



# Is Guardianship My **ONLY** Option?

PEATC's Transition to Adulthood Series





## Is Guardianship My **ONLY** Option?

Every day, parents of people with disabilities ask this question across Virginia. Because, every day, people, and professionals they trust tell them they *must* get guardianship of their children. They may hear that they *must* get guardianship, or they can't go to IEP meetings. They may hear that they *must* get guardianship for health care. They may hear that they *must* get guardianship to keep their children safe.

And, every day, parents follow this advice and spend time and money on lawyers, doctors, court costs, and evaluations because they think guardianship is their *only* option.

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 know (or think) that your child can or may be able to make some or all of those decisions, guardianship isn't your *only* option.

That doesn't mean guardianship is always wrong. If people *really* can't make decisions or direct their lives, guardianship can be a good thing. But, if people can make even some 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.”<sup>1</sup>

Studies show that in almost all guardianships, the Judge takes away *all* of the person's rights.<sup>2</sup> 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.<sup>3</sup> In a legal sense, it's like the person doesn't exist.

So, guardianship isn't and shouldn't be the *only* option if your child can make decisions (or can learn to make decisions) by themselves or with help. There are other paths you can take. There are other options you can use to empower your children 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.<sup>4</sup>

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? You may ask a friend for advice or a professional for information, or you may have "go to" people in your lives that you talk to 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.*

Supported Decision-Making burst into public view when a Virginian named Jenny Hatch became the first

person to win the right, at trial, to use it instead of being put into a permanent guardianship.<sup>5</sup> Jenny showed the Judge that she had people in her life who helped her understand, make, and communicate her decisions. Because she had this support, she didn't (and still doesn't) need a guardian.

Jenny's victory was covered in national and international news, and she became known as the "rock that started the avalanche" of Supported Decision-Making.<sup>6</sup> Since Jenny's case, over a dozen states have passed laws recognizing Supported Decision-Making as an option and alternative to guardianship.



# Answering the Question with Supported Decision-Making

If your child can use (or learn to use) Supported Decision-Making, guardianship isn't your *only* option.

“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.<sup>7</sup> When they do, they can have more control over their lives and more self-determination.<sup>8</sup> 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.<sup>9</sup>

For example, a recent study in Virginia found that people with disabilities who used Supported Decision-Making





were more independent, self-confident, were better at making decisions, and made better decisions.<sup>10</sup>

Of course, people with disabilities may need different types of support or more support than you. 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 your child can use Supported Decision-Making unless you 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."<sup>11</sup>

# Supported Decision-Making: Making it Work

How can your child try Supported Decision-Making? The first thing to do is think about the ways they *already* use it. There are *already* areas in their life where they get help to make decisions and do the things they have to do.



However, the things they 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 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.<sup>12</sup>

### **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 before. 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 receive support now and before, the ways they'd like to be supported, and who may be able to help them.

### **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, Community Service Boards, and Centers for Independent Living.

In other PEATC 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 his or her 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**

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 important because Virginia law says that Judges must consider whether people can use “less restrictive alternatives” like Supported Decision-Making before ordering them into guardianship.<sup>13</sup>

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 friends, family members, and professionals like doctors and attorneys to demonstrate 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.

You should create an Agreement with your child that works best for them. 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 may at least want to *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:

## **PARENT EDUCATIONAL ADVOCACY TRAINING CENTER**

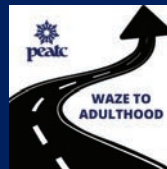
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# References

- 1 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.
- 2 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.
- 3 e.g. Karp, N., & Wood, E. F. (2007). Guardianship monitoring: A national survey of court practices. *Stetson L. Rev.*, 37, 143.
- 4 Blanck, P. & Martinis, J. (2015). "The right to make choices": The national resource center for SDM. *Inclusion* 3(1), 24-33.
- 5 For information about Jenny Hatch and her case, see [www.jennyhatchjusticeproject.org](http://www.jennyhatchjusticeproject.org)
- 6 Vargas, T. (2013, August 2). Woman with Down syndrome prevails over parents in guardianship case. *The Washington Post*. Available at: [https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751\\_story.html](https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html)
- 7 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.
- 8 e.g. Blanck & Martinis, 2015.
- 9 See, e.g., Bradley, V., et al. (2019). What do NCI data reveal about the guardianship status of people with IDD?. Available at: [https://www.nationalcoreindicators.org/upload/core-indicators/NCI\\_GuardianshipBrief\\_April2019\\_Final.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf); 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.
- 10 Martinis, J. & Beadnell, L. (2021). "I learned that I have a voice in my future": Summary, findings, and recommendations from the Virginia supported decision-making pilot project. Available at: <http://www.supporteddecisionmaking.org/node/488>
- 11 National Guardianship Association. (2015). Position statement on guardianship, surrogate decision making, and supported decision making." Retrieved from [http://www.guardianship.org/documents/NGA\\_Policy\\_Statement\\_052016.pdf](http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf)
- 12 Martinis, J. (2019). Strategies for supported decision-making. *Impact* 32(1), 45.
- 13 Va Code Ann. 64.2-2007



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