

The Right to Make Choices



Introduction to Supported Decision-Making



The Right to Make Choices

How would you feel if, suddenly, you didn't have any control over your life? What if you weren't allowed to choose who to see, what to do, and where to go, or if someone else controlled your money, decided where you live or whether you can work or get married?

It's hard to do, isn't it? Because those are the types of decisions – big and small, silly and smart – you've made your whole life. These are the choices that tell the world “This is who I am.” We call a person's authority to make the decisions that shape and direct his or her life **“The Right to Make Choices.”**¹

You'd hate to lose that, wouldn't you? The Right to Make Choices is such a basic part of our lives, so built in to our values and beliefs in Life, Liberty, and the Pursuit of Happiness, that the idea of it being taken away is at first unimaginable, then horrifying.

But that feeling – that painful, frustrating feeling – of having no say in your life is exactly what people with disabilities have felt for thousands of years. In Rome, two thousand years ago, if you were considered “feeble-minded,” a *curator* would be put over you to decide what type of life you'd live.² In the 1500s, an English law said that if you were an “idiot” or a “lunatic” you'd be placed under the control of a *committee*, who would make decisions for you.³

In the United States, when a Court decides that a person can't manage his or her life due to a disability, it places that person under *guardianship*. The guardian is then given the power to make decisions in place of the person, in the areas where the Court feels the person can't make them.⁴

Before we go further, we want to make a few things clear. We're not saying that no one should ever be placed under guardianship. We're not saying that you're wrong or evil if you're a guardian or are considering guardianship. The decision to seek guardianship is an intensely personal one that only the people involved can make, after carefully reviewing all the facts and alternatives.

However, we are saying **that people should not be placed under overbroad or undue guardianship**. That is, guardianships over people who can use other options to make their own decisions or guardianships that take away more rights than absolutely necessary. This paper tells you about an option called **Supported Decision-Making** that may be able to help people with disabilities stay in control of their lives, make their own choices, and have better life outcomes - all without the need for a guardian.

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**



Exercising the Right to Make Choices: Self-Determination

Remember how bad it felt to think about losing your Right to Make Choices? That's because it feels good to decide for yourself what you'll do and who you'll do it with. The technical term for **being in control of yourself and your life is self-determination**. People with *self-determination* do things instead of having things done to them, they are *causal actors* who take action to make their own decisions and chart their own life course.⁵

It doesn't just feel good to have self-determination, it's good for you. Decades of studies have found that when people with intellectual and developmental disabilities have more self-determination, they are more likely to live independently, be employed, make more money, and be safer.⁶

Losing the Right to Make Choices: Overbroad and Undue Guardianship



[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 Hatch¹³

Guardianship can decrease self-determination because it takes away some or all of a person's Right to Make Choices and gives that power to the guardian. When guardianships are imposed on people who can make their own decisions or take away more rights than are necessary – when they are *overbroad* or *undue* – they can cause a “significant negative impact on [the person's] physical and mental health.”⁷

That's because **losing self-determination hurts**. Studies have shown that when people are denied self-determination they can feel “helpless, hopeless, and self-critical,”⁸ have less ability to function,⁹ be less healthy, and live less long.¹⁰

Today, even though we have more ways to help more people be more independent than ever before, the number of people under guardianship is growing at an alarming rate. We have programs like Special Education, Vocational Rehabilitation, and Medicaid Waivers that are designed to help people become self-determined, productive, members of society. There are state and federally funded agencies whose purpose is to advocate for people with disabilities to have better lives. And yet, the estimated number of people under guardianship has tripled since 1995.¹¹ Even worse, the vast majority of these guardianships - over 90%, in one study – are full or “plenary,” taking away all of the person's self-determination and Right to Make Choices.¹²

Empowering the Right to Make Choices: Supported Decision-Making

So, if we know that people with disabilities who have more self-determination can have better lives, that losing self-determination can cause harm, and that overbroad and undue guardianship can take away a person's self-determination, **shouldn't we look for ways to help people increase their self-determination and avoid overbroad and undue guardianship?**

This is especially true because of the results of a recent study analyzing the quality of life of thousands of people with developmental disabilities across the country. The National Core Indicators study found that, among people with similar abilities and limitations, those *without guardians* were more likely to:

- Live independently
- Have a job
- Have friends other than family and paid staff
- Date and socialize in their community; and
- Practice the religion of their choice

than those *with guardians*.¹⁴

Of course, some people with disabilities may need help understanding and making decisions. Because of that, **we must, as a state and society, develop a way for people with disabilities to get the help they need to be self-determined and manage their own lives**, free from overbroad and undue guardianship.

