

SUPPORTED DECISION MAKING

A guide for people with disabilities and their families

About this Guide

This guide is adapted (with permission) from the American Civil Liberties Union's "Making A Supported Decision Making Agreement: A Guide for People with Disabilities and their Families." It is intended to provide individuals with disability and their families with information on how to make a supported decision-making agreement that is individualized to the person with disability.

The activities in this guide are meant to assist the person with disability and their family to evaluate choice making, support needs and consider who is the best person to help the person in decision-making.

Many options, other than guardianship, are available to provide counsel, guidance and assistance with making decisions. The principles of Informed Choice, Person Centered Planning and Self-Determination dictate that adults with disabilities are respected and supported in making their own life decisions. Individuals who can make life decisions with support from others around them should be enabled to do so.

Supported decision-making is recognized as a less restrictive alternative to guardianship; whereby, trusted supporters are afforded the legal status to be with the adult, participate in discussions, help gather and evaluate information, consider and communicate decisions so individuals with Intellectual and/or Developmental Disabilities ("I/DD") understand the situations and choices they face and can make their own decisions without the need for a guardian.

Terms to Know

- Agreement = something that you say you are going to do
- SDM = Supported Decision Making
- Supporter = a person who looks out for and encourages someone (family or friend)
- Witness = someone who agrees to the genuineness of a document or signature by adding their own signature.
- Decider = the person being supported when they make their choices

We all make supported decisions every day – Supported Decision Making Agreements make sure other people respect the decisions you make with help or support and keep you as the decider.

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SECTION 1: WHAT IS SUPPORTED DECISION MAKING?

Supported decision-making, or SDM, is a way to get help in making choices. Supported decision-making means that you make your own choices. You can choose family, friends or staff who you want to help you make your choices.

The people who help you understand and make your choices are called supporters. They are there to help you, but you are the one to make the final decision. You are called the decider.

You should read and talk about this guide with people you trust. This book has questions and activities that will help you think about how you want to use supported decision-making.

It will take a while to read through this book and do all of the activities. You might spend a month or more working on it. That's OK! Using supported decision-making takes time.

Though this guide is written with the primary audience of the decider in mind, whether you are a supporter, individual, or even a provider, there is something here for you to think about as you at every stage of your journey.

SECTION 2: THINKING ABOUT CHOICES

This activity will help you think about how you make choices. You can talk about what kind of help you like and don't like. You can think about choices you have made and what you liked and didn't like when you were choosing.

Think about a choice that you made. It could be a choice about:

- Where you live
- What you will do in school
- Where you work
- Who you spend time with
- If you want to go to the doctor
- If you want to go on a date
- What and when you eat
- How you spend and save your money
- ...or anything else!

Stop and think about what choice you remember...

Write down the choice that you want to think about and talk about:

Stop and think **who made the choice. . .**

Who made the choice – did you have help or did someone take over?

I made the choice alone

I made the choice, but someone helped me. The people who helped me were:

Someone else made the choice for me. The person who made the choice for me is:

Think about **how you made the choice. . .**

When you made your choice, did you. . .

- ...talk about it? Who did you talk with?
- ...write down your possible options?
- ...write down the good and bad things about each choice (pros and cons)?
- ...visit places (like a home, office or school)?
- ...do research?
- ...talk to people who had made the same choice before?

List what you did to help you make your choice:

Think about how you **felt** about the choice. . .

What did you like and dislike about making this choice?

- Did you feel like you understood your choice?
 - Yes or No
- Did you understand all of your options (different choices you could make)?
 - Yes or No
- Could you communicate or tell someone about your choice?
 - Yes or No
- Did anyone help you tell someone about your choice?
 - Yes or No
- Did you have enough time to make sure you were happy with your choice?
 - Yes or No
- Did you know what to do if you had questions about your choice?
 - Yes or No
- Did you feel like you could say “no” if you did not want help?
 - Yes or No
- Are you happy now with the choice you made?
 - Yes or No
- Could you change your mind if you wanted to make another choice?
 - Yes or No

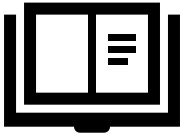






List what you liked and did not like about making this choice.

