



1



SUPPORTED DECISION MAKING
Guardianship and Conservatorship
are not your ONLY Choices!



“When are you getting guardianship? Have you considered getting a conservator?”

Every day, parents and family members of people with disabilities across Connecticut are asked “When are you applying for guardianship or conservatorship?”

People and professionals and their own families tell them they have to get guardianship of their children with intellectual and developmental disabilities and teachers tell them they must get guardianship or they can't go to IEP meetings. Doctors tell them they must get guardianship to be involved in their children's health care. Friends tell them they must get guardianship to keep their children safe.

Every day, people who are aging, people with mental illness and people with cognitive disabilities like brain injuries are put in conservatorships because families are told that this is the best way to help.

And, every day, families spend time and money on lawyers, court costs, and evaluations because they think guardianship or conservatorship is their only choice.

**Sometimes it is.
A lot of times it isn't!
There Are Other Options!**

Supported Decision Making is one of those options.

Supported Decision Making: What is It?

Supported Decision Making (SDM) is getting help when you need it, from people you choose, so you can make your own decisions¹. That's how we all make decisions.

EVERYONE.

Think about what you do when you have to make a tough choice, or a decision about something you don't know a lot about, or just want to "talk it out." You may ask a friend for advice or a professional for information, or you may have "go-to" people you talk to about specific things. They help you "think through" the issues and discuss the "pros and cons" of your choices. That way, you can understand your options and you choose the one that's best for you. When you do that, you're using SDM. People give you support, so you can decide. That's it. People with disabilities use SDM, too!

Guardianship and Conservatorship Take Away a Person's Right to Make Choices

Guardianship and conservatorship are legal processes where a Probate Judge takes away a person's right to make decisions — like where to live, 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 the person who is aging or has a disability can or may be able to make some or all life decisions, guardianship or conservatorship are not your only choices.

That doesn't mean guardianship or conservatorship are always wrong. If people really can't make decisions, guardianship or conservatorship can be helpful. But, if people can make decisions, by themselves or when they get help, putting them in guardianship or conservatorship may hurt them.

Guardianship and conservatorship take away people’s right to make choices and control their lives — their self-determination. Years and years of studies show that when people lose self-determination through guardianships or conservatorships they don’t need, it can have a “significant negative impact on their physical and mental health, longevity, ability to function, and reports of subjective well-being.”²

In almost all guardianships, the Probate Judge takes away all of the person’s rights³. In these “full” or “plenary” guardianships, the guardian has the power to make the most basic and personal life, health, financial, and other decisions instead of the person⁴. In Connecticut, conservatorships can also severely restrict, a person’s rights. In a legal sense, it’s like the person doesn’t exist.

So, guardianship and conservatorship aren’t the only option if a person can make decisions or learn to make decision by themselves or with help. There are other choices. There are other ways you can use to empower them to be as independent as possible.

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



THE Jenny Hatch STORY



SDM burst into view when a young woman named Jenny Hatch became the first person to win the right to use it instead of being put into a permanent guardianship⁵. 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 SDM⁶.

Since Jenny's case, over twenty states have passed laws recognizing SDM as an option and alternative to guardianship and conservatorship.



Why Should I Try Supported Decision-Making?

If the person who is aging or has a disability, like Jenny, can use SDM (or learn to use SDM), guardianship and conservatorship aren't your only choices. "Many, if not most" people with disabilities, even those with the most significant disabilities can use SDM to make at least some decisions in their lives.⁷ When they do, they can have more self-determination because they'll have more control over their lives.⁸ 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.⁹ Another study found that young adults with disabilities who used SDM were more independent, self-confident, better at making decisions, and made better decisions.¹⁰

Most of the time, there's no way to know if a person can use SDM unless you try. That's why you may want to at least try SDM before seeking guardianship or conservatorship, except in extreme situations. If it works, the person can live as independently as possible, have more self-determination, and may have a better life.

We are 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."¹¹

How Can I Try Supported Decision-Making?

Once you decide to try SDM, the next thing to do is figure out the best ways to make it work. The first step is realizing that you're probably using SDM already! There are almost certainly areas in their life where the person gets or has gotten help to make decisions — maybe something as simple as choosing what to eat or do or wear. The way you give them advice or choices is a form of SDM, even if you don't call it that!

That's important because 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 SDM — when and how they want to be supported and who they want support from — will be different for each person. **That's the Golden Rule of SDM: Support Others the Way they Want to be Supported.**



**Here are some steps you can take
and tools you can use to explore
and start using SDM.¹²**

5 HELPFUL STEPS



STEP 1 • LISTEN AND THINK

SDM should always be based on the person's strengths, needs, and interests. Therefore, you should start by encouraging them to think about the types of decisions they would like support to make. The [Missouri Stoplight Tool](#) can help people identify what they do well and the life areas where they want help.



STEP 2 • IDENTIFY OPPORTUNITIES

Now that you know where the person wants support, the next thing to do is identify how they want to be supported. The best way to do that is by exploring how they use support now and how they have been supported before. The [Supported Decision Making Brainstorming Guide](#) can help people identify ways they like being supported to make decisions. Then, once you've found what has worked well before (or something new they want), you can use it in other life areas.



STEP 3 • FIND SUPPORTERS

Next, connect with people and professionals that can provide the support the person wants. Don't forget to consider support you may be able to receive from state agencies or programs like Special Education, Vocational Rehabilitation, and Centers for Independent Living. In our other brochures, we'll show you ways you can use SDM in these and other programs.

You can also watch [videos](#) that can help you learn about SDM and organizations that can help.



STEP 4 • PUT IT TOGETHER

Next, work with the person and their supporters to develop an SDM 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.



STEP 5 • PUT IT IN WRITING

We recommend that you put your SDM plan in writing. While you don't have to put your plan in writing we think it's helpful. People can show their SDM plans to friends, family members, and professionals like doctors to show how they make decisions and want to be treated. They can also review their plans from time to time to make sure things are working well or change things if they're not.

You should create a plan that works best for the person. 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 or conservators, we think the National Guardianship Association's position makes sense: you should at least try SDM.

Wherever you are on your SDM journey, whether you're just gathering information or you're ready to write a plan, we can answer your questions or connect you with people and organizations that may be able to help. Feel free to contact us at: SDMinfo@gmail.com or visit ctsilc.org

References

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

This brochure was adapted, with permission, from material published by the Missouri Developmental Disabilities Council.

²Wright, 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.

³Teaster, P., Wood, E., Lawrence, S., & Schmidt, W. (2007). Wards of the state: A national study of public guardianship. *Stetson Law Review*, 37, 193-241.

⁴e.g. Karp, N., & Wood, E. F. (2007). Guardianship monitoring: A national survey of court practices. *Stetson L. Rev.*, 37, 143.

⁵For information about Jenny Hatch and her case, see www.jennyhatchjusticeproject.org

⁶Vargas, 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

⁷Salzman, 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.

⁸e.g. Blanck & Martinis, 2015.

⁹See, 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; 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.

¹⁰Martinis, 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: https://supporteddecisionmaking.org/resource_library/summary-findings-and-recommendations-of-the-virginia-supported-decision-making-pilot-project/

¹¹National 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

¹²Martinis, J. (2019). Strategies for supported decision-making. *Impact* 32(1), 45.

The preparation of this booklet was financed under an agreement with the Connecticut Council on Developmental Disabilities.



**SUPPORTED DECISION
MAKING COALITION •
CONNECTICUT**

SDMinfo@gmail.com



**CT State Independent
Living Council**

151 New Park Avenue
Hartford, CT 06106

860-681-7599
ctsilc.org