Supported Decision-Making, or SDM, is a way to do that. When people with disabilities use SDM, they "work with trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the need for a guardian."¹⁵

When Caroline was under guardianship, she was oppressed and had no self-esteem because of emotional and mental abuse. Then, the guardianship was ended and she was allowed to come and live with me. With love and encouragement from someone who always believed in her (me!) and the grace of God, it took Caroline no time at all to become comfortable with who she truly is: smart, kind, capable of learning anything and everything about life.

When Caroline first came to live with me, she had a lot of questions about life and I helped her a lot. But, with support, she has learned to do so many things. Caroline couldn't even make a frozen pizza in the oven when she first came to live with me. Now, she Googles recipes and cooks great meals. She learned to take the bus and go where she wants. She became employed and moved to jobs that paid more money. She has started college, and researched and filled out all the forms she needed. She has her own apartment and great friends.

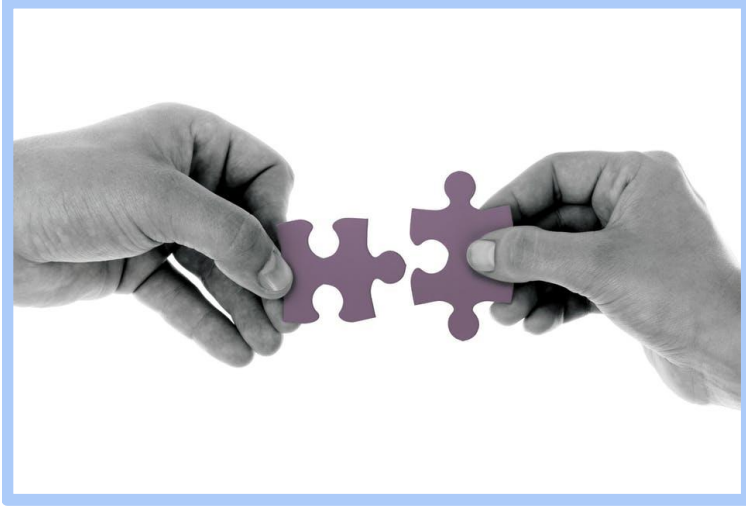
Most importantly, she is no longer fearful of making a mistake. She makes her own decisions and consults me when she needs to (which has become less as she has learned to do more things). It's been 3 years since she got out of her guardianship and it has been a great joy to watch her grow and mature into a young lady with confidence, dreams and desires!

- Trudi Cunningham



Empowering the Right to Make Choices: Supported Decision-Making, Cont.

Think about it: isn't that just a fancy way to describe how we *all* make decisions? And **don't we *all* need help managing our lives?** When you go to the doctor and she talks about "brachial obstructions" and the costs and benefits of taking "erythromycin" versus "zithromax," what do you do? When your mechanic says your car has a "blown head gasket," how do you know whether to pay for repairs?



You probably ask a friend or family member or do some research so you can cut through the jargon and figure out what's going on and what to do. You may ask your sister the doctor for advice when you need to make a medical decision, go to your friend the accountant at tax time, or search the internet. That's just common sense – if you know you don't know enough, you find the information you need to make the best possible, most informed decision you can.

When you do that, **you're using Supported Decision-Making.** You're getting the help you need to make the decisions you face. **The vast**

majority of people with disabilities can do the same thing.¹⁶ Some people may need more help than you or a different type of help. But that doesn't mean that they can't make their own decisions. It just means that they need someone to make decisions *with* them instead of *for* them – just like you.

People with disabilities around the country are using SDM to make their own decisions. Laws have been passed in Texas and Delaware recognizing people's right to use SDM. The American Bar Association,¹⁷ National Guardianship Association,¹⁸ and the United States Department of Health and Human Services¹⁹ have endorsed the use of SDM. And people like Jenny Hatch have cited their ability to use SDM to avoid or be released from overbroad and undue guardianships. As Jenny said, **"I don't need a guardian. I just need a little help!"**²⁰



As more and more people with disabilities use SDM to make their own decisions and manage their own lives, preliminary research is showing that SDM can increase their self-determination.²¹ That make sense, doesn't it: when people make their own decisions, they are more self-determined. So, **using SDM can give people with disabilities access to the benefits of self-determination: increased independence, employment, and community integration.**

Practicing the Right to Make Choices: Using Supported Decision-Making

How, specifically, can people use SDM? The first thing to realize is that every person is an individual. We all make decisions in different ways, and we all need different types of support.

