan this code with your
smart phone's camera for
additional resources.**

Or visit go.unmc.edu/mmi-sdm



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