Some things I liked about making this choice	Some things I did not like about making this choice

SECTION 3: THINKING ABOUT SUPPORT

Supported decision-making lets you get help or support in making your own choices. Everyone gets support in making choices every day.

Some kinds of support are:

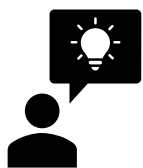
	Plain language information. This means written information in provided in simple words. This helps everyone understand what is being talked about.
	Information in pictures or explained. This means getting information in pictures or by someone talking to you.
	Research to learn more about choices. This means looking for information like on the internet, at the library, or from somewhere you trust so you can understand the things you like or don't like about a choice.
	Help in knowing what choices you have. This means asking someone for advice or where to find plain language information, something explained or even just getting help to go somewhere to get more information.
	Extra time to think about choices. This means that if you need time and space to go through your decision making process, that is a kind of support. Sometimes we need quiet or a break before we make a choice and that is okay.
	Visits and trials. This means trying out different choices, to see how you feel and which one you like. If you are trying to decide on a new place to live, maybe you would visit the neighborhood at different times to see if it is where you would like to live.
	Reminders about important dates and times. This means that maybe you just need some help remembering to go somewhere or meet with somebody. Once you're there, the choices are all up to you!



Help in thinking about pros and cons. This means making lists of the good and bad parts of different choices. A “pro” is something that you think is good about a choice. A “con” is something you think is not good about a choice. This doesn’t make the choice all good or all bad, you are trying to decide how you feel and can get help figuring out what is important to you.



Having a supporter come to a meetings and appointments with you. This means that you can have someone you trust there with you when you are hearing about choices or making choices. They can sit and listen if you want or they can help you communicate or something different that you need. You are in charge even if you have someone there with you.



Talking to experts who know a lot about your choice. This is a lot like research but from people who have special knowledge about your choice. Experts can also help with pros and cons about choices, maybe they have made those choices themselves before.



Reminding you of your values. Supporters can help you remember what is most important to you. They can remind you how these things might affect your choice. This does not mean telling you what their feelings about your choices are – it means that if you shared with them how important something was to you, they can help you stay true to yourself and not be pressured or rushed into something you don’t want.




Classes to learn about healthy choices. This means going to an information session or some classes to learn more about what might be good for you in your life.



Help communicating a choice. After you have made a choice, someone might make sure that everyone understands and responds to your choice.



Technological support. This means using your phone or computer or tablet to help with choices. Some people use their phones for research, reminders, or just to call a friend or family member to get advice. Other people

	may use technology to help them communicate their choices or access information about their choices.
	<p>Advice from supporters. This means hearing someone else’s opinion – their opinion may be based on their experiences, feelings, or research so even if you get advice, you are still the decider. Always be careful to choose people you trust. Sometimes people you don’t trust could give advice that is good for them but not for you</p>

**Those are a lot of ways to get support!
Here is an example in action...**

Mary lives with her mom and dad and is over 18. Now she wants to move away from home like many of her friends.

Mary has a bank account, but the letters she gets from the bank are confusing. Her mom explains to Mary how much money she gets every month, and how much she can spend each month on rent. Mary’s mom is taking the information from the bank and giving Mary **plain language information**.

Once she knows how much money she can spend, Mary’s service coordinator helps her find apartments that she can afford. Mary makes a list of her choices. The service coordinator takes Mary to **visit each apartment**, so she can see what they look like.

The service coordinator also helps Mary write lists of **pros and cons** of each apartment. One apartment is very big but is far from the bus Mary would need to take to work each day. Another apartment is smaller, but is very close to the bus stop so she would not have to wake up as early to make it to transportation.

In the smaller apartment, Mary can get to work or see her friends quickly. In the big apartment, Mary will have more room for her things, but she will need help going to see her friends or take longer to get to work.

Mary shows her list of pros and cons to her mom and dad.

Mary’s dad reminds Mary of how much she likes taking the bus and how important it is for her to be able to visit with her friends and travel alone without waiting for someone else to give her a ride. Her dad is **reminding Mary of her values**, those things that are important to Mary.