So, SDM starts with a commitment to three principles:

- That *EVERYONE* has the Right to Make Choices to the maximum of their abilities;
- That if people need help – even a lot of help – making decisions, it doesn't mean that they need guardians or must give up their Right to Make Choices; and
- That there are as many ways to give and get help as there are people. So, if one way of providing support doesn't work out, you can always look for and try another.²²



Once you make that commitment, there are steps you can take to learn and support each person's decision-making preferences, methods, and "voice":

- *Listen and Think:* Talk with the person. What are his or her interests and goals? What kind of decisions does the person make now and how? What kind of decisions does the person want to make but has trouble with?
- *Identify opportunities and challenges:* What kind of support does the person need to make decisions and reach his or her goals? What challenges does he or she face?
- *Find Friends:* Learn about and contact people, agencies, and organizations that can provide the supports the person needs to overcome those challenges.
- *Coordinate Support:* Work with the person and his or her supporters to develop a plan for who will provide the help the person needs and how it will be provided.
- *Memorialize Effort:* You may want to, but don't have to, create a written record of your plan. Written plans can help you stay organized and ensure appropriate follow-up.²³

Model forms and plans to help you explore and implement SDM are available from several organizations.²⁴

Practicing the Right to Make Choices: Using Supported Decision-Making

My son, Ben, grew up very much included in our community, in school and in life, and it was important to me and my husband to make sure that continued in adulthood. We knew that we were committed to helping Ben with choices and decisions and would never cut him out of that, but we wanted to make sure that someday when we weren't around or able to help him anymore, that someone else wouldn't be able to control his life and make choices and decisions that he wouldn't want or that would cut him off from what was important to him.

When Ben turned 18, my husband and I became Ben's power of attorney for decisions around money. We opened a joint bank account and helped Ben learn to use a debit card to make purchases. We set up a special needs trust to help provide for quality of life items or needs in the future, and set up a trust committee of people he trusts. This committee is key as they will be able to help Ben manage his trust in the future, and they will be his "go to" people when he needs help with things.

We also thought about skills that we could help Ben develop and life experiences he could have that would help him be more self-determined and able to help manage his own life. For instance, we have worked with him to not be dependent on having a family member or paid staff with him at all times. We also worked on everyday things like carrying a wallet with ID or learning to tell time with a digital watch.

Ben is now 27 years old, and for the past 9 years has been doing great without having a guardian. We help him talk to doctors and other medical professionals and make decisions about his health. Ben is out and about in the community buying things he needs, having lunch with friends, going to the movies and other places he likes to go, using his debit card. He has a say in all decisions about his life.

Ben's ability to access the community and participate in life without restrictions from a guardian are what has made this possible. Having the freedom to make choices and have lots of different life experiences, and yes, even sometimes make mistakes, has helped set the stage for Ben's life in the future – to NOT have a 24 hour/day paid life with someone else in control, but rather the inclusive, self-determined, good life that he wants for himself, that we always dreamed he would have.



- Jane St. John

Protecting the Right to Make Choices: Missouri Law

Supported Decision-Making isn't only a way for people to make their own decisions and direct their lives, using it is consistent with state law. Missouri's Probate Code says that a Court may *only* place people under guardianship if they are "*incapable* of meeting some or all of his essential requirements for food, clothing, shelter, safety or other care" or "*unable* to manage some or all of his financial resources."²⁵

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*?

So, given the potential benefits of self-determination and SDM, and the requirements of Missouri Law, shouldn't we at least attempt to use SDM to help people make their own decisions before seeking guardianship? Maybe that's why the National Guardianship Association – an organization made up of guardians, for guardians, that provides training and certification to guardians - says:

Alternatives to guardianship, *including supported decision making*, should *always* be identified and considered whenever possible *prior* to the commencement of guardianship proceedings.²⁶



Attorneys are taught to zealously defend our client's rights, including the most basic American right to "liberty and justice for all." As Americans, we treasure our liberty: our right to act as we please, make our own decisions, and pursue happiness in our own unique way.

Unnecessary and overreaching guardianships take away that liberty and, all too often, obstruct access to legal resources and funds that would ensure legal justice. Unfortunately, guardianship is often the first and only option for families who have a loved one with disabilities.

I had the honor of advocating for Caroline Glenn's right to "liberty and justice" and to help her be freed from an overreaching, unnecessary guardianship and a system that failed her. Today, Caroline lives where she wants, works, furthers her education, and makes her own decisions with the support of her friends and community. Supported Decision-Making has changed her life and given her the opportunity to pursue "the good life."

Today, I'm proud to call Caroline my friend. Her story tells us all to do our part to protect everyone's right to live, love, work, play and pursue our life dreams and goals, with the support we need and want to do so. It's about providing "liberty and justice" not only for some, but truly "for all."

- Elizabeth Moran

We Can Help!

If you are thinking about ways to use SDM for yourself or a loved one, we can help you find information, connect you with people and organizations that may be able to help you, and answer your questions.

