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# A Self-Advocate's Guide to COVID-19

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The Coronavirus or COVID-19 is changing our lives in many ways for a while. As of March 9, 2020, Green Mountain Self-Advocates has been co-hosting 3 zoom meetings a week for and by people with intellectual and developmental disabilities. In response to our conversations we have created this toolkit about the Coronavirus written in plain language. We focus on “need to know” information. Our goal is to for people with intellectual and developmental disabilities to have plain language information during this national crisis.



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*This toolkit made possible by the generous support of The Autistic Self-Advocacy Network.*





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# A Self-Advocate's Guide to **COVID-19**

## Part 1: Basic Covid-19 Information By And For People With Disabilities

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The Coronavirus is a new disease spreading around the world. Part 1 focuses on “need to know” information about the Coronavirus. It is in plain language. Our goal is to keep people with disabilities healthy during this global crisis. Part 1 is available in 11 languages at: <https://selfadvocacyinfo.org/resource/plain-language-information-on-covid-19/>

# Basic Covid-19 Information

## By And For People With Disabilities

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### What is COVID-19?

- It is a new illness spreading around the world.
- It's nickname is coronavirus.



### How do you get it?



- Someone with COVID-19 gives you their germs.
- When they cough or sneeze, their germs get in the air, on you, and on things.



- Germs get into your body through your mouth, nose, and your eyes.

### What happens if you have it?



A fever of 100.4°F  
(38°C) or higher



Coughing



Hard time  
breathing

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**If these things happen to you, it does not mean you have coronavirus. Lots of people get a fever or cough.**

**You could just have a cold or the flu.**

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### **If I am sick, when should I call a doctor?**



- If you have a cough or fever, call your doctor.
- Do not go to your doctor's office unless your doctor tells you to.
- If you get services tell your case manager and support staff that you feel sick.

**Call your doctor, do not go to the office.**

### **How sick do you get?**



- Most people do not get very sick. It is like having a cold or the flu.
- Some people get very sick and need to go to the hospital. Older people and people with disabilities are more likely to get very sick.

## How can I stay healthy, or not get it?

### Wash your hands.



- Use lots of soap and water.
- Wash for at least 20 seconds.  
If it helps, count to 20.
- Wash after using the bathroom or being in public (like going to a store).
- If soap and water are not available, use hand sanitizer. Know that washing well with soap and water is still better.



### Cough or Sneeze into your elbow.



Coughing and sneezing into your elbow stops germs from going into the air and onto your hands.

### Try not to touch your face



- Do not rub your eyes.
- Do not touch your mouth.
- Do not touch your nose.

Remember, this is how germs get in your body.



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If you have to touch your face, do it with a tissue or in the shower.

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### Try to keep your hands busy:



- Tap your knee.
- Use a fidget spinner.
- Use hand sanitizer.
- Doodle.
- Squeezing a stress ball.
- Play a game on your device.

### If I am sick, what should I do?

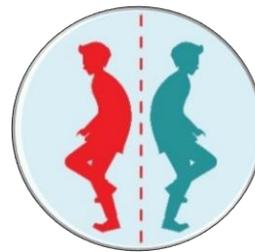
Call your doctor. Do NOT go to a hospital or Urgent Care.



Stay Home



Use tissues,  
then throw  
them away



Avoid  
contact with  
others



Keep  
objects and  
surfaces  
clean

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**Call your doctor again if you are getting worse. Call back if you are having trouble breathing. Do what your doctor says.**

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### **If my staff person is sick, what should I do?**

- Doctors say if you are sick stay home. Do not go to work. A sick staff person should stay home until they are well.
- Tell your team. Tell your case manager.



### **What do I do if someone I live with gets sick?**

Someone else living in your home could get coronavirus or think they have these germs in their body.



- Stay away from the sick person. And try to stay at least 6 feet (2 meters) away from places where the sick person has been.
- Keep washing your hands well.

**Call your case manager.** A plan will be made to keep you apart from the sick person. You should still call and send notes to them.

## How do I say hello to my friends?



- No handshaking.
- No hugging.
- No fist bumps.
- Smile, video chat, text, call, message

## You should stay home most of the time.

Many places have Stay-at-Home orders from their Governors.

Most of these orders says you can only leave your house to:



- walk, exercise
- get groceries or medicine
- work if you are needed
- go to a doctor's appointment
- get take-out food

## If you MUST go out in public:



- Wash your hands before and after.
- Stay 6 feet (2 meters) apart from other people.
- Wear a face mask that covers your nose and mouth when near people.

This change is only for a while. The Governor will tell us when the Stay-At-Home order is over.

## Why is it important to do all of this?



- You do not want your grandparents to get sick, do you?
- Some people with disabilities get sick really easily. You would feel awful if you got your friends or family sick.

## Is there a shot to get, so I do not get sick?

No. There is not a shot or vaccine to stop the coronavirus.

## Is there a medicine?



- There is no medicine for COVID-19.
- Take medicine used when you have a cold or flu.
- Drink lots of water. Get plenty of rest.

## What do I say to my friends if they get scared?

Talk to someone you trust. You can show them this booklet for ideas on what to do.



## I have a job. I am worried about missing work.



- When there is a Stay-at-Home order in your town many people will not be working. Some will be working from home.
- You need to keep in touch with your job.



If you are working, you need to keep you safe. Your boss or support staff will make sure you know what to do. They will get you a mask and gloves to use when in public.

## Make a plan for staying at home.



- Who can go food shopping for you?
- Who will call to check in on you?
- What to do if your support staff calls in sick?
- Make sure you know your doctor's phone number.

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**Talk to your self-advocacy group, friends, family, or support staff about your worries and concerns.**

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If you have been near a person with Coronavirus, tell someone. A person can have coronavirus in their body and not feel sick. It takes a few days to get sick. This virus spreads very easily. You do not want to give it to others.



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# **A Self-Advocate's Guide to COVID-19**

## **Part 2: Tips For Working With Support Staff During Covid-19**

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In March 2020, the Self-Advocacy Resource and Technical Assistance Center held a focus group online with peer leaders from across the country. We talked about issues we are all facing working with support staff during the Coronavirus outbreak. Self-advocates wrote these tips.

# Tips For Working With Support Staff During Covid-19

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The Coronavirus or COVID-19 is changing our lives in many ways for a while. It is changing the ways we get support and services.

These tips can help you deal with the changes.

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## Nothing About Us, Without Us



- Talk directly to me. I want to be a part of all talks about me.
- Think about the words you use. People are using many new words. There is a list of words to know that goes with this booklet.

## Make a Written Plan

Make a written plan with your case manager. Get a copy. Ask for details to be put on a calendar.



- Decide what you need help with.
- Decide when it needs to happen. Ask yourself, “Can I wait a couple of hours or wait a day or a week for this to happen?”
- Decide who will help you.
- Can staff help you over the phone? Or does it need to be in person?

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## For Example:



**Meals:** Can you heat up a prepared meal or do you need help preparing every meal?

**Grocery Shopping:** Do you need help once a week or every 2 weeks?

**Showering:** Do you need help every day or every 3 days?

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## You and Your Case Manager Need to Agree to a Plan

Make sure you get it in writing



- Include what to do if staff do not show up.
- List who to call if you need help.  
(Include family or friends.)
- Include what to do if you get sick. Who to call if you cannot reach your doctor.

## How To Deal With New Support Staff

If you get new support staff:



- Your agency must tell you before it happens.
- Try to meet new staff over the phone first.
- Make a plan on how to train new support staff.
  1. What do you want them to know?
  2. Who can help you with the training?
  3. Go over your plan with your new support staff.

## Being Safe When At Home



Do not open your door to strangers. If they are new staff you will be told they are coming. Talk to someone you trust before giving away your food, money or other things.

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### If my staff person is sick, what should I do?

Doctors say sick people must stay home. A sick staff person should stay home until they are well. Tell your team and case manager.

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Look at the list of your emergency contact numbers at least once a week. Put them in your phone. Talk with your staff about:

- When to call your doctor
- When to call the agency crisis number
- When to call 911

## If You Get Sick

### Attendant Care



Many people need help when they are sick. If you are sick and cannot take care of yourself call your case manager. They will help you set up services. Decide what is safe and what meets your needs.

## PPE – Personal Protective Equipment

Germs get into a person's body through the nose, mouth and eyes.



So, your staff may use:

- Gloves
- Masks
- Goggles or glasses

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**Who is responsible for getting these supplies?**

**If you get services from an agency** - they will buy these things.

**If you manage your own services** - you must buy these items.

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## Things To Ask Your Case Manager

Put your case manager's number in your phone.



**If you live in a residential program:**

- Ask what will happen if you get the Coronavirus.
- Ask what will happen if someone you live with gets it.

**If you have a job** your case manager can help you stay in touch with your boss. If you are not working right now they can help you figure out how to pay your bills. They can help you apply for benefits to help people during the Coronavirus.



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Check your emergency fact sheet.

Make sure it is up to date.

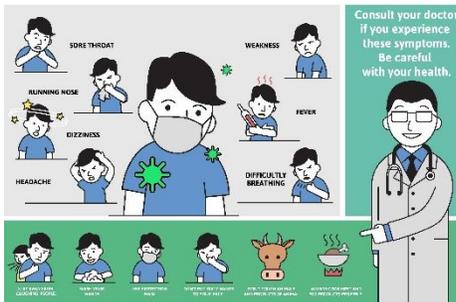
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### Med check:



- See how much medication you have.
- Know when you can get a refill.
- Find out if your meds can be delivered or mailed to you.
- Should you ask your doctor to order extra meds as a backup.

### What is helpful?



The Coronavirus is changing our lives in many ways for a while. Staff should explain if they are using new ways to help you. Staff should often ask if you have any questions.

Some people live with their support person.

**If the support person gets sick, they must tell your case manager.** If anyone in the house gets sick, the case manager must be told. You may be able to leave and stay somewhere else for a while.



## What To Do If Someone You Live With Gets Sick?



Stay away from the sick person.  
They should be in their own room.  
Do not go into their “sick” room.



The sick person should wear a mask if they come out of their room. The sick person should have their own bathroom that no one else uses.



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**Wash your hands with soap and water  
as much as you can.**

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## Emotional Support



You may have lots of feelings during this time. You may feel lonely or worried. Life may be more stressful now. Make a list of things to do to bring down your stress level.

Try out new ways to keep in touch with family and friends.



**Use this basic checklist when staff or friends call or stop by:**



- What food do you have in your house?
- Check on what household supplies or medicines you have and what you need.

**Talk about:**



- Are you feeling sick?
- How are you sleeping?
- How are you feeling emotionally?  
Are you upset or worried?
- What things do you wish you had help with?

## **Staff Will Be Teaching You New Ways To Stay Healthy**

Staff will support you to:

- Stay 6 feet (2 meters) away from others when in public.
- Cough or sneeze into your elbow.
- Wash your hands often.
- Try not to touch your face.
- Use a phone or internet to talk to your therapist.
- Use a thermometer to take your temperature.





Learn about the latest Coronavirus orders put out by your governor. Understand there are some things that are good ideas to do. And there are some things you have to do.

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## Protecting Rights



Ask your case manager for the number for Protection and Advocacy in your state. Or you can find it at: <https://www.ndrn.org/about/ndrn-member-agencies/>

Call them if you think you are not getting needed treatment. Also, call if you think a friend is not getting needed medical treatment.



**We need to speak up, so our support staff are treated fairly.** Their rights as workers must be protected.

**Disability Rights are Workers Rights.**



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# **A Self-Advocate's Guide to COVID-19**

## **Part 3: Sample Advocacy Letter About Patients with Intellectual Disabilities Having a Support Person With Them When in the Hospital**

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This is a letter was written by self-advocates. Many hospitals are not allowing patients to have visitors. This is because of the Coronavirus emergency. Advocates want to change that rule for patients with disabilities. Many people with disabilities need a support person when in the hospital. This letter has examples of what to say to make that change happen.

# Sample Advocacy Letter About Patients with Intellectual Disabilities Having a Support Person With Them When in the Hospital

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Dear \_\_\_\_\_,

We are \_\_\_\_\_, a disability rights organization representing people with intellectual and developmental disabilities (IDD). We have reviewed your hospital policies restricting visitors during Covid-19 emergency. On April 10, the Governor of New York and their Health Department changed their guidance regarding hospital visitation during the COVID-19 outbreak. We are asking you to allow people with intellectual and developmental disabilities to have someone with them when in the hospital. Here are some of the reasons why we are requesting this immediate change:

## **Communication Issues That Are Of A Medical Necessity:**

- Some people use devices to speak, like a letter board or typing on an iPad. Many of us need assistance to use devices to communicate.
- Often people with IDD do not use complete sentences, and it may take us a long time to finish a thought. Some of us might not have the words to describe our symptoms.
- Most of us do not understand what the doctors are saying. We need things constantly explained in smaller and smaller details.

- For some, it may be impossible to explain why a medical procedure must be done. In those situations, we need someone we know and trust with us to tell us that what is about to happen is okay.
- Many people with IDD cannot self-report. To receive the best medical treatment, we need someone who can recognize and interpret our non-verbal communication. Someone who can see that we are in pain and can read those signs.

### **Other Barriers To Accessing Medical Treatment:**

- Without someone there, a person with IDD hospitalized for other reasons, may wander off and be exposed to COVID-19. A person should not be restrained if having someone there would keep them in bed.
- Some autistic people cannot tolerate strong smells, flashing lights, sudden or odd noises. Hospitals cannot very easily limit exposure to those things. We need someone to help us if we experience sensory overload.
- Some people with IDD need support to comply with medical treatment. We need support to not touch any tubes or needles that must go into our bodies.
- Many people with IDD have gone through bad things in life. We are 5 times more likely to experience violence than someone without a disability. Being in a hospital can remind us of the bad things that have happened to us in the past. We might react as if the bad things are still going on.
- If we have panic attacks, we need someone who knows how to help us relax.

- Many autistic people have a hard time in new situations. They say that when you meet one person with autism, you have met only one person with autism. We cannot simply give a list of generic directions to hospital staff on how to interact with an autistic person. We need support from someone who understands our individual needs.
- Finally, parents of a woman with IDD with a serious underlying health condition told us that they will not seek medical treatment for their daughter if it requires her to be in the hospital without support. We worry that other parents will make the same decision.

The New York State policy issued April 10th states that during this pandemic crisis: “Hospitals are required to permit a patient support person at the patient bedside for ... patients with intellectual and/or developmental disabilities....” [tinyurl.com/nys-c19-apr10](https://www.tinyurl.com/nys-c19-apr10). We call for immediately implementing a similar policy in \_\_\_\_\_.

We know there are many decisions regarding the COVID-19 outbreak demanding your attention. Allowing people with IDD to have someone with them when hospitalized is essential for the person to have the best health outcomes and it also puts less demands on the medical staff.

Thank you for your leadership and support during these uncertain times.

Sincerely,



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# **A Self-Advocate's Guide to COVID-19**

## **Part 4: COVID-19 Medical Information Form for People With Disabilities**

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This form helps you think about what support you need if you must stay in the hospital. Many hospitals have new rules to keep people safe during the Coronavirus outbreak. Your hospital may say you cannot have any visitors. Fill out this form with your team. It will help you advocate for your rights. It can help you get the medical treatment and supports you need.

# COVID-19 Medical Information Form for People With Disabilities

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**I am a person with a disability.**

**Please read this before you help me.**

**My name:** \_\_\_\_\_

**I like to be called:** \_\_\_\_\_



**I communicate by:** (check all that apply)

- Talking
- Writing or typing
- Pictures
- Sign Language
- Pointing to words
- Using a device

**Please describe:** \_\_\_\_\_

**If you do not understand me, please call:**

**Name:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

**My doctor's name:** \_\_\_\_\_

**My doctor's phone:** \_\_\_\_\_



**My typical reaction to a medical exam:**

- Cooperate
- Afraid
- Try to stop what you are doing





**Advocacy Alert: Many hospitals are not allowing patients to have visitors because of COVID-19.**

Talk to your team. Think about what support you need if you must stay in the hospital. Tell the hospital, **“I have a disability. If I have to stay in the hospital”:**

- I can stay on my own in the hospital.
- I can stay on my own if I always get support by phone when getting medical updates or making decisions. I need phone support from  
Name: \_\_\_\_\_ Phone: \_\_\_\_\_
- I cannot stay in the hospital alone. I must have a patient support person to help with advocating, communicating, understanding or self-care.




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To Protect Your Rights in Vermont call 1-800-834-7890.  
Leave a message. Say your name and the hospital you are at. Disability Rights Vermont will call you as soon as possible.

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**If you have an advance directive or a living will, bring a copy to the hospital.**

If you do not have a living will, think about what you want.

1. If you cannot breathe, do you want a machine to help breathe for you?
  - Do you want it at all?
  - Do you want to try to see if it could help?
  - Do you want to use it for as long as you need it?
2. If your heart stops, do you want your doctor to try to restart it with pushing on your chest, medications, and electric shocks?
3. If you cannot eat or drink like you usually do, do you want food and water to be given to you through a tube to your stomach or in a vein?



**This form can help you get the support you need when in the hospital.**



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# A Self-Advocate's Guide to **COVID-19**

## Part 5: How People On SSI And SSDI Get A Stimulus Check

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The Coronavirus is changing our lives in many ways for a while. In April 2020, the federal government started giving \$1,200 to most adults. This money is to help people during the Coronavirus outbreak. It is called an Economic Impact Payment. Some people call it a Stimulus check. Part 3 explains how people on SSI or SSDI get the \$1,200 payment.

# How People On SSI And SSDI Get A Stimulus Check

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The federal government is giving \$1,200 to most adults. This money is to help you during the Coronavirus outbreak. It is called an Economic Impact Payment.

Some people call it a Stimulus check. Most adults on SSI and SSDI will get the \$1,200. The money is coming from the IRS. The IRS will send a check to your home or put the money in your bank account.

## Be aware of **scams**



The IRS will not call you. They will not send you an email. Do not talk to people asking for personal information. Do not give out your bank account information.

Work with someone you trust before filling out any forms about your stimulus check. Beware of emails with attachments or links. Special offers to help you get your stimulus check are dangerous. Do not open those emails. Do not click on those attachments or links.

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How much money will I get?

Most people will get \$1,200.

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## Will the stimulus check “mess up” my benefits?

The stimulus money will not count as “income.” It will not “mess up” your SSI or SSDI. You have 1 year to spend the \$1,200. It will **not** reduce your:



- SSI
- Section-8 or other housing assistance
- Medicaid
- Food Stamps

## What Do I Have to Do To Get the Money?

**If you filed a tax return** last year or this year you will get the money automatically. You do not have to do anything. If you get your tax refund put directly into your bank account that is how you will get the \$1,200. If you get your refund check in the mail, a \$1,200 check will be mailed to you.

**If you have been getting SSI or SSDI for a long time** you are all set. You will automatically get the \$1,200. You do not have to do anything.

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## There are 2 ways people on SSI or SSDI get the money:



1. If your SSI or SSDI is put into a bank account then the \$1,200 will go into the same bank account.



2. If your SSI or SSDI checks are mailed, then the \$1,200 will come in the mail.

**If you started getting SSI in 2020 you will not automatically get the \$1,200.** If you did not file taxes and got your first SSI check in 2020 you need to sign up to get a stimulus check. Work with a person you trust to sign up on the **IRS's Non-Filers** website.

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### Who will not get the \$1,200?

If your parents claim you as a dependent on their taxes you will not get a check. Ask your parents if they claim you as a dependent.

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### If you need more information:



- Ask the person you trust to help you with your benefits.
- Protection and Advocacy may be able to help you. You can find one near you at:

<https://www.ndrn.org/about/ndrn-member-agencies/>



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# A Self-Advocate's Guide to COVID-19

## Part 6: Unemployment Benefits During the Coronavirus Emergency

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On March 13, 2020, President Trump declared a National Emergency concerning the Coronavirus outbreak. Then on March 27<sup>th</sup>, Congress passed the Cares Act which increased money available for unemployment benefits. People who are eligible for unemployment get an extra \$600 a week from the federal government until July 31, 2020. The rules say during this National Emergency, the \$600 a week does **not** count as income for other programs like food stamps and Medicaid. We are telling self-advocates to work closely with someone you trust to make sure you follow the unemployment rules. If President Trump cancels the declaration of a National Emergency it may affect your Medicaid or other benefit programs.

# Unemployment Benefits During the Coronavirus Emergency

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## Because of the Coronavirus Emergency Did You ...



- Stop working?
- Lose your job?
- Work fewer hours?

You may be eligible for **Unemployment**

## Apply for unemployment benefits right away...



- If you had a job, and now you are not working because of the Coronavirus.
- Or if you are working less, because of the Coronavirus

Even people who only worked a few hours a week and lost their jobs can get special new unemployment.

## How much money will I get?

It depends on where you live. Each state has different rules. The good news is that there are 2 pots of money!



A state looks at how much money you made in the past year. How much you get depends on how big your paycheck was.

If the state gives you unemployment, then you will also get an extra \$600 per week from the federal government. This is called a bonus payment. This goes through the end of July.



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Tiffany earned \$100 a week. She got laid off. She is getting unemployment. She is getting \$50 from her state. Plus \$600 from the feds. That is \$650 a week. And \$2,600 a month.

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## Will getting this money “mess up” my Medicaid or Food Stamps?

**No.** President Trump declared a National Emergency. The \$600 weekly bonus payment will not count as income for Medicaid and Food Stamps. You can get the \$600 weekly payment and still get Food Stamps. You can keep getting Medicaid.

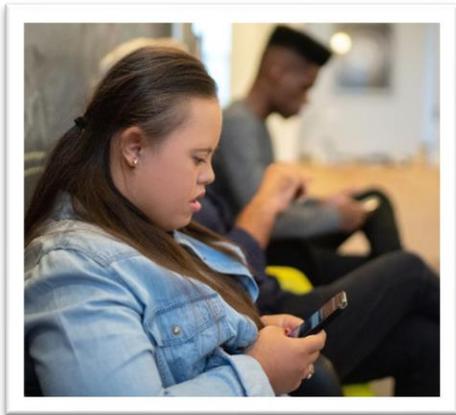


Tiffany will tell the Food Stamp office and the Medicaid office she is making \$50 a week on unemployment. The \$600 does not count.

## How will it affect my SSI?

- The \$600 bonus payment you get each week is a lot of money. It will change your SSI. You will get less SSI money. You may even stop getting SSI.
- Now do not panic. You can get SSI back when you stop getting unemployment. Remember the \$600 bonus payments will end on July 31, 2020. Call the Social Security office then to get your SSI back.
- You will not have to reapply. If you are off SSI for less than a year it is easier to get it back.

In February when Tiffany was working she earned \$400 a month.



Her SSI was \$625. Her total income for February was \$1025.00

In March she got laid off because of the Coronavirus. She signed up and got unemployment. She stopped getting SSI. Her income for May was \$2,600.

**Do the math! \$2,600 is way more money than \$1025.00!**

**If your SSI stops, contact your Medicaid office.** Ask for help from your agency if you get services. You will have to tell Medicaid your income information. This will keep you on Medicaid.

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We strongly recommend working with a Benefits Counselor.



Tiffany lives in Vermont. The Medicaid program in Vermont does a better job of helping people compared to some states. In many states the amount of money you can make when getting Medicaid is much lower than in Vermont. A Benefits Counselor or case manager can work with you to make sure you do not lose Medicaid.

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### **“Wow what can I do with the extra money?”**

Put it in your ABLE account. You will lose your SSI if you have more than \$2000 in the bank. If you do not have an ABLE account this is a great time to start. This website <https://www.ablenrc.org/> has information about opening an account.



### **How do I apply for Unemployment?**

Use google to find the unemployment office in your state. If you have support staff they can help you call or apply online.

### **If I am approved, what do I do to keep getting unemployment?**

You need to call once a week. You have to answer questions about why you did not work or why you worked less hours. You report one week at a time. Remember you may get unemployment if you are still working and your hours are reduced.

## What can I do if I get a letter saying I am not eligible for unemployment?



Try applying for **Pandemic Unemployment Assistance**. This is a new program for people. It helps people even if they only worked a few hours a week. This may give you up to \$191 a week. Remember each state is different. The good news is all people approved for unemployment get the \$600 weekly bonus from the federal government.

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**The Pandemic Unemployment Assistance program is new. Your state may still be working out the details. Contact your unemployment office to find out how to apply.**

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## What should I do if my application for Unemployment is denied?

- **If you are denied benefits, contact Legal Aid for help.**  
You can find a Legal Aid office in your state at:  
<https://www.lsc.gov/what-legal-aid/find-legal-aid> or call  
202-295-1500
- **Protection and Advocacy may be able to help you.** You can find one near you at:  
<https://www.ndrn.org/about/ndrn-member-agencies/>



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# A Self-Advocate's Guide to **COVID-19**

## Part 7: VT Developmental Services During the Coronavirus Outbreak

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The Coronavirus or COVID-19 is changing our lives in many ways. It is changing the way people with developmental disabilities are getting services for a while. This booklet was created by Green Mountain Self-Advocates in partnership with Developmental Disabilities Services Division, State of Vermont. Our goal is to clearly communicate some of the basic guidelines about what must be happening when receiving Developmental Services during the Coronavirus outbreak.

The rules in your state may be different. Use this booklet as an example of how the government can work with self-advocates to use plain language when describing services.

# VT Developmental Services During the Coronavirus Outbreak

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**Governor Scott said we must Stay-At-Home until at least May 15.**

The order says you can only leave your house to:



- walk, exercise
- get groceries or medicine
- work if you are needed
- go to a doctor's appointment
- get take-out food

**If you MUST go out in public:**



- Wash your hands before and after.
- Stay 6 feet (2 meters) apart from other people.
- Wear a face mask that covers your nose and mouth when near people.

This change is only for a while. The Governor will tell us when the Stay-At-Home order is over.

**What About My Services?**



Remember you have rights.

Your team must ask your opinion when changing your services. You must be included. Your guardian (if you have one) must be included.



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Some services may stop for a while. You must be told why. **Your agency must give you a plan in writing saying how they will help you.** Once the emergency is over, your case manager will help you get services again.

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## My Case Manager



- Your case manager must talk to you once a week. Let your case manager know if you want to talk more often.
- If you are having a difficult time, staff may come see you in person. They will be wearing a mask and gloves.
- If you need help from a staff person right away, call or email your case manager.

## My Staff

- Remember there is an order to Stay-At-Home. You are staying home. Your staff are staying home. Staff may call you or use Facetime or video chat to spend time with you.
- It may be possible to meet with your staff to do things outside like go for a walk. You need to stay 6 feet (2 meters) away from each other.



## What About My Job?



- You and your staff will keep in touch with your job.
- If you are working, you need to keep you safe. Your staff will make sure you know what to do. They will get you a mask and gloves to use when in public.

- If you are not working, staff will help you find out when you can go back to work. Staff will help you fill out the forms to get unemployment benefits.



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## Other Changes

**If a staff person comes to your house they must wear a mask and gloves. Do not let them in if they are not wearing a mask and gloves. The agency will provide the masks and gloves.**

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## Important things for you to do



- Let your case manager know if you are sick. If you live with someone, ask them to tell your agency if you are sick.
- If someone you live with is sick, they must tell you and your case manager. Your case manager will tell you what to do to not get sick.
- If someone you live with is tested for COVID-19, you must be told.



- Your case manager should talk to you about what will happen if you get sick. There must be a written plan. Your case manager should go over it with you. Get a copy of your plan.

- If you get sick or someone in your house gets sick you might have to go stay someplace else. You will be involved in that decision. Your guardian (if you have one) will be involved. If you have to stay someplace it should only be for a short period of time.



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### You need to tell someone:

**If your staff or case manager are not following these new rules, tell someone. If you are not getting the services you need, tell someone.**

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### You Can Call:



**The State:** 802-863-7240, press 4, and leave your name and number or email

[AHS-DAILCOVIDInquiries@Vermont.Gov](mailto:AHS-DAILCOVIDInquiries@Vermont.Gov)

**Disability Law Project:** 800-889-2047 You will need to leave your name and number. Someone will call you back.

**Your Case Manager:** It is important to let your agency know if you have concerns.



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# **A Self-Advocate's Guide to COVID-19**

## **Part 8: Coronavirus Plain Language Glossary or Words To Know**

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These are words you may be hearing or seeing due to the Coronavirus outbreak. These definitions were written by a team of self-advocates and their aspiring allies.

# Coronavirus Plain Language Glossary or Words To Know

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1. **Advisory** - a notice or warning given to protect you. It says what you should and should not do. The governor in your state is sending out advisories about the Coronavirus.

2. **Agency** - a place where people with disabilities get services.

3. **Agency Crisis Number** - if you are in an emergency, you call this number to get help. You get this number from your agency. Ask your case manager to write the number down.



4. **Airborne** - in the air. For example, if you sneeze germs travel through the air.

5. **Alerts** - warnings of a dangerous situation.

6. **Anxiety** - being nervous, feeling afraid, worried something bad is going to happen.



7. **Asthma** - this illness is in your lungs. Your airways swell up and it is hard to breath. This is a long-term illness. Some people get better. Others have trouble breathing their whole life.

8. **Asymptomatic** - a person has an illness like the Coronavirus, and they feel fine. They can give the illness to others. They find out they had the illness by taking a test.

9. **Cases** - number of people who have the virus.
10. **Cardiovascular** - having to do with your heart and blood vessels.



[www.cdc.gov](http://www.cdc.gov)

11. **CDC (Center for Disease Control)** - a department in the United States government. They protect people from getting sick. The CDC is a leader in the fight against the Coronavirus.

12. **Checklist** - a list made to keep track of what is needed. It shows what is completed and not completed.
13. **Chronic Bronchitis** - the tubes that carry air to your lungs swell up. You cough a lot and have a hard time breathing. It lasts a long time.



14. **Clean and disinfect** - to wash something and to kill germs and viruses. For example, use a half of cup of bleach in 1 gallon of water to kill germs. Or use a wipe that has 50% - 70% alcohol.
15. **Contagious** - a person who has an illness might get you sick too. The illness spreads from one person to another.
16. **COPD - Chronic Obstructive Pulmonary Disease** – an illness in the lungs that makes breathing hard. It gets worse over time.
17. **Coping** - dealing with a hard situation.
18. **COVID-19** - it is a new illness spreading around the world. Its nickname is coronavirus.



19. **Electronic devices** - computers, smart phones, tablets, etc.

20. **Diabetes** - an illness that happens when you have too much sugar in your blood. It also means you have a problem with turning the food you eat into energy.



a. **Type 1 Diabetes** - the person does not make any insulin. Insulin is a chemical in your body that helps you turn the food you eat into energy.

b. **Type 2 Diabetes** - the person makes some insulin. Insulin is a chemical in your body that helps you turn the food you eat into energy.

21. **Discrimination** - Treating people badly because of who they are. The United States Office of Civil Rights said clearly that people with disabilities should get the same medical care as everybody else. Taking away medical care because of a disability is a type of discrimination.



22. **Droplets** – a small drop of fluid. The Coronavirus goes from one person to another when moisture comes out of a sick person's body when they sneeze or cough.

23. **Dry cough** - a cough that is not wet. There is no mucus.

24. **Elders** - people that are over the age of 65.

25. **Emergency Contact Information** - numbers you can call in case you are in an emergency. For example: 911, your doctor, family member, support staff, etc.



26. **Emphysema** - a lung disease that makes it hard for you to catch your breath.

27. **Energy** - the power you get from food or from exercising. Find ways to keep exercising when you are staying at home.

28. **Epidemic** - an illness that most people get.

29. **Epidemiology** - studying how an illness starts and how it spreads.

30. **Essential workers** - People who do jobs that keep us healthy and safe. Each state decides what businesses and services to keep going during an emergency. For example, people who work at a hospital, grocery store, fire or police station etc.

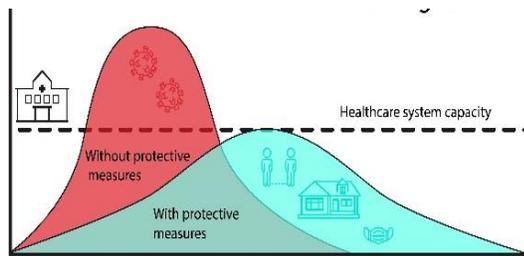
31. **Exposure** - to be around something.  
To come in contact with something.



32. **Fever** - your body gets hot to try to fight off a virus. If your fever is 100.4 degrees Fahrenheit (38 degrees Celsius) or higher, call your doctor.

33. **Flu** - it is like having a bad cold, but worse. You feel sleepy, weak, and your muscles may ache.

34. **Flattening the Curve** - the red tall mountain shows how many people



might get sick if we do nothing. The green smaller hill shows how many people will get sick if we stay home. The green is better. If too many people get sick at the same time we cannot help them.

35. **Guidelines** - list of instructions that doctors and scientists have agreed on.



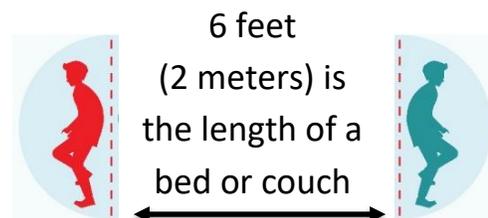
36. **Hand washing** - use lots of soap and water. Rub soap on all parts of your hands for 20 seconds. Then rinse under running water to wash away the soap and germs.

37. **Health Department** - a public office in every state that helps people manage their health.

38. **Hot Spot or Epicenter** – the place where many people have a virus at the same time. The virus is also in many other places. We all need to do what our state is recommending to prevent the spread of the virus.

39. **Immunity** - When a person cannot get or catch a disease. Scientists are developing a vaccine to give to people so they will not get this virus.

40. **Isolation** - these rules are for a sick person who has the Coronavirus. Stay home. Do not go outside. Stay in a separate room in your house, away from others. It possible use your own bathroom. Wear a mask when you come out of your room. Clean and disinfect everything you touch.



41. **Medication** - Prescribed by your doctor to help you maintain your health. There are no approved meds that cure Coronavirus.



42. **Meditation** - A person may be quiet, close their eyes, and/or focus on their breathing. You will feel relaxed. It can be done by yourself or with others.

43. **Mitigation** - What we all are doing to reduce the spread of the virus. For example, staying home, staying 6 feet (2 meters) away from others.

44. **NIH - National Institutes of Health.** (Where Dr. Anthony Fauci works!) A department in the United States government that does research on why people get sick.

45. **Normal temperature** - When your body is 98.6 degrees in Fahrenheit or 37 degrees Celsius.



46. **Pandemic** - an illness that spreads around the world.

47. **Panic** - a sudden and intense feeling of being scared.



48. **Pedometer** - is a small device like a watch that you can wear on your wrist. It counts every step you take.



Even though you are stuck at home try to get 4,000 steps a day.



49. **PCA or Personal Care Attendant or Assistant** - support staff who work with people with disabilities in their home. They may help them eat, bathe, use the bathroom, get in and out of bed, take meds or do some housework.

50. **PPE - Personal Protective Equipment** - Germs get into a person's body through the nose, mouth and eyes. People may use gloves, a face mask, goggles or glasses to keep germs out of their body.

51. **Physical activity** - Something you do with your body. Walking is a physical activity. Keep active when you are staying at home.

52. **Pneumonia** - is an illness when you get an infection in your lungs.

53. **Prescription** - medicine your doctor tells you to take.

54. **Prevention** - what you can do to avoid getting sick.

55. **Provider** - A place where you get support or health care services.

56. **Quarantine** - These rules are for people who are not sick and have been near someone who has the Coronavirus. Stay home. If possible, stay in a separate room in your house. Do not go outside. It is done to slow the spread of an illness. The governor of your state will say how long you must stay home.





57. **Relaxation Techniques** - things you can do to reduce stress. For example, yoga, singing, dancing, watch a funny movie or daydreaming.

58. **Respiratory Problems** - having trouble breathing and/or coughing a lot.



59. **Sanitize** - is the same as clean and disinfect.

60. **Self-Care Plan** - how you will take care of yourself or get the help you need. The plan should be in writing.

61. **Shelter-In Place Order** - a Governor says stay where you are.

62. **Social Distancing** - when in public stay 6 feet (2 meters) away from others. It really is about physical distancing. If you are next to someone.



- You put your arm out.
- They put their arm out.
- And you should not be touching.

63. **Stay at Home Order** - Stay home. Do not go to work or school.

- Can I go outside? Yes. Stay 6 feet (2 meters) away from people.
- Can I get groceries or medication? Yes. Stay 6 feet (2 meters) away from people.

64. **Stimulus Check** – It is also called Economic Impact Payments. The federal government is giving \$1,200 to most adults. The money is to help people during to the Coronavirus. You do not need to sign up. The money is automatically deposited into bank accounts. People on SSI and SSDI will get the \$1,200. For more info go to IRS.gov.



65. **Stress** - your body and mind reacting to a difficult situation. A feeling of pressure.

66. **Symptom** - A change in your body that might mean you are sick. For example: a fever, dry cough, or having a hard time breathing.



67. **Testing** - checking to see someone has an illness. There are different kinds of tests. A nurse may put a swab up your nose.

68. **Therapist** - A counselor. A person who is skilled in helping someone control their emotions or deal with problems.

69. **Thermometer** - A device used to see how warm your body is. It measures your body temperature. You put the device in your mouth, under your tongue and wait. In the hospital they run the device over your forehead and neck.



70. **Treatment** - The care or medicine you get to feel better.

71. **Triage** - If there are a lot of sick people at the hospital, there are rules to decide who gets helped first. Who gets treatment first?

72. **Unlearn** - stop doing a habit. For example, during the Coronavirus we must stop shaking hands or standing next to someone.



73. **Vaccine** - a shot that protects you from getting the flu or other illnesses.

74. **Ventilators** – A machine that helps people breathe. It puts air into and out of your lungs. is used when people are not able to breathe

75. **Virus** - a sickness you get when germs get into your body.
76. **Wheeze** - there is a whistling sound when the person is breathing. They are having trouble breathing.
77. **Zoom** - a free app to have a video call with up to 100 people for 40 minutes. It can be used on a smart phone, computer or tablet. If you pay money you can have video calls for longer.

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### Resources Used To Create This Glossary

These plain language definitions were written by a team of self-advocates and their aspiring allies from Green Mountain Self-Advocates. Some definitions were adapted from information from the following resources.

“Everyday Words for Public Health Communication.” *Centers for Disease Control and Prevention*, U.S. Department of Health & Human Services,

<https://www.cdc.gov/healthcommunication/everydaywords/>

“Plain Language Medical Dictionary.” *University of Michigan Taubman Health Sciences Library*,

<https://www.lib.umich.edu/taubman-health-sciences-library/plain-language-medical-dictionary>

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# **A Self-Advocate's Guide to COVID-19**

## **Part 9: Know Your Rights: Bringing a Supporter to a Hospital or a Doctor's Office**

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On June 9, 2020, the Office of Civil Rights made it clear that all people with disabilities are allowed to bring a supporter with them when in a hospital or a doctor's office. This booklet describes how you can speak up for your rights. To see a video made by self-advocates using the information in this booklet go to:

[https://www.youtube.com/watch?v=9y1rOWyf\\_XM&t=63s](https://www.youtube.com/watch?v=9y1rOWyf_XM&t=63s)

# Know Your Rights: Bringing a Supporter to a Hospital or a Doctor's Office

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## For People with Disabilities

COVID-19 or the Coronavirus has caused big changes in how hospitals and doctor's offices work. They are not letting people visit patients.

Here is why:

1. Hospitals are worried that visitors could catch COVID-19.
2. And visitors who have COVID-19 can give it to other people.

Some visitors who have COVID-19 might not even know they are sick.

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**These new rules about no visitors can be a problem. Many people with disabilities are not be able to go to a hospital or doctor's office alone. People with disabilities may need help to communicate and understand what is happening.**

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## There is the good news.



On June 9, 2020, the Office of Civil Rights made it clear that all hospitals must allow people with disabilities to bring a supporter to the hospital or a doctor's office. Here is how to advocate for a supporter to be with you.

### Tip #1

- Tell the hospital you have a disability. Tell them you need a supporter with you.
- It will help to say your supporter is a “reasonable accommodation” under the Americans with Disabilities Act.

### Tip #2

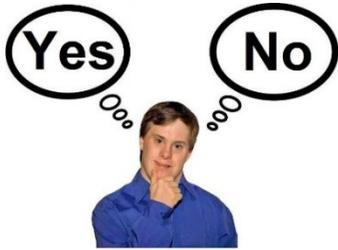
Explain why you need a supporter to get good healthcare. If you have trouble speaking, do this with your supporter.



- **To help you communicate.**  
You may need someone who understands the way you express yourself. You may need help using a communication device.



- **To help you with personal care.**  
You may need someone who knows how to assist you to eat, shower or go to the bathroom.



- **To help you make decisions.**  
When making a decision, you may need help understanding what choices you have.



- **To help you talk to doctors and nurses.**  
Doctors talk about things that are hard to understand but are important for your health. You may need someone who knows you to help you understand what a doctor is saying.



- **To help you feel safe.**  
Some people cannot feel safe unless the right person is with them. Some people, when they do not feel safe, panic. They may try to run away. That is not safe. This is why some people might need the right person to be with them.

## Laws that Protect Your Rights

People with disabilities have rights.

These Laws protect our rights.

- The **ADA or Americans with Disabilities Act** says you cannot discriminate against people with disabilities in all areas of public life.
- **Section 504 of the Rehabilitation Act** says any program that gets federal money must give people with disabilities equal opportunity and equal access.

Both laws require hospitals and doctor's offices to make **reasonable accommodations** or change rules for people with disabilities. For example, many hospitals do not let dogs in the hospital. But they have to let service dogs in the hospital.

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On June 9, 2020, the Office of Civil Rights made is clear that all hospitals must allow any disabled patients to have a supporter with them. You can read the requirements at:

<http://www.gmsavt.org/ocf-june-6-2020/>

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## Here are more details for you and your supporters.



1. Hospitals must provide personal protective equipment (PPE) for your supporter to keep them safe. PPE means a mask, gloves, goggles or a gown.

2. You can more than one supporter. Your supporters must take turns being with you. You may only be allowed to have one supporter with you at a time.



3. Your supporter can leave the hospital to take a break and come back later.

4. People with all different types of disabilities are allowed to have a supporter with them in the hospital or doctor's offices.



5. Your supporter is allowed to eat, drink, and use the bathroom while they are in the hospital.



6. The medical staff must write down how to best communicate with you.

Communication with people with disabilities needs to be as effective as communication with people without disabilities.

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**People with disabilities in ALL states are allowed to have a supporter with them when in a hospital or a doctor's office.**

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**If you need more information:**



- Ask the hospital to give you a copy of their policy. It will list a contact person. Call if you have questions.
- Protection and Advocacy may be able to help you. You can find one near you at:

<https://www.ndrn.org/about/ndrn-member-agencies/>