



My Health, My Life, My Choices: Supported Decision-Making and Health Care

My Health, My Life, My Choices: Supported Decision-Making and Health Care

What if I need help taking care of myself? What if my doctors don't understand me or I don't understand them? What do I do if it's hard to manage my medication?

People with disabilities ask these questions every day.

We all need to take care of our health. We have to go to doctors, take medicine, eat right, and be safe. But none of us do it alone. We all have people in our lives who help us take care of ourselves and be healthy.

This brochure will tell you about ways you can take care of your health with help from people you trust. That's called Supported Decision-Making or SDM.

Taking the Lead: Self-Determination

Do you like being in charge of your life? Do you want to be the one who decides who you spend time with, where you go, and what you do? We all do.

When you make decisions about your life, it's called self-determination. When you're self-determined you make choices instead of someone else telling you what to do. When you go to the doctor, you talk to the doctor and decide what to do.

It's good to be self-determined and self-determination is good for you. Studies show that when people with disabilities make more decisions and are more self-determined, they have better lives: they're more likely to be healthy, independent, and safe. So, self-determination is the key to living your best, healthiest life.

Getting Help: Making Self-Determination Work

But being self-determined doesn't mean you never need help. Like we said, everyone needs help. We all get different kinds of help from different people at different times. We may:

- Ask friends and family for advice about relationships.
- Talk to co-workers about ways to do our jobs better.
- Go to professionals for help with health and money.

Getting help doesn't mean you're not self-determined. It means you're getting what you need to make the best decisions about your life. Getting help is smart because it helps you be self-determined.

It's especially important to get help when you go to the doctor. You may not be feeling well or you might be nervous. It may be hard to explain what's wrong or to understand what the doctor is talking about. That's why it's good to have someone with you to make sure that you and the doctor understand each other.

Here are some ways you can get help making health decisions.

Someone Else Makes the Decision: Guardianship

If a Judge decides that you can't make decisions, the Judge will choose a guardian to make decisions for you.

If you really can't make decisions, guardianship may be good for you. But, your guardian should still help you make as many choices as you can. So, your guardian and doctor should make sure you have a chance to:

- Talk about how you feel and what you want.
- Ask questions and learn about what you need to be healthy.
- Say what you think you should do or what medicine you should take.

Getting Help to Make Your Own Decisions: Supported Decision-Making

Another way is to make your own decisions with help from people you trust. That's called Supported Decision-Making or SDM.

Isn't that how we all make decisions? When you have to make a tough choice and don't know what to do, or just want to "talk it out," what do you do?

You get help. We all do. You may ask a friend for advice or a professional for information to a family member for their opinion. They help you "think through" the issues, discuss the "pros and cons," or figure out what you could do. That way, you can understand your choices and pick the one that's best for you.

When you do that, you're using Supported Decision-Making. People

you trust give you support, so you can decide.

Health care decisions can be hard. You and your doctor have to understand each other:

- The doctor has to understand how you're feeling.
- You have to understand what the doctor thinks you should do.
- You have to decide what to do and tell the doctor.

Supported Decision-Making can help you do all those things. People you trust can help you:

- Explain how you're feeling.
- Understand and answer questions from the doctor.
- Understand what the doctor says you should do to take care of yourself.
- Think of questions to ask the doctor.
- Make sure the doctor understands your questions.
- Think about your options and what you want to do.
- Help you think about your options and discuss them with the doctor.

Using Supported Decision-Making for Your Health and in Your Life

Even though everyone needs help sometimes, we all need help at different times and in different ways. So, you should find the ways and supporters that work best for you.

Here are some ways you can use Supported Decision-Making in your life.

When do you Want to use Supported Decision-Making?

First, think about when you want to use Supported Decision-Making. Remember, Supported Decision-Making is about you and your life and health. So, think about times when you want someone to help you take care of your health or about a time when it would have been good to have help in your life.

It might help to talk to people you trust. Ask them when they think

you could use help or how they could help you.

You can also use on-line tools. The Missouri Stoplight Tool can help you think about your health and other life areas where you may want help making decisions.

How do you Want to be Supported?

Next, think about how you want to be helped. Start by thinking about help you've gotten before. Did someone go to the doctor with you or give you good advice? How did they do it? What have you done before when you had to make a tough choice? If something worked well before, you might want to try it again.

The Supported Decision-Making Brainstorming Guide can help you think of ways you used Supported Decision-Making before and how you may want to use it now.

Who can Help?

Next, think about who can help you when you need it. You can talk to your friends, family members, and professionals. Tell them about when and how you want help and ask if they'll help you with your health and in your life.

Remember, there are many different ways to get help. You can work with different people, at different times, to help you do different things. You may want:

- A friend to go to appointments with you.
- Your family to help you remember to take your medication.
- Your case manager to help you pick your providers.
- A healthcare professional to help you make a plan to take care of yourself.

After you talk with the people you want to help you, make a plan for how they'll do that. The Setting the Wheels in Motion guide can help. It was designed to help parents, but you can also use it work with people in your life.

Writing it Down

Finally, we think it's a good idea to write a Supported Decision-Making

Agreement that says when you want help, who you want to help you, and how they'll help you. You don't have to put your plan in writing, but if you do you can give it to your doctors and other people in your life so they'll know when you want help and who will be helping you.

You don't have to use a special form to write a Supported Decision-Making Agreement. You can write one that works best for you. There are model forms you can use or you can work with advocates or attorneys to help you write your own form.

Always remember, it's your health, your life, and your decisions. So, choose the help and helpers who work best for you!

REFERENCES

- 1 e.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; Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education & Training in Developmental Disabilities*, 38(2), 131-144; 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.
- 2 Blanck, P & Martinis, J. (2015). "The right to make choices": The national resource center for SDM. *Inclusion* 3(1), 24-33.
- 3 e.g. Martinis, J. & Blanck, P. (2019). *Supported Decision-Making: From Justice for Jenny to Justice for All. A Theory to Practice Guide*. Virginia: Something Else Solutions Press.
- 4 Martinis, J. (2019). Making it happen: Strategies for supported decision-making. *Impact* 32(1), 45.

This brochure 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).

We Can Help!

Wherever you are on your Supported Decision-Making journey, we can answer your questions or connect you with people and organizations that may be able to help. Feel free to contact us at:

Disability Rights Nebraska

134 S. 13th St., Suite 600

Lincoln, NE 68508

402-474-3183

www.disabilityrightsnebraska.org

Brad Meurrens, Public Policy Director, brad@drne.org

Nebraska Council on Developmental Disabilities

301 Centennial Mall South

Lincoln, NE 68509

402-471-2330

www.dhhs.ne.gov/pages/DD-Planning-Council.aspx

Nebraska University Center for Excellence in Developmental Disabilities

Munroe-Meyer Institute for Genetics and Rehabilitation

6902 Pine Street

Omaha, NE 68106

402-559-6483

www.unmc.edu/mmi

The Nebraska Council on Developmental Disabilities is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$527,570 with 100% funding by ACL/HHS. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusion. Points of view or opinions do not, therefore, necessarily represent official ACL policy and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

**Scan this code with your
smart phone's camera for
additional resources.**



Or visit [disabilityrightsnebraska.org/
what-we-do/supported-decision-making](http://disabilityrightsnebraska.org/what-we-do/supported-decision-making)



Disability Rights Nebraska
Protection and Advocacy for People with Disabilities