It is very important to Mary to be independent. Mary decides to move to the smaller apartment, so she can get to work on her own and see her friends quickly.

Mary made her own choice, but her parents and her service coordinator helped her understand, think about, and make her choice.

Mary used **supported decision-making**.

Questions to Think About

- Did you use any support in making the choice from the activity in Section 2?
- Can you think of support that would have helped you make that choice?
- Have you used supports in other choices?

Activity: Make a List of Supports That Can Help You

Make a list of supports that can help you. You can also circle the ones on the previous pages.

Supports that can help me

SECTION 4: WHEN DO I WANT SUPPORT?

You can make lots of choices on your own. But you might need or want support making some kinds of choices, especially difficult or important choices.

This activity will help you think about all the choices you have to make in your life.

You will think about whether you want to make those choices alone, or with support, or if you want someone else to make those choices for you. This will help you decide how you want to use supported decision-making.

The worksheet below describes different parts of your life.

Think and talk about whether you can do each thing by yourself or if you want support to do it.

Think about how you make these choices now, and whether you want to change anything.

You don't have to check a box for all of these areas now. Some of them might not be important to you. You might want to think more about some of them before you decide.

If you want support, write down what kinds of support you want. There are many, many kinds of support a decider can get. Look at the list of supports in Section 3 to help you think of ideas.

When Do I Want Support?







Check the boxes to say if you want support in each area.





If you check the box that says "I want support to do this," you can write what kind of support you want.

You do not have to check a box for everything, just the ones you want.

	I can do this alone 	I can do this with support 
Communication		
Telling people what I want and don't want.	<input type="checkbox"/>	<input type="checkbox"/>
Telling people how I make choices.	<input type="checkbox"/>	<input type="checkbox"/>
Making sure people understand what I say.	<input type="checkbox"/>	<input type="checkbox"/>
Home and Friends		
Choosing where I live.	<input type="checkbox"/>	<input type="checkbox"/>
Choosing who I live with.	<input type="checkbox"/>	<input type="checkbox"/>
Choosing what to do for fun.	<input type="checkbox"/>	<input type="checkbox"/>
Choosing who to spend time with.	<input type="checkbox"/>	<input type="checkbox"/>
Keeping my room or home clean.	<input type="checkbox"/>	<input type="checkbox"/>
Finding support services and hiring and firing my support staff.	<input type="checkbox"/>	<input type="checkbox"/>
Personal Care		
Choosing what I wear.	<input type="checkbox"/>	<input type="checkbox"/>
Getting dressed.	<input type="checkbox"/>	<input type="checkbox"/>
Choosing what to eat and when to eat.	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of my personal hygiene (bathing, brushing hair, brushing teeth).	<input type="checkbox"/>	<input type="checkbox"/>
Remembering to take medicine.	<input type="checkbox"/>	<input type="checkbox"/>
Travel		
Traveling to places I go often (work, stores, friend's homes).	<input type="checkbox"/>	<input type="checkbox"/>
Traveling to places I do not go often (doctor's appointment, special events, vacation).	<input type="checkbox"/>	<input type="checkbox"/>

	I can do this alone 	I can do this with support 
Jobs		
Choosing where I want to work.	<input type="checkbox"/>	<input type="checkbox"/>
Understanding my work choices.	<input type="checkbox"/>	<input type="checkbox"/>
Choosing classes or training I need to get a job I want, and taking these classes.	<input type="checkbox"/>	<input type="checkbox"/>
Applying for a job.	<input type="checkbox"/>	<input type="checkbox"/>
Going to my job every workday.	<input type="checkbox"/>	<input type="checkbox"/>
Health Choices		
Choosing when to go to the doctor or the dentist.	<input type="checkbox"/>	<input type="checkbox"/>
Making medical choices in everyday situations (checkup, medicine from drug store).	<input type="checkbox"/>	<input type="checkbox"/>
Making medical choices in serious situations (surgery, big injury).	<input type="checkbox"/>	<input type="checkbox"/>
Making medical choices in an emergency.	<input type="checkbox"/>	<input type="checkbox"/>
Relationships		
Choosing if I want to date, and who I want to date.	<input type="checkbox"/>	<input type="checkbox"/>
Making choices about sex.	<input type="checkbox"/>	<input type="checkbox"/>
Making choices about marriage.	<input type="checkbox"/>	<input type="checkbox"/>
Making choices about birth control and pregnancy.	<input type="checkbox"/>	<input type="checkbox"/>
Making choices about my privacy and who I tell about my relationships.	<input type="checkbox"/>	<input type="checkbox"/>
Making choices about what I do with my body.	<input type="checkbox"/>	<input type="checkbox"/>

	I can do this alone 	I can do this with support 
Staying Safe		
Making safe choices around the house (turning off the stove, having fire alarms).	<input type="checkbox"/>	<input type="checkbox"/>
Making safe choices in my community.	<input type="checkbox"/>	<input type="checkbox"/>
Understanding and getting help if I am being treated badly (abuse or neglect).	<input type="checkbox"/>	<input type="checkbox"/>
Making choices about alcohol and drugs.	<input type="checkbox"/>	<input type="checkbox"/>
Money		
Paying the rent and bills on time.	<input type="checkbox"/>	<input type="checkbox"/>
Keeping a budget so I know how much money I can spend.	<input type="checkbox"/>	<input type="checkbox"/>
Making big decisions about money (opening a bank account, signing a lease, buying a car).	<input type="checkbox"/>	<input type="checkbox"/>
Making sure no one is taking my money or using it for themselves.	<input type="checkbox"/>	<input type="checkbox"/>
Being a Citizen		
Signing contracts and formal agreements.	<input type="checkbox"/>	<input type="checkbox"/>
Choosing who to vote for and voting.	<input type="checkbox"/>	<input type="checkbox"/>
(Write in other choices/activities)		
	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 5 – WHO ARE MY SUPPORTERS?

This will help you think about who you want to support you.

Supported decision-making has both **supporters** and **deciders**.



You are the decider.

You can choose who will be your supporters. You can have many supporters. You might want some supporters to help you with some things, but not others. For some things, you might want two or three people to support you. For other things, you might just want one supporter.

You can always change your mind and change your supporters.

Every supporter should be:

- ✓ Someone you trust
- ✓ Someone who agrees to be a supporter



The people I might want to be my supporters are (write as many people as you want):

- _____
- _____
- _____

You can choose different supporters for different decisions. Maybe your friend can help you research choices about where you live but you want your mom to remind you about your doctor's appointments.

SECTION 6 – TALKING TO MY SUPPORTERS

You will have to ask your supporters if they can help you. They might say no. They can still be your friends even if they don't feel like they can be your supporter

You will talk to the people who might be your supporters. You will find out if they can support you, and you will talk about how they will support you.

Make a time to meet with each person you want to support you. You can have meetings with each person separately, or with many people together. This is up to you. Your supporters only need to know about each other if you want them to or if they need to work together to support you.

Give them a copy of the paper "What is Supported Decision-Making and What Does a Supporter Do?" (at the end of this guide) to help them understand what you want to talk to them about.

Many people don't know about supported decision-making, so you might have to explain it. They might be worried they have to take responsibility for the choices you make when they help.

When you meet with your supporters, you should talk about:

- ✓ What kind of support or help you want from this person.
- ✓ Whether this person agrees to be a supporter.
- ✓ How you want to get support.
- ✓ Whether your supporters can talk to each other when you are not there.

Fill out the worksheet about working with supporters on page 17 with each person who might support you. There is an extra copies at the end of this guide.

