



5



SUPPORTED DECISION MAKING Aging



Supported Decision Making Through the Years

Our minds and bodies change over time. That is a fact of life. One day, we may need more help to do things. We may come to depend more on friends, family members, and professionals to help us.

That's a good thing. We should want people in our lives who care about us and support us when we need it.

In this brochure, we'll show you how you use Supported Decision Making, or SDM, to plan for and get the help you need to keep living your best, most independent life.

We know that loss of ability can happen at any age, and aging is not inevitability about loss of ability. This brochure is simply about planning for what may happen.

Needing Help Doesn't Always Mean You Need a Guardian or Conservator

As we said, it's a good thing when people in your life want to help you. However, some people may think that, just because you need some help, you can't do things for yourself. That may lead to someone trying to put you in guardianship or conservatorship.

Guardianship and conservatorship are legal processes where a Judge decides whether you can make decisions and direct your life. If the Judge decides that you can't, they will take away some or all of your rights to make decisions about your life and give them to someone else. Studies show that, most of the time, Judges take away all of the person's rights.¹ In that case, your guardian or conservator will have the power to decide where you live, whether you work, who you can spend time with, what you do, what kind of health care you get, and how to spend your money.²

Guardianship and conservatorship can be helpful if you need them. If you really can't make decisions or manage your life, they may be right for you. But, if you can make your own decisions, by yourself or when you get help, guardianship and conservatorship can be harmful. That's because they take away people's control over their lives - their self-determination. Research shows that when people lose self-determination it can have a "significant negative impact" on their health and quality of life.³

If you have a guardian or conservator, they should still encourage and support you to make choices and express yourself. For example, if they have the power to make health care decisions for you, they should listen to you, answer your questions, and respect your opinion. That way, you'll have as much self-determination as possible.

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 decisions⁴. That's how we all make decisions.

EVERYONE.

Think about what you do when you need 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 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.

You've probably used SDM, even if you didn't call it that. For example, you may have:

- Asked friends for advice about relationships, so you can decide whether to date or marry someone.
- Talked to family members about your health needs, so you can get the care you need and want.
- Discussed work issues with a supervisor or co-worker so you can do your best on the job.
- Worked with financial or other advisors to manage your money.

When you use SDM to make your own decisions, instead of having someone else make decisions for you, you have more self-determination because you have more control over your life. That's good! It's also good for you. Studies show that when older adults and people with disabilities have more self-determination, they can have better lives: they are more likely to be independent, healthy, and safe.⁵



Using Supported Decision Making to Make Plans for When you May Experience Physical or Cognitive Change

Here are some ways you can use SDM to make sure you have the help you want and need if you experience physical or cognitive change in the future.

1 MAKE A LIST OF YOUR GOALS

First, think about and describe the kind of future life you want. This is important because it will help people understand your future goals and set up the services and supports you'll need to reach them.

You can use SDM to do this. Start by talking with people you trust about the life you want. Is there a city or town you want to live in? Do you want to live in your own home, with a roommate, or with several other people in shared living? Are there medicines that work well for you or that you don't want to take? What kind of activities do you want to do? Do you want to work?

For example, a person's list of goals might look like this:

MY GOALS

Where I want to live: I want to live in Norwalk, near my family.

How I want to live: I want my own apartment or house. I don't want to live in a nursing home or group home. I'd rather live by myself, but wouldn't mind having a roommate.

Health Care: I don't want to take medicine that makes me sleepy or makes it hard for me to think.

Working: I want a job or to do volunteer work. I'm interested in working with people who have the same interests that I do.

Education: I like learning new things. I'm interested in learning about photography, the internet, and computers.

Activities: I want to travel to new places, go to concerts and shows, and Red Sox games. There are tools and guides that can help you do this. For example, the Arc's Center for Future Planning, at <https://futureplanning.thearc.org>, can help you talk with people in your life about your goals, make your list, and share it with the people in your life.

2 MAKE A LIST OF THE SUPPORTS YOU NEED

Next, make a list of the help you want to reach your goals and in your day-to-day life. That will help you identify and set up services now and for the future.

This is a good time to use SDM. Talk to people you trust and respect. Ask them when they think you need help and how they can help you. Then, write down the times you'd like to get support and how you'd like to be supported.

For example, a person's list of supports might look like this:

WHEN I WANT TO BE SUPPORTED AND HOW

When I go to the Doctor: I want someone to come with me to help the doctor and me understand each other.

When I am managing money: I want someone to help me make a budget and work with me to make sure I am not overspending.

When I am at home and in the community: If I need it, I want someone to help me take care of myself and to help me take part in community activities, meet new people, and do new things.

When I am planning my retirement: I want to work with someone to help me plan for and manage my pension and Social Security. I want that person to help me identify, plan for, and pay for the things I want to do during my retirement.



ON-LINE TOOLS AND GUIDES TO HELP MAKE YOUR LIST

For example, the **Missouri Stoplight Tool**, at <https://www.moddcouncil.org/uploaded/Guardianship%20Manual%20Appendix%201.pdf>. can help you think about times when you want support. You can also use it when you're talking to people you know, so you can ask their opinion about things you may need help doing.

The **"Supported Decision Making Brainstorming Guide,"** at <http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>, can help you think about how you want to be supported now and in the future.

3 MAKE A LIST OF YOUR SUPPORTERS AND HOW THEY SUPPORT YOU

Next, make a list of your supporters and how they help you. Your supporters can be family, friends, or professionals who help you live your best life. For example, your doctors provide medical care and prescribe your medicine. Your friends and family help you go out in the community and in your day-to-day life. A personal care attendant may help you take care of yourself in your home and in the community.

SDM can help you do this. Your supporters can help you identify other people who support you, talk with them about how they can help you, and put the list together. Your list should include each supporter's name, address, telephone numbers, and email.

For example, a person's list might look like this for her doctor and personal care attendant:

Dr. Jada Jackson

Gives me medical care and prescribes my medicine

Address: 555 Main Street, Anytown, Connecticut

Email: JadaJackson@DrJackson.com

Office phone: 555-555-5555

Cell phone: 333-333-3333

Thomas Jones, Personal Care Attendant

Helps me take care of myself in my home and in the community

Address: 111 South Street, Anytown, Connecticut

Email: TommyJones@email.com

Office phone: 555-444-3333

Cell Phone: 444-333-2222



4 CONNECT WITH NEW SUPPORTERS

Throughout your life and, especially, as you age, you should try to identify new supporters who can help you now and in the future. For example, when you're identifying the help you want, you should contact Connecticut government and private agencies that can provide it.

The Connecticut Department of Aging and Disability Services, at <https://portal.ct.gov/aginganddisability> has information and links to agencies that can provide services and supports as you age. You can also call the Department to request services or to get information at 800-537-2549.

5 PUT YOUR PLANS IN WRITING: SUPPORTED DECISION MAKING AGREEMENTS

We recommend that you create written plans that describe your goals for now and the future, when you want support, the kinds of support you want, and who will provide it. One way to do that is to write a Supported Decision Making Agreement.

Supported Decision Making Agreements describe how you will make decisions and work with your supporters so you can reach your goals, meet your needs, and live your best life. You can share your Agreement with your friends, family, and professionals you work with like doctors, lawyers, case managers, bankers, and others. That will help them understand how you want to live your life and that they should respect your choices.

You don't have to use a special form to make a Supported Decision Making Agreement. You can write an Agreement that works best for you. The National Resource Center for Supported Decision Making has model Agreements you can adapt or use at <http://supporteddecisionmaking.org/node/390>.

We recommend that you work with your supporters, advocates, or a lawyer to help you write your Supported Decision Making Agreement. You can use the lists you made about your goals, needs, and supporters to help you do this. You can also use guides like "Setting the Wheels in Motion," at <http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>, to help you think about when you want support, the kind of support you want, and who you want to support you. The guide was designed to help parents work with their children with disabilities, but anyone can use it to work with the people in their life.

However, you should be aware that Connecticut law does not currently recognize Supported Decision Making Agreements as legally binding. Therefore, while they may serve as a guide and others may follow them, there is no law that says they have to. So, you may also want to consider other legal documents like Powers of Attorney and Advanced Directives, too.

6**PUT YOUR PLANS IN WRITING: POWERS OF ATTORNEY AND
ADVANCED DIRECTIVES**

You can also create legal forms like a Power of Attorney or Advanced Directive to plan for the future and make sure that people know what you want and respect your decisions. A Power of Attorney or Advanced Directive gives someone the right to do things or make decisions for you. In general, you use an Advanced Directive to give someone the right to make decisions about your health care. You use a Power of Attorney to give someone the right to make any other type of decision.

The good thing about Powers of Attorney and Advanced Directives is you can say how and when people should make decisions for you. That's different from a guardianship or conservatorship where Judges usually give someone the power to make decisions for you whenever and however they want. For example, in an Advanced Directive, you can give someone the right to make health care decisions only if 2 doctors find that you can't make decisions and then only after using SDM to find out what you want. You can also say that the person can never agree to certain medicine or treatments or that the person must make the decision you would make, even if he or she doesn't agree with you.

There is almost no limit to the ways you can customize a Power of Attorney or Advanced Directive to help you meet your needs and work with supporters. However, because they are legal documents, we recommend that you talk to a lawyer to help you create them.

7**MAKE A PLAN FOR THE END**

It's not fun to think about your last days, but it is important. If you make a plan now, you can tell people how you want to be treated at the end of your life - because you may not be able to tell them when that time comes.

For example, you can make a plan that describes medical treatments you do or don't want, whether you want a memorial service, whether you want to donate your organs, and where (or whether) you want to be buried. That way, when your time comes, you can end your journey the way you lived it – with you in control as much as possible.

This is a great time to use SDM. Talk with people you trust about what you'll want as you approach the end of your life. There are free tools and guides that can help you do this. "Ending Life Well," at http://www.aging-and-disability.org/en/ending_life_well, and "The Conversation Project," at <https://theconversationproject.org/starter-kits/>, can help you talk with people in your life plan and make sure your last days are the way you want them to be.

8 SHARE AND UPDATE YOUR INFORMATION

When you have your lists and plans ready, share them with your supporters. We recommend that you give copies to the people you trust and work with the most in your life: your friends, family, and professionals like doctors, case managers, personal care attendants, and others. That way, they'll know what you want and need, who else supports you, and how and when you want to be supported.

Your goals, needs, and supporters will probably change over time. Therefore, we recommend that you work with your supporters to review your lists and plans at least twice a year. If something in your life changes – if you have a new goal, want new support, or have new supporters - you should change your lists and plans. Then, share the new information with your supporters to make sure they know what you want and need!





We Can Help!

Wherever you are on your SDM journey, whether you're just gathering information or you're ready to move forward with SDM, 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

- ¹Teaster, P., Wood, E., Lawrence, S., & Schmidt, W. (2007). Wards of the state: A national study of public guardianship. *Stetson Law Review*, 37, 193-241.
- ²e.g. Blanck, P. & Martinis, J. (2015). "The right to make choices": The national resource center for supported decision making. *Inclusion* 3(1), 24-33.
- ³Wright, 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.
- ⁴Blanck, P. & Martinis, J. (2015). "The right to make choices": The national resource center for SDM. *Inclusion* 3(1), 24-33.
- ⁵e.g., 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; Mallers, M. H., Claver, M., & Lares, L. A. (2014). Perceived control in the lives of older adults: The influence of Langer and Rodin's work on gerontological theory, policy, and practice. *The Gerontologist*, 54(1), 67-74; O'Connor, B. P., & Vallerand, R. J. (1994). The relative effects of actual and experienced autonomy on motivation in nursing home residents. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 13(4), 528-538.

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

CONNECTICUT



**CT State Independent
Living Council**

151 New Park Avenue
Hartford, CT 06106

860-681-7599
ctsilc.org

