

# Self-Directing Services and Supports during the COVID-19 Pandemic

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## Introduction

Although anyone can get sick with—or die of—COVID-19, the risks are higher for people who need long-term services and supports, or LTSS for short. LTSS help older adults and people with disabilities with self-care and everyday tasks, such as cooking, bathing, managing medications, and running errands. Most LTSS in the United States are funded by Medicaid, a government healthcare program for low-income people. Some people get support in institutions like nursing homes and group homes, but others receive support at home. When Medicaid pays for people to get services at home, these are called home- and community-based services, or HCBS.

There are a few reasons why COVID is more dangerous for people who use HCBS.

- ▶ First, care workers often work with more than one person throughout the week. The more people workers visit, the more likely they are to come in contact with the virus and spread it to their clients.
- ▶ Second, people who use HCBS often have more than one disability or illness that increases their risk of COVID infection.
- ▶ Third, people who have home-based services may also get support from other programs in the community, such as adult daycares. HCBS users are likely to come into contact with a lot of people at once—and increase their chances of getting sick.

## About the study

We conducted a study to learn how HCBS users felt about the help they received during the pandemic, protected themselves from the coronavirus, and stayed healthy. Some states have HCBS programs that allow people to make choices about the kinds of services they receive. Medicaid calls this self-direction. In self-direction, HCBS users have the right to hire, supervise, and fire care workers. They can also choose their services with the money that they receive from the government. We decided to work with people who used self-direction because they had more control over the kinds of help they received.

We talked with 36 HCBS users in 11 states—Texas, Kansas, Massachusetts, California, New Jersey, Alaska, Ohio, North Carolina, New York, Illinois, and Florida—about how making

their own choices helped them during the pandemic. Specifically, we wanted to know the answers to these questions:

- ▶ How did participants feel about the help they received at home during the pandemic?
- ▶ How did participants protect themselves from COVID-19 infection?
- ▶ How did participants stay healthy?

## Participant responses

### How did participants feel about the help they received at home during the pandemic?

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#### Hiring and firing workers

Because they had the right to choose their workers, participants could make rules for COVID safety. For example, they could say that workers must wear masks, avoid parties and other large in-person gatherings, and wash their hands frequently. If their workers didn't follow those rules, participants could fire them.

As one participant said:

**“ Oh, I had to get rid of somebody because they wouldn't go along with the mask and the hand-washing and all that. They didn't think it was real. They thought it was just blown out of proportion. So I had to dismiss that person, which was a bummer.**

This participant was able to think about how much risk he was willing to take—and fire workers who didn't wear masks, wash their hands, or otherwise protect him from the coronavirus.

Another participant had a similar experience:

**“ We had to be able to say, 'If you don't do what we want you to do, we're going to have to fire you. We can't have you socializing in parties and stuff.' And because they're Filipino, and having parties**

**with family and friends is part of their culture, so we knew it was really hard on them. But yeah, it's important that we could say that to them.**

Even though this participant didn't fire any of his workers, he felt safer knowing that he had the right to change workers if one of them put him in danger. x

The infographic features a dark grey background with a blue vertical bar on the left. At the top, the text 'SELF-DIRECTION' is in white, followed by the title 'Hiring and firing workers' in a larger, white, italicized font. Below the title, there are two quote blocks. The first quote is accompanied by a red speech bubble icon with a white 'X' inside. The second quote is accompanied by an icon of three stylized figures in blue, red, and yellow, with a red speech bubble icon containing a white 'X' to their left.

**SELF-DIRECTION**  
*Hiring and firing workers*

**“Oh, I had to get rid of somebody because they wouldn't go along with the mask and the hand-washing and all that. They didn't think it was real. They thought it was just blown out of proportion.”**

**“We had to be able to say, 'If you don't do what we want you to do, we're going to have to fire you. We can't have you socializing in parties and stuff.'”**

## Hiring relatives

Medicaid-funded HCBS programs allow people to hire family members as care workers. Participants said that hiring relatives helped them keep receiving care during COVID, feel safe during visits, and stay connected to other people.

One participant said:

**“ Well, I have been able to keep the one that I have, and the only reason I've been able to keep her is because she's related to me. Had she not been related to me, she would have been out the door and on about her business, I'm pretty sure.**

Someone else said that her long-standing relationship with her care worker made her feel safe:

**“ And you know, I’ve known her for years. Really, she’s related to me. And she takes very, very good care of me. Very good care. Even with the pandemic she has her gloves on, she has her mask on. When she takes me to the store, she makes sure that I’m masked up and my gloves on and she’s masked up. I mean she’s good. I don’t want nobody to come in my house and take her place. Nobody can come in and take her place.**

## SELF-DIRECTION

### *Hiring relatives*



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## Responding to changing participant needs and worker schedules

For many participants, the pandemic limited the kinds of help they could get at home. Some participants went without help because the pandemic restricted participants’ ability to find and keep workers. One participant said:

**“ Well, the biggest challenge is finding attendants. I think, well, if there’s a lot of people unemployed, but I don’t think they want to**

**work in a situation like this or... I don't know. It's been probably twice the difficulty of finding a good PCA.**

Participants also went without help when their workers became sick or were in contact with someone who was infected. Others avoided hiring new workers because this might expose the participants to the coronavirus.

The pandemic added new limits even for participants who still had workers. For example, workers' new COVID-related responsibilities took time away from everyday tasks like cooking, cleaning, and errands.

As one participant told us:

**“ The CDC started saying, 'You know, you got to clean up these places, you got to keep the countertops clean, you got to wipe down the doorknobs, you got to wipe the lights.' So, we started zooming in on, 'Before you leave, make sure you wipe down that countertop with these disinfectant wipes and make sure the doorknobs are cleaned off and the telephones are wiped down, and all that,' which took time away from what I normally had them working on.**

## SELF-DIRECTION

### *Responding to COVID-related changes*



“Well, the biggest challenge is finding attendants. I think, well, if there's a lot of people unemployed, but I don't think they want to work in a situation like this or... I don't know. It's been probably twice the difficulty of finding a good PCA.”

## How did people protect themselves from COVID-19?

### Developing guidelines for COVID-19 safety

Participants set guidelines for their workers to reduce the likelihood of catching and spreading the virus. These guidelines included absences (for example, “And even if she wakes up with a snuffle, she doesn’t come into work”) and workday routines. Here’s how one participant described his routine:

**“ Every time they come in, that’s part of the routine they have to do is to make sure those wipes come out and everything gets wiped down, and they have their gloves on, and they wash their hands all the time, and they have their masks on and all that stuff’s in place. And it took a little while to implement that because it wasn’t a habit, it wasn’t a habit for some of these people - and it wasn’t a habit for me always. So, yeah, it took some readjusting, but now we do it, we do it because we have to.**

Some workers were given safety guidelines by the service agencies they worked for, but most HCBS users and their workers created their own routines.

#### SELF-DIRECTION

### *Developing guidelines for COVID-19 safety*



*“Every time they come in, that’s part of the routine they have to do is to make sure those wipes come out and everything gets wiped down, and they have their gloves on, and they wash their hands all the time, and they have their masks on and all that stuff’s in place.”*



## **Coping with inadequate responses from public health and service systems**

Participants recognized the protective benefits of masks, other protective equipment, COVID tests, and vaccinations. Unfortunately, some people didn't have the chance to get the equipment or treatment they needed. For example, one participant said:

**“ Because at the beginning of the pandemic, there wasn't really [an] easy way to access masks, and that's why we had to improvise in my mom making masks for us.**

Someone else said that although she was able to get tested easily, her workers were less fortunate.

That wasn't the only difficulty that participants faced. At the beginning of the vaccine rollout, information about vaccines and their availability was often spotty. All this led to confusion and frustration among participants and their workers:

**“ And I'm now worried—am I going to get the shot? I called my doctor's office. They keep saying they don't have the shot. I don't have a computer, so I can't go on and find out stuff.**

And someone else said:

**“ Everything was just sort of set in stone for older people—which is fine—but I just feel young people with disabilities get forgotten, and for some people that aren't born with a disability, they don't realize that young people with disabilities exist, so then we just sort of have to—we get swept under the rug.**

Although some participants said that agencies helped them find information and resources, others said that agencies could have been more helpful.

**“ It was more recently, like in the middle, kind of towards the beginning/middle. It just came. They didn't say it was coming. It just came, and then I got on the website and I saw everybody else**

was thanking them for the packages and stuff like that. So, I thought that was really neat because it was a lot of necessities that we really needed.

## SELF-DIRECTION

### *Problems with public health and service systems*



“Because at the beginning of the pandemic, there wasn’t really [an] easy way to access masks, and that’s why we had to improvise in my mom making masks for us.”



“And I’m now worried—am I going to get the shot? I called my doctor’s office. They keep saying they don’t have the shot. I don’t have a computer, so I can’t go on and find out stuff.”

## How did people stay healthy?

### Struggling to meet basic needs

Most people had to pay out of pocket for masks, gloves, hand sanitizer, and other items—and had less money to cover their other needs because of it:

- “ So, even out of what little income I have—which, for me, is just Social Security—I was buying better-quality medical gloves on Amazon.
- “ Ever since the pandemic, my income has gone down because I recently lost jobs...I’ve dealt with—well, still dealing with—food insecurity right now, and then a lot of it is just trying to make ends meet when it comes to paying for just certain things.

At the beginning of the pandemic, many hospitals limited access to medical equipment, such as respirators and ventilators, that people with disabilities needed in their everyday lives. Hospitals used this equipment for COVID patients, leaving less of it for people with other health needs.

“ I’ve run into other issues—vent supplies. They’ve been rationing our vent supplies since the beginning. I knew this was going to happen the first week of March... I’m getting one vent circuit a month when I used to get one a week. So I’ve been getting constant, major airway infections ending up on IV antibiotics on a monthly basis.

## SELF-DIRECTION

### *Struggling to meet basic needs*



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“Ever since the pandemic, my income has gone down because I recently lost jobs...I’ve dealt with—well, still dealing with—food insecurity right now, and then a lot of it is just trying to make ends meet when it comes to paying for just certain things.”

## Putting off healthcare visits

Other participants felt that they had to put off everyday healthcare visits because of COVID. As one participant said:

“ I was supposed to go for a repeat scan on my breast back in March. And because of the pandemic I put off the appointment. And I kept putting it off, but I should not have done that. I was just diagnosed this week with breast cancer.

## Self-Directing Services and Supports during the COVID-19 Pandemic

Another participant avoided checkups because they and their care worker wanted to avoid catching the virus:

**“ We both need dental work. And we didn’t do it at all because we were so afraid we’d get COVID if we went, because we have to have our dental work done in the hospital setting. So we haven’t done that. And we haven’t seen a doctor for an actual physical where they’re right there with you now for over a year.**

Some participants worried about being hospitalized with COVID, since hospