

Staying Healthy, Staying Connected: Supported Decision-Making in a Pandemic

Pandemic. COVID-19. Social Distancing. Personal Protective Equipment.

No one thought about those words in 2019. But now they're everywhere. They make us think of people dying and about staying away from our friends and wearing masks.

Sometimes, it feels like no one knows what to do or that we'll never get back to normal. At times like these, it's more important than ever to support the people we care about and get the support we need.

This brochure will show you ways you can use Supported Decision-Making to stay healthy and connected now and in the future.



What is a Pandemic?

A pandemic is a disease that spreads around the world. We all know about diseases that we can catch from other people, like a cold or the flu. When people all over the world get a disease at the same time, it's called a pandemic.

Right now, we are in a COVID-19 pandemic. COVID-19 is a contagious disease because one person can give it to others by coughing, sneezing, or even breathing on them. COVID-19 is so contagious that millions of people, all over the world, have caught it.

COVID-19 affects different people in different ways. Some people don't even know they have it. Others feel like they have a cold or the flu. Some people get so sick they have to go to the hospital. And some people die from it.

The COVID-19 pandemic will end someday. There will be a treatment or a vaccine or so many people will get it that it won't get many people sick anymore. But, another pandemic can come at any time.

It's important to take care of yourself during the COVID-19 pandemic, so you can get what you need to stay healthy and stay connected to your family, friends, and supporters. That'll help you get through this pandemic and be ready when the next pandemic comes.






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 about your life.¹

Isn't that how everyone – people with and without disabilities – makes decisions?

When you have to make a tough choice, or a decision about something you're not



familiar with, 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 decision for you.

Here are some ways you've probably used Supported Decision-Making in your life:

- Asking friends for advice about relationships, so you can decide whether to date or marry someone.
- Talking to family members about budgeting and spending money, so you can decide whether to buy something.
- Working with a job coach or mentor so you can choose where to work.
- Learning about community activities from your case manager so you can meet new people and do new things.

It's simple. They give you information and advice. You make the decision. They support, you decide. ***That's Supported Decision-Making.***

Supported Decision-Making is a great way to make your own plans and decisions for your life.



It feels good to be the one in control, to be the one who makes the plans and decides what to do, doesn't it? It's also good for you! When you make your own decisions and control your life, that's called being *self-determined*. Studies show that when people with disabilities are more self-determined, they have better lives: they are more likely to be independent, employed, and safer.²

Using Supported Decision-Making in a Pandemic

Getting through a pandemic is about three things: Being Healthy and Safe, Being Connected and Supported, and Being Ready. Here's how Supported Decision-Making can help you with each.

BEING HEALTHY AND SAFE

Because we're in a pandemic right now, the most important thing you can do is stay healthy and safe. That's especially true for people with disabilities who may also have other health conditions that can make them get sicker or die from COVID-19.

The best way to stay healthy and safe in a pandemic is to stay home and by yourself whenever you can. COVID-19 spreads when a person coughs, sneezes, or breathes on or near another person. So, if you're at home by yourself, you won't catch COVID-19 from someone else.

If you do have to leave your home or be with other people - and we all have to do that sometimes - you should practice **Social**

Distancing. That means staying at least 6 feet away from other people whenever you can. That way, if a person coughs or sneezes, they will be probably be too far away to get you sick.

If you have to be around other people, you should all wear **Personal Protective Equipment or PPE**. The most basic PPE is a medical mask and gloves. That way, if you're around other people, you'll be less likely to get sick if they cough, sneeze, or breathe on you or if you touch something they touched.

Social Distancing and PPE are especially important if you have people coming to your home to support you. You may have family, friends, or professionals like Direct Support Professionals or therapists come to your home to help or work with you. If that's the case, they should keep coming, but you should all be as safe as you can. Ask them before they come if they're feeling sick or if they've been around anyone who is sick. If so, you should ask them not to come if they're a friend or family member. If they're a professional, you should ask the agency they work for to send someone else to you.

When people come to your home (or if you're around other people in the community), you



should all wear PPE. You should also ask them to wash their hands as soon as they come in. It's also a good idea to use hand sanitizer often. That way, you'll all be as safe and healthy as possible.

Supported Decision-Making can help you think of ways to stay healthy and safe during a pandemic. Talk to people you trust to help you make decisions about what to do, where to go, and who to spend time with. There may be times when you want to go somewhere or do something, but you're not sure if it's safe. What if you want to go to a restaurant or out with friends? You should talk to people who support you, like family members or professionals you

work with, and think about whether that's something you have to do or just want to do. If you don't have to go somewhere, you should probably stay home because that's the best way to stay healthy in a pandemic.


We all have to go places and be with people, even in a pandemic.

Using Supported Decision-Making can help you think about and decide the best, safest way to do that. Your supporters may remind you to wear PPE when

you go out with friends, or make sure you sit at least 6 feet away from other people. They can also help you explore options like having appointments using Facetime, Zoom, or other apps or using delivery services to get your groceries and medicine.



BEING CONNECTED AND SUPPORTED



It's hard to stay by yourself, even during a pandemic. We need to be with other people. Otherwise, we can get lonely and depressed. So, it's important to stay connected with your family, friends, and professionals who support you. That way, you can keep your spirits up and stay in touch with people you care about. There are many ways to stay connected, supported, and safe.

Here are a few ideas:

- Have a dance party using apps like Facetime or Zoom. You and your friends can take turns being the DJ and everyone can sing and dance to the music!
- Have a “virtual pot luck dinner” by setting up a group telephone or video call where you cook at your home while they cook at theirs and talk about the food or anything you want.
- Have “Sunday brunch” with your family or friends by setting a day and time every week to catch up with each other.
- Play video games online with friends.

- Have a “movie night” with your friends when you all watch the same movie at your homes and talk or text with each other about it.
- Play “board games” with your friends by downloading apps like Scrabble, Words with Friends, or Monopoly where you can play against each other and chat while you’re playing.
- Connect with family and friends on apps like Facetime or Zoom and share photos of each other and tell stories about those times.
- Trade “mix tapes” with your friends by creating playlists using music apps like Spotify or Apple Music. Send your friends songs that remind you of them and ask them to do the same thing for you.
- Schedule “check ins” with your family, friends, or professionals to discuss how you’re doing and whether you need some extra support.
- Take a “social distancing field trip” with friends by going to a park for a picnic or a hike, while staying 6 feet apart and wearing PPE.

This is a great time to use Supported Decision-Making to think of and set up



ways to stay connected with your family, friends, and professionals. Talk with them and ask how they're doing and what they wish they were doing. Then talk about ideas, like the ones we just listed, for ways you can spend time together. Maybe they'd like to try something on the list or maybe they'll have other ideas. When you come up with something you'd like to do together, do it!

The best part is, while you're talking with them about ways to be connected, you're connecting with them! That way, Supported Decision-Making can help you get and stay connected with the people you care about.

If you do get sick, you have a right to be supported so you can get good health care. For example, if you have to go to the hospital, you can have a supporter with you who can help you work or talk with your doctors and other professionals so they know how you feel and what you need. For tips on how you can use Supported Decision-Making for your health care, please see our brochure “My Health, My Decisions” at <https://bit.ly/sdmhealthcare>.

You can use Supported Decision-Making to help you plan and set up what you need if you get sick. You can work with your supporters to create a Power of Attorney or Supported Decision-Making Plan that says the support you want, how you want to be supported, and who you want to support you if you get sick. Then, if you do get sick, you can show the Power of Attorney or Plan to your health care professionals.

BEING READY

As we write this brochure, it's July of 2020. The COVID-19 pandemic is still going on, and health experts say it'll still be here in 2021.

So, it's important to be prepared now, so you can take care of yourself and stay healthy, safe, and connected. That way, when the pandemic ends, you'll have what you need to be prepared for the next one.

Here are some things you should think about and be prepared for:


- What will you do if people who support you, like your family members, friends, or professionals like Direct Support Professionals or your Case Manager, get sick?
- How will you make sure you have enough food and medicine if you have to stay home for a while?
- How will you stay in touch with your family, friends, and the people you care about?
- What will you do if your doctor cancels your appointment or wants to meet by phone or video?



This is a great time to use Supported Decision-Making. Talk to the people you trust so you can find answers to these questions as soon as possible. We recommend that you work with them so you can make a list of things you need to stay healthy and safe, especially if you're not able to leave your home.

We recommend that your list include:

- Enough food and bottled water for at least two weeks.
- A charger and battery pack for your cell phone, if you have one.

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- A first aid kit.
 - Any equipment you need, like a wheelchair, hearing aid, eyeglasses, or other assistive technology, and supplies like batteries to keep them working.
 - Your medicine and a list of the medicines you take, what you take them for, the dose you take, and how you can get refills.
 - A copy of your insurance card.
 - Supplies for your service animal, if you have one, for at least a week.

Once you've made your list, you should make sure that you have those things in your home at all times. That way, if you have to stay home in this pandemic or the next one, you'll know you have what you need to get by until it's safe to leave.

You should also keep a list of your supporters and how you can stay connected to them. Your supporters are the people you trust and who help you. They can be family, friends, neighbors, or professionals you work with like Doctors, Job Coaches, or Direct Support Professionals.

Think about who your supporters are and how they help you. For example:

Your Doctors provide medical care and prescribe your medicine. Your friends and family members help you do things in the community and in your day-to-day life. Your Case Manager helps you set up supports and take part in activities. Your list should include their name, address, telephone number, cell phone number, and email.

For example, your list might say this for your doctor and your best friend:

Dr. Jane Smith

Gives me medical care and prescribes my medicine

Address: 555 Main Street,
Jefferson City, Missouri.

Email: JaneSmith@DrSmith.com.

Office phone: 555-555-5555

Cell phone: 333-333-3333

Malik Jones, Best Friend

We do things in the community together and he gives me advice

Address: 111 South Street,
Jefferson City, Missouri.

Email: MalikJones@email.com

Office phone: 555-444-333

Cell Phone: 444-333-2222

You can use Supported Decision-Making to work with your supporters and make the list. They can help you identify people who should be on your list, talk to them about how they can help you, think up ways you can stay connected with them, and put the list together.

The “Setting the Wheels in Motion” guide³ has worksheets that can help you make your list by thinking about the kinds of help you want, when you want it, and who you want to help you. The guide was designed to help parents work with their children with disabilities, but you can also use it work with the people in your life.

The link to the guide is

<http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

For more information on ways to prepare and stay supported in an emergency situation, please see our brochure “Shelter from the Storm” at <https://bit.ly/sdmemergencies>.

References

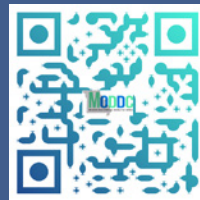
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We Can Help!

Even if you've only just started thinking about ways to stay safe, connected, and prepared in this pandemic and future ones, 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

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