

## Self-Employed and Self-Determined

### Guardianship is not your ONLY choice!

Every day, parents across the United States ask themselves if guardianship is the only option for their children with disabilities. Because, every day, people and professionals tell them they *have to* get guardianship – to manage their children’s work, health care, money and lives.

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, even though guardianship can limit or remove rights and opportunities for self-employment and independence.

### What Is Guardianship?

Guardianship (called “conservatorship” in some states) is a legal process where a judge takes away one person’s right to make some or all decisions – like whether to work, where to live and what health 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. However, if people *can* make decisions by themselves or when they get help, putting them in guardianship can hurt them.

### What’s the Problem with Guardianship?

When guardianship is right for the person, it can be helpful. If it’s not, though, it can limit their quality of life and opportunities. 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>i</sup>

Guardianship, especially when it’s not needed, can also limit people’s opportunity to work, especially in self-employment. For example, banks may not let people open a business bank account or apply for a loan if they do not have the legal right to make financial decisions. Similarly, vendors, suppliers or customers may not want to set up service agreements with a business owner who does not have the legal right to sign contracts.

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. In this document, we’ll focus on an option called Supported Decision-Making.

## What Is Supported Decision-Making?

Supported Decision-Making, or SDM for short, is getting help when you need it, from people you trust, so you can make your own decisions.<sup>ii</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? *We all do*. You may ask a friend for advice, professionals for information or ask a family member if they know someone who can help you. When you do that, you're getting "a second opinion" or getting what you need to make "an informed choice" or avoid "making a snap judgment." It all adds up to the same thing: if you need help to make a decision, get it!

When you do that, you're using SDM by working with someone you trust to help you think about and make decisions. Your supporters help you identify options, discuss the pros and cons of each and help you identify solutions. That way, you can understand your options and choose the one that's best for you.

That's what SDM is all about. People you trust give you support, so you can decide. *That's it.*

That's particularly important if your child is interested in becoming self-employed. By using SDM, they can get the help they need to make decisions like the type of business to begin, who to hire, how to budget or advertise and how to manage people and money.

## How Can Supported Decision-Making Help?

If your child can use (or learn to use) SDM, 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 SDM to make at least *some* decisions<sup>iii</sup> including how to manage their money,<sup>iv</sup> whether to engage in social and romantic relationships<sup>v</sup> and taking part in medical and mental health care<sup>vi</sup> and legal representation.<sup>vii</sup> In addition, using SDM can increase people with intellectual and developmental disabilities (I/DD) self-confidence and skill at making decisions.<sup>viii</sup> Aren't these the exact decision-making skills people need to start and run a business? So, if your child is interested in becoming self-employed, SDM can help them reach that goal!

In addition, when people use SDM to make their own decisions, instead of having a guardian make decisions for them, they can have more control over their lives and more self-determination.<sup>ix</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, earn more money, live independently, be more involved in their community and be safer.<sup>x</sup> Another study found that people with disabilities who used SDM were more

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

Of course, people with disabilities may need different types of support or more support, though 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.

We're not the only ones recommending SDM. 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>xii</sup>

## **How Does Supported Decision-Making Work with Self-employment?**

If your child or someone you support is interested in self-employment, SDM is a perfect approach. The reality is that everyone who pursues self-employment, disability or not, needs support making decisions. In fact, it can be helpful to think of self-employment as a team sport! Let's look at the core steps of self-employment and see how SDM can support each step.

### **Step 1: Business Concept**

The first step of self-employment is to identify a business concept that fits the potential business owner with a disability. The business concept should match the person's strengths, interests and conditions of employment. Through SDM, you can help a person identify those details, explore business ideas that match and decide whether one idea is a good enough match to move forward with.

### **Step 2: Business Feasibility**

The second step is to gather some facts and find out if the business concept could make enough money. Through SDM, you can help a person decide what support they need to gather the facts, such as contacting a Small Business Development Center (SBDC) counselor. You can also help the person review the facts gathered during this step and decide if the business is worth starting. To make this decision, not only should the facts show the business could be profitable, they should also continue to show the business is good match with the person's strengths, interests and conditions of employment.

### **Step 3: Business Planning**

The third step is to create a plan to start the business. Through SDM, you can help a person decide what support they need to create their plan. When creating the plan, there are also lots of decisions that need to be made, such as how the business will produce the products or services, who will support them with business operations and

management and how they will fund the start-up expenses. It takes a team to think through each of these decisions; SDM is a perfect fit!

#### **Step 4: Business Launch**

The fourth step is to implement the business plan and launch the business. Through SDM, you can help the person sort through the decisions that come up when opening a business. For example, if the person needs more support than expected producing their products or delivering their services, you can help brainstorm ideas for getting the needed support.

### **How to Create a Supported Decision-Making Plan**

If you're thinking about using SDM with your child or another loved one, 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. While the details will be different for each person, here are steps you can take and tools you can use to help people explore and identify when, where, how and from whom they want support.

#### **Listen and Think**

Supported Decision-Making should always be based on the person's unique 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, including in employment, what they do well and what they want help to do.

#### **Identify Opportunities and Challenges**

Next, explore the ways the person has been supported before and would like to be supported going forward. 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<sup>xiii</sup> can help people identify support methods that have or haven't worked before and ways they'd like to be supported going forward.

#### **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 Vocational Rehabilitation and Centers for Independent Living. There are also videos<sup>xiv</sup> that can help you identify ways to use SDM and organizations that can provide support.