Worksheet: Meeting Guide For a Possible Supporter

Decider's Name: _____

Possible Supporter's Name: _____

I (Decider _____) want support from this person in these parts of my life:
(look at Section 4 for more information about these areas)

Living and Working

- | | |
|--|--|
| <input type="checkbox"/> Choosing work or day programs | <input type="checkbox"/> Getting to work or programs |
| <input type="checkbox"/> Choosing where to live | <input type="checkbox"/> Keeping my home clean |
| <input type="checkbox"/> Selecting support services | <input type="checkbox"/> Finding, hiring, firing staff |

Personal Care

- | | |
|---|---|
| <input type="checkbox"/> Clothing Choices | <input type="checkbox"/> What I eat and when I eat |
| <input type="checkbox"/> Personal hygiene | <input type="checkbox"/> Remembering to take medicine |

Staying Safe

- | | |
|---|--|
| <input type="checkbox"/> Safe choices at home | <input type="checkbox"/> Safe choices in the community |
| <input type="checkbox"/> Help if I am treated badly | <input type="checkbox"/> Choices about alcohol and drugs |

Money

- | | |
|--|-----------------------------------|
| <input type="checkbox"/> Paying rent and bills | <input type="checkbox"/> Saving |
| <input type="checkbox"/> Protecting my money | <input type="checkbox"/> Spending |

Relationships

- | | |
|---|---|
| <input type="checkbox"/> Free time/recreation | <input type="checkbox"/> Dating and sex |
| <input type="checkbox"/> Marriage | <input type="checkbox"/> Birth control |

Health Choices

- | | |
|---|---|
| <input type="checkbox"/> When to go to the doctor | <input type="checkbox"/> Medication |
| <input type="checkbox"/> Non-emergency care | <input type="checkbox"/> Emergency care |

- Mental health care

Communication

- | | |
|--|---|
| <input type="checkbox"/> Expressing likes and dislikes | <input type="checkbox"/> Expressing choices |
|--|---|

Other

Write any other areas where you want support:

The kind of support I want from this person is:

(look at Section 3 for ideas about different kinds of supports like Research, Advice, and More!)

I want to communicate with this supporter in these ways (check as many boxes as you want):

Talking on the phone

Texting

In Person

Other: _____

I want to get support from this supporter at these times (check as many boxes as you want):

On a regular schedule. Write down how often you will meet with this person, like “every week” or “every month.” We will meet every: _____

Only when I have a question or want advice.

Questions my possible supporter has about Supported Decision-Making:

Questions I have about Supported Decision-Making:

SECTION 7 – WRITING A SUPPORTED DECISION MAKING AGREEMENT

- 1) You have thought about when you want support and thought about the kind of support you want.
- 2) You have talked to people who can support you.

You are ready to put together your supported decision-making agreement!

This activity will help you write out your agreement. It will also make sure all your supporters know each other and agree to support you. **You don't have to use a form but the form might help you.**

In Nevada, all you need is something that is in writing, names one or more supporters, say what a supporter can and can't do, be signed by the decider and any supporters, and have two other people sign to say that the decider and supporters were there and made the agreement.

What to do:

1. Look at the Supported Decision-Making Agreement sample form.
2. Look back at Section 5 to remind yourself who will be your supporters and what kind of support they will give you.
3. Fill out the Supported Decision-Making Agreement, *but do not sign it yet*. Write down who your supporters are and what help you want from them.
4. Plan a time that all of your supporters can meet with you. They should all be together at the same time.
5. Plan to have two witnesses, who are not supporters, available at the meeting. In Nevada, a Supported Decision-Making Agreement is required to have two witnesses.
6. When everyone is together, someone will read the Supported Decision-Making Agreement out loud. This is important to make sure everyone understands the agreement.
7. Sign the agreement. You sign the agreement to say that you want to do supported decision-making.
8. Have your supporters sign the agreement. They sign the agreement to say that they will help you make your own choices. They also sign the agreement to say that they know that you are the decider.
9. The witnesses will sign and date the agreement. The witnesses sign the agreement to say that they saw you and the supporters sign the agreement.
10. Congratulations! You are ready to start using supported decision-making! Some people like to celebrate.

SECTION 8 – WHERE CAN I LEARN MORE?

- American Civil Liberties Union Disability Rights Program

<http://www.aclu.org/supported-decision-making-resource-library>

- National Resource Center on Supported Decision-Making

<http://www.supporteddecisionmaking.org>

- Center for Public Representation Supported Decision-Making Pilot Project

<http://www.supporteddecisions.org>

- Nevada Governor’s Council on Developmental Disabilities Council

<http://www.nevadaddcouncil.org>