

Do I HAVE to get Guardianship?

1



Supported Decision-Making Series

It's a question parents of people with disabilities face every day. Because, every day, people and professionals tell them they must get guardianship of their children. Teachers tell them that they must get guardianship if they want to go to IEP meetings. Lawyers tell them they must get guardianship to manage money. Doctors say they must get guardianship for health care.

Every day, parents follow this advice and spend time they don't have and thousands of dollars on lawyers, court costs, and evaluations because they think that's their only option.

Sometimes it is. Often it isn't.

Answering the Question

Guardianship is a legal process where a Judge takes away a person's rights to make decisions – like where to live, whether to work, who to spend time with, and what kind of medical care to get – and gives them to someone else. So, if you know (or think) that your child can or may be able to make decisions, you don't HAVE to get guardianship.

In most guardianships, the Judge takes away all of the person's rights.¹ In these "full" guardianships, the guardian has the right to make the most basic and intimate health, personal, and financial decisions for the person.² In a legal sense, it's like the person doesn't exist.

We're not saying that guardianship is always wrong. For people who truly can't make decisions, guardianship can be a good thing. But, if people can make decisions, either independently or when they get help, guardianship can be harmful.

That's because guardianship takes away people's right to make choices and control their own 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.”³

You don’t HAVE to get guardianship if your child can make decisions (or can learn to make decisions) by him or herself or with help. There are other options. There are ways you can empower your children to direct their own lives and be as independent as possible.

This brochure, and the ones to follow, 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 everyone – people with and without disabilities – makes 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? You may ask a family member or professional you know about finances or health care, go to a coworker about your job, or talk to your best friend when you have relationship problems. They help you “think through” the issues and “clear things up.” 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. It's simple, really: they give you support, so you can decide.

That's Supported Decision-Making.



Answering the Question with Supported Decision-Making

If your child can use (or learn to use) Supported Decision-Making, you don't HAVE to get guardianship.

“Many, if not most” people with disabilities, even those with the most significant disabilities can use Supported Decision-Making.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 safer.⁷

Of course, people with disabilities may need different types of support, more intense support, or support for a longer time than you. But, the principle is the same: they get support from people and use that support to make decisions, 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, you can't or won't know if someone can use Supported Decision-Making unless you try. That's why we believe you shouldn't rush into guardianship except in extreme circumstances. Why not try Supported Decision-Making first to see if it will work? If it does, 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 appropriate.

That's not just our belief. It's 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."⁸

Supported Decision-Making: *Putting it into Practice*

If you want to try Supported Decision-Making, what should you do? First, think about the ways you **already** use it. You know that there are areas in your life where you need some help. You get that help from people you trust. Using their help, you make decisions.

However, the life areas where you need support, the type of support you use, and the way you use it are different than they are for other people. Everybody has different things they do well, things they need support to do, and ways they like to be supported. Therefore, the **practice** of Supported Decision-Making will be different for each person.

Always remember: with Supported Decision-Making, **one size does not fit all**. When you're starting Supported Decision-Making, the most important thing you can do is explore and identify when the person wants support, who the person wants support from, and how the person wants to be supported.

Think of it as the Golden Rule
of Supported Decision-Making:
**Support Others 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.⁹



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 decisions he or she makes now and those the person needs help 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. You can download and use the Stoplight Tool at: <https://moddcouncil.org/uploaded/Guardianship%20Manual%20Appendix%201.pdf>

Identify Opportunities and Challenges

Next, explore the types of support the person wants to use. One way to do this is to talk about the support he or she uses now. If one way of supporting the person works well, think about trying it for other life areas.



If you're not sure what to try, brainstorm about ways you can give and get support. At the same time, think about what might be stopping the person from using that support.

The [Supported Decision-Making Brainstorming Guide](http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf) can help people explore ways they receive support now, the ways they'd like to be supported, and who may be able to help them. Access the guide at <http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>



Find Supporters

Next, connect with the 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, Person Centered Planning, and Centers for Independent Living.

In later 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.

You can view some at:

<https://goo.gl/SCQmkQ>

Coordinate Supports

Next, work with the person and his or her supporters to develop a Supported Decision-Making plan laying out who will support the person and how the person will use that support.

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 people can work together with their supporters.

You can download and use the guide at:
<http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>



Put it in Writing

We recommend that you create written Supported Decision-Making Agreements describing the life areas where the person wants support, the support he or she wants, who will provide support, and how that support will be provided.

Written Agreements show that the person uses Supported Decision-Making. This is important because Missouri law says that Courts must consider whether people use Supported Decision-Making before ordering them into guardianship.¹⁰ Therefore, Supported Decision-Making Agreements can protect people if someone tries to put them in a guardianship.

People can show their Supported Decision-Making Agreements to doctors, attorneys, bankers, and others to show how they make decisions and want to be treated. They can also review their Agreements from time to time to make sure things are working well or change things if they're not.

Missouri law recognizes Supported Decision-Making Agreements but does not require that you use a specific form. Therefore, you can create an Agreement that works best for your child.

There are model forms you can review and adapt here:

<http://supporteddecisionmaking.org/node/390>

You may also work with advocates or attorneys to help you write your own form.

References

1. Teaster, P., Wood, E., Lawrence, S., & Schmidt, W. (2007). Wards of the state: A national study of public guardianship. *Stetson Law Review*, 37, 193-241.
2. e.g. Karp, N., & Wood, E. F. (2007). Guardianship monitoring: A national survey of court practices. *Stetson L. Rev.*, 37, 143.
3. Wright, J. (2010). Guardianship for your own good: Improving the well-being of respondents and wards in the USA. *International Journal of Law and Psychiatry*, 33(5), 350-368.
4. Blanck, P. & Martinis, J. (2015). "The right to make choices": The national resource center for SDM. *Inclusion* 3(1), 24-33.
5. Salzman, L. (2010). Rethinking guardianship (again): Substituted decision making as a violation of the integration mandate of Title II of the Americans with Disabilities Act. *University of Colorado Law Review*, 81, 157-244.
6. e.g. Blanck & Martinis, 2015.
7. Wehmeyer, M.L., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children*, 63(2), 245-255; Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal on Mental Retardation*, 110(3), 193-204.
8. National Guardianship Association. (2015). Position statement on guardianship, surrogate decision making, and supported decision making." Retrieved from http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf
9. These steps have been identified and/or described in our publication Introduction to Supported Decision-Making, at: http://moddcouncil.org/?page_id=whatsnewstory&id=68 as well as Gustin, J. & Martinis, J. (2016). Change the culture, change the world: Increasing independence by creating a culture of coordinated support. *Apostrophe Magazine*; Francisco, S. & Martinis, J. (2018, in press). Supported decision-making: Do I HAVE to get conservatorship? *WITH Foundation*; Martinis, J. (2018, in press). Supported decision-making: Making it happen. *National Resource Center for Supported Decision-Making*. See, also, American Bar Association. (2016). PRACTICAL tool for lawyers: Steps in Supported Decision-Making, https://americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
10. Missouri Code, Chapter 475.075



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 an Agreement, we can answer your questions or connect you with people and organizations that may be able to help.

Feel free to contact us at:
(800) 500-7878
moddcouncil.org



OUR NETWORK PARTNERS

**Missouri Protection and
Advocacy Services**
(800) 392-8667
moadvocacy.org

**UMKC Institute for Human
Development, UCEDD**
(816) 235-1770
ihd.umkc.edu

This document was developed in partnership and with support from the Missouri Developmental Disabilities Council (PL 106-402) and Something Else Solutions, LLC (somethingelsejm@gmail.com).