#### **Coordinate Support**

Next, work with the person and their supporters to develop a plan for how they'll use SDM. The Setting the Wheels in Motion guide<sup>xv</sup> 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 some states require them if the person uses SDM. Even if they're not required, SDM agreements can be helpful because they show that the person uses SDM as an alternative to guardianship. The person can then show the agreement to friends, family members and professionals like bankers, attorneys and doctors to demonstrate how they make decisions and want to be treated.

You should create an Agreement with your child that works best for them. There are model forms<sup>xvi</sup> 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* SDM.

Wherever you are on your SDM, 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:

[info@disabilitysmallbusiness.org](mailto:info@disabilitysmallbusiness.org). For other resources, visit our [Disability Small Business website](#).

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## **REFERENCES**

This document was adapted, with permission, from material published by the [Missouri Developmental Disabilities Council](#). This document was developed in partnership with Jonathan Gerald Martinis, LLC ([jgmartinisllc@gmail.com](mailto:jgmartinisllc@gmail.com)).

- i 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.
- ii Blanck, P. & Martinis, J. (2015). "The right to make choices:" The national resource center for SDM. *Inclusion* 3(1), 24-33.

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- iii 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; Harding, R. & Tascioglu, E. (2018). Supported decision-making from theory to practice: Implementing the right to enjoy legal capacity. *Societies* 8, 25; Browning, M., Bigby, C., & Douglas, J. (2020). A process of decision-making support: Exploring supported decision-making practice in Canada. *Journal of Intellectual and Developmental Disability* 46(2), 138.
- iv The Center for Public Representation. (n.d.). SDM and Financial Decisions. Retrieved from: [SupportedDecisions.org/Getting-Started-With-Supported-Decision-Making/SDM-And-Financial-Decisions](https://SupportedDecisions.org/Getting-Started-With-Supported-Decision-Making/SDM-And-Financial-Decisions)
- v e.g., Boni-Saenz, A. (2015). Sexuality and incapacity. *Ohio State Law Journal*, 76, 1201. Harris, J. (2015). The role of support in sexual decision-making for people with intellectual and developmental disabilities. *Ohio State Law Journal*, 77, 83. Series. L. (2015). Relationships, autonomy, and legal capacity: Mental capacity and support paradigms. *International Journal of Law and Psychiatry*, 40, 80. Vehmas, S. (2018). Persons with profound intellectual disability and their right to sex. *Disability and Society* 34, 519.
- vi e.g, Enck, G. (2021). Healthcare decisions are always supported decisions. *The American Journal of Bioethics*, 21 (11), 29, p. 30; Sapolsky, R. (2017). *Behave: The biology of humans at our best and worst*. New York, New York. Penguin Press; Kokanovic, et al. (2018). Supported decision-making from the perspective of mental health service users, family members supporting them, and mental health practitioners. *Australian and New Zealand Journal of Psychiatry* 52(9), 826. Browning, M., Bigby, C., & Douglas, J. (2014). Supported decision-making: Understanding how its conceptual link to legal capacity is influencing the development of practice. *Research and Practice in Intellectual and Developmental Disabilities* 1(1), 34.
- vii e.g. Arstein-Kerslake, A., Gooding, P., & McSherry, B. (2021). Supported decision-making in criminal proceedings: A sociolegal empirical study. *Journal of Disability Policy Studies*, doi: 10442073211026332.
- viii e.g., Devi, N., et al. (2019). Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography. *Journal of Policy and Practice in Intellectual Disability* 17(2), 143. Wong, M.J., et al. (1999). Decision-making capacity. *Med. L. Rev.* 7, 269; 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: [Thearcofnova.org/WP-Content/Uploads/Sites/6/2021/02/SDM-Pilot-Project-Final-Report-2.2.21.pdf](https://Thearcofnova.org/WP-Content/Uploads/Sites/6/2021/02/SDM-Pilot-Project-Final-Report-2.2.21.pdf)

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- ix e.g. Blanck & Martinis, 2015.
- x See, e.g., Bradley, V., *et al.* (2019). What do NCI data reveal about the guardianship status of people with IDD?. Available at: [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.
- xi Martinis and Beadnell, 2021.
- xii National Guardianship Association. (2015). Position statement on guardianship, surrogate decision making and supported decision making.” Retrieved from [Guardianship.org/Documents/NGA\\_Policy\\_Statement\\_052016.pdf](https://guardianship.org/Documents/NGA_Policy_Statement_052016.pdf)
- xiii [SupportedDecisionMaking.org/Resource\\_Library/Supported-Decision-Making-Brainstorming-Guide](https://SupportedDecisionMaking.org/Resource_Library/Supported-Decision-Making-Brainstorming-Guide)
- xiv [YouTube.com/Playlist?list=PLKdIRbjdmxgeDSVBZhEFyzzIi9zjO3Mc](https://www.YouTube.com/Playlist?list=PLKdIRbjdmxgeDSVBZhEFyzzIi9zjO3Mc)
- xv [Health.UCDavis.edu/MindInstitute/Centers/CEDD/pdf/SDM-Wheels.pdf](https://www.Health.UCDavis.edu/MindInstitute/Centers/CEDD/pdf/SDM-Wheels.pdf)
- xvi [SupportedDecisionMaking.org/Resource\\_Library/SDM-Model-Agreements](https://SupportedDecisionMaking.org/Resource_Library/SDM-Model-Agreements)