

Getting Older, Getting Better

Supported Decision-Making
through the Years

We all get older - it's a fact of life.

One day, we may realize that we don't move or think as quickly as we used to, or that we need more help to do things.

As we get older, we may 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 and support us.

In this brochure, we'll show you how you can work with the people in your life, using Supported Decision-Making, to plan for and get the support you need to live your best, most independent life as you get older.

Needing Help Doesn't Always Mean Needing a Guardian

As we said, it's a good thing when people in your life want to help you. However, some people may think that, because you need help, you can't manage your life or make your own decisions. That may lead to someone trying to put you in guardianship.

Guardianship is a legal process where a Judge decides whether you can make decisions. If the Judge rules that you can't, he or she will take away some or all of your rights to make decisions about your life and give them to someone else. In most guardianships, the Judge takes away all of the person's rights.¹ So, if you are put in a "full" guardianship, your guardian 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

We're not saying that guardianship is always bad or wrong. If you truly can't make decisions, guardianship may be right for you. But, if you can make your

own decisions, with or without help, guardianship can be harmful. That's because guardianship takes 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're in a guardianship, your guardian should still encourage and support you to make choices and express yourself.

For example, if your guardian makes health care decisions for you, your guardian and doctor should listen to you, answer your questions, and respect your opinion about treatment or medicine you do or don't want. That way, you'll have as much self-determination as possible.



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 without a guardian.⁴

Isn't that how everyone – people with and without disabilities - makes decisions? When you have to make a tough choice or just want to “talk it out,” what do you do?

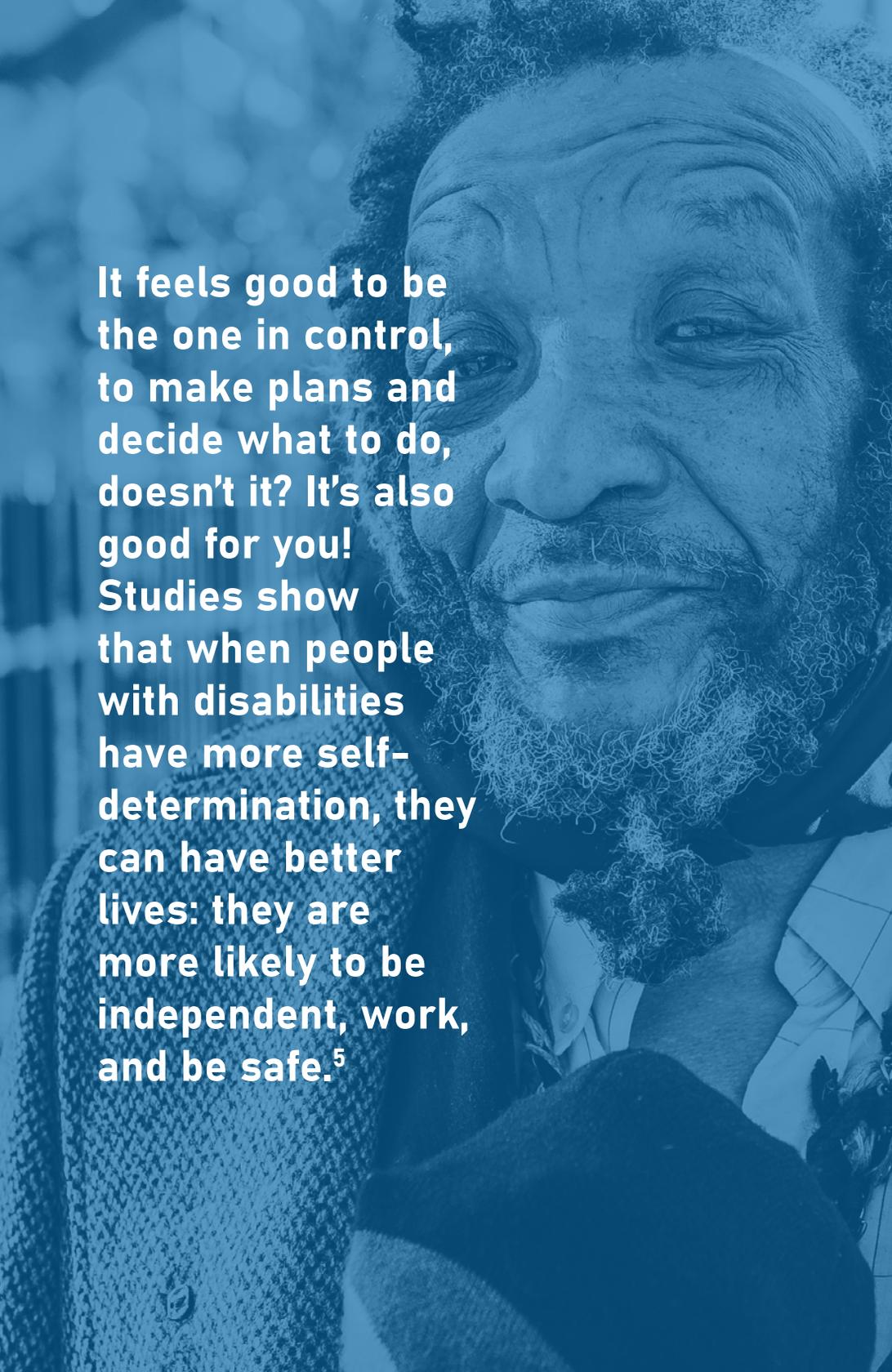
You get help, don't you? You go to your friends, family or people you work with so they can help you understand your options, think about what to do, and make the best choice for you. It's simple. They give you information and advice. You make the decision. They support, you decide.

That's Supported Decision-Making.

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

- Asked friends for advice about relationships, so you could decide whether to date or marry someone.
- Talked to family members about money, so you could decide whether to buy something.
- Worked with a job coach or mentor so you could choose where to work.
- Met with your case manager to create a Person Centered Plan or set up community activities and supports.

When you use Supported Decision-Making to make your own decisions, instead of having a guardian make decisions for you, you have more self-determination because you control your life.



It feels good to be the one in control, to make plans and decide what to do, doesn't it? It's also good for you! Studies show that when people with disabilities have more self-determination, they can have better lives: they are more likely to be independent, work, and be safe.⁵

Using Supported Decision-Making to Make Plans for When You Get Older

Here are some ways you can use Supported Decision-Making now to make sure you have the help you want and need as you get older.

MAKE A LIST OF YOUR GOALS

First, you should use Supported Decision-Making to describe the kind of life you want when you're older. This is important because it will help people understand your future goals and set up the services and supports you need to reach them.

Talk with people you know and 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 Jefferson City, 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 don't mind having a roommate, but I don't want more than one.

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

Working: I want a job or to do volunteer work. I like working with people. I'm interested in computers and tools.

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

Activities: I want to travel, go to art shows and music concerts, and Cardinals 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 your friends, family members, and professionals.

MAKE A LIST OF WHAT YOU NEED

Next, think about and make a list of the support you want to reach your goals and in your day-to-day life. The list will help you and your supporters set up your services now and in the future.

This is a good time to use Supported Decision-Making. Talk to people in your life who 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 saving money and don't spend more than I have.

When I am working: I have a job coach who helps me at work. I want to keep working and having a job coach. I want to get more job training and get a job working with computers.

When I am at home and in the community: I have a personal care attendant who helps me take care of myself. I want to keep working with her so I can do more community activities, meet new people, and do new things.

When I am planning my supports: I want to meet with my case manager before plan meetings to talk about my options so I can make my Person Centered Plan.

When I am planning my retirement: I want to work with someone to help me plan for and manage my retirement funds (including my pension). I also want to work with someone to help me identify, plan for, and do the things I want to do during my retirement.

You can use on-line tools and guides to help make your list. For example, the Missouri Stoplight Tool, at <http://bit.ly/mostoplighttool>. 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.

MAKE A LIST OF YOUR SUPPORTERS AND HOW THEY SUPPORT YOU

Next, you should think about and make a list of your supporters and how they help you. Your supporters are people you trust, who help you live your best life. They can be family, friends, or professionals. 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. Your personal care attendant helps you take care of yourself in your home and in the community. Your case manager helps you set up supports and take part in activities.

You can use Supported Decision-Making to 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,
Jefferson City, Missouri.

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,
Jefferson City, Missouri.

Email: TommyJones@email.com

Office phone: 555-444-333

Cell Phone: 444-333-2222



CONNECT WITH NEW SUPPORTERS

You should also try to identify new supporters who can help you now and as you get older. For example, when you're thinking about the help you want, you should contact Missouri government and private agencies that can provide those services and supports.

The Missouri Disability Portal, at <https://disability.mo.gov/aging.htm>, has information about and links to agencies that serve older adults and people with disabilities.

Also, if you're not working with the Division of Developmental Disabilities, we recommend that you contact them. To find the office nearest you, go to: <https://dmh.mo.gov/dd/facilities/> or call 1-800-364-9687.

The Division can help you apply for a Medicaid Waiver program. If you qualify for a Waiver, you can receive many supports and services to help you stay healthy and independent all through your life.⁶ Even if you're not eligible for a Waiver program, you may qualify for services from the Division. If you qualify, you can work with the Division to develop a plan to receive the supports and services you need now and in the future.⁷

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 in Missouri. 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.

A Supported Decision-Making Agreement can also show that you don't need a guardian. Missouri law says that Judges should not put people in guardianship if they can use Supported Decision-Making.⁸ Therefore, a Supported Decision-Making Agreement may protect you if someone tries to put you in a guardianship.

PUT YOUR PLANS IN WRITING: POWERS OF ATTORNEY & 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 where Judges usually give guardians the right to make all decisions how and when they want. For example, in an Advanced Directive, you can give someone the right to make health care decisions only if two doctors find that you can't make decisions and then only after using Supported Decision-Making 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.



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 says if you want to pass away at home, if possible. Your plan can also describe medical treatments you do or don't want, whether you want a memorial service, and where (or whether) you want to be buried. That way, people will know what you want and, 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 time to use Supported Decision-Making. Talk with your friends, family, and professionals about what you'll want when 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 your supporters and make plans so your last days are the way you want them to be.

SHARE YOUR INFORMATION WITH YOUR SUPPORTERS AND UPDATE IT

When you have your lists, plans, and Agreements ready, you should 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 in your life, who else supports you, and how and when you want to be supported.

Your goals, needs, and supporters will probably change over time. You could have different plans, support needs, and people in your life next month, next year, or five years from now. 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.

References

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6. Missouri Division of Developmental Disabilities. (2018). Missouri's medicaid waivers for individuals who have developmental disabilities (fact sheet). Available at: <https://dmh.mo.gov/dd/progs/waiver/docs/waiverfactsheet.pdf>
7. Missouri Division of Developmental Disabilities. (n.d.). Individual, family, and guardian info. Available at: <https://dmh.mo.gov/dd/individualFamilyGuardianInfo.htm>
8. e.g. Missouri Code, Chapter 475.075



We Can Help!

Whether you're just starting to think about your future or you want to put a plan in place, we can help! We can answer your questions or connect you with people and organizations that may be able to work with you.

Feel free to contact us at:
(800) 500-7878
moddcouncil.org



OUR NETWORK PARTNERS

**Missouri Protection and
Advocacy Services**

(800) 392-8667
moadvocacy.org

**UMKC Institute for Human
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