Contact us at:

Missouri Developmental Disabilities Council

P.O. Box 687

1706 E. Elm Street

Jefferson City, MO 65102

Phone: 573.751.8611

Toll Free: 800.500.7878

REFERENCES

1. "The Right to Make Choices" is a phrase and concept developed by Quality Trust for Individuals with Disabilities (www.DCQualityTrust.Org) and The National Resource Center for Supported Decision-Making (www.SupportedDecisionMaking.Org). Quality Trust and the National Resource Center are national leaders in advancing everyone's Right to Make Choices through SDM. For more information, please see their websites.
2. Fleming, R., & Robinson, C. (1993). Care of incompetent adults: A brief history of guardianship. *The Arizona Attorney*, 30, 16-42.
3. Regan, J. (1972). Protective services for the elderly: Commitment, guardianship and alternatives. *William and Mary Law Journal*, 13, 569-622.
4. Quality Trust for Individuals with Disabilities. (2013). Supported decision-making: An agenda for action. Retrieved from http://bbi.syr.edu/news_events/news/2014/02/Supported%20Decision%20Making-2014.pdf
5. Wehmeyer, M. L., Palmer, S., Agran, M., Mithaug, D., & Martin, J. (2000). Promoting causal agency: The self-determined learning model of instruction. *Exceptional Children*, 66(4), 439-453.
6. See, e.g., Karrie A. Shogren *et al.*, Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities, 4 *J. Special Educ.* 256 (2015); Laurie Powers *et al.*, My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education, 34 *Child. & Youth Services Rev.* 2179 (2012); Janette McDougall *et al.*, The Importance of Self-Determination to Perceived Quality of Life for Youth and Young Adults with Chronic Conditions and Disabilities, 31 *Remedial & Special Educ.* 252 (2010); Ishita Khemka *et al.*, Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse, 110 *Am. J. Mental Retardation* 193 (2005).
7. Wright, J. L. (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.
8. Deci, E. (1975). *Intrinsic motivation*. New York: Plenum Press.
9. Winick, B. (1995). The side effects of incompetency labeling and the implications for mental health law. *Psychology, Public Policy and Law*, 1(1), 6-42.
10. Wright, J. L. (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.
11. See, Winsor C. Schmidt, *Guardianship: Court of Last Resort for the Elderly and Disabled*. Durham, NC: Carolina Academic Press (1995); Sandra L. Reynolds, Guardianship Primavera: A First Look at Factors Associated with Having a Legal Guardian Using a Nationally Representative Sample of Community-Dwelling Adults. 6 *Aging and Ment. Health*, 109-120 (2002); Brenda K. Uekert, Richard Van Duizend, R., Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform. In *Future Trends in State Courts 2011: Special Focus on Access to Justice* (2011). Available at: http://www.guardianshipcert.org/files/publicpolicy/Uekert_Van_Duizend_Adult_Guardianships.pdf (last visited April 18, 2017).

12. Pamela Teaster, *et al.*, Wards of the State: A National Study of Public Guardianship. *Stetson Law Review*, 37, 193-241 (2007).
13. From www.JennyHatchJusticeProject.org/Jennys_Words.
14. Human Services Research Institute and The National Association of State Directors of Developmental Disabilities Services, *National Core Indicators Study*. Available at: www.nationalcoreindicators.org (statistics on guardianship provided by representative of HSRI).
15. Blanck, P., & Martinis, J. G. (2015). "The right to make choices": The national resource center for supported decision-making. *Inclusion*, 3(1), 24-33.
16. 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.
17. See, e.g., <http://www.americanbar.org/groups/disabilityrights/resources/article12.html>
18. See, e.g., http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf
19. See, e.g., https://acl.gov/NewsRoom/blog/2015/2015_01_28.aspx
20. See, e.g., http://supporteddecisionmaking.org/choices_brochure
21. Blanck, P., & Martinis, J. G. (2015). "The right to make choices": The national resource center for supported decision-making. *Inclusion*, 3(1), 24-33.
22. See, e.g., Dinerstein, R. (2012). Implementing legal capacity under article 12 of the UN convention on the rights of persons with disabilities: The difficult road from guardianship to supported decision making. *Human Rights Brief*, 19, 8-12.
23. Gustin, J. & Martinis, J. (2016). Change the culture, change the world: Increasing independence by creating a culture of coordinated support. *Apostrophe Magazine*. Available at: <http://apostrophemagazine.com/vermont-change-culture-disabilities>
24. See, e.g., <http://supporteddecisionmaking.org/content/resource-library>; <http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>
25. Missouri Revised Statute 475.075
26. See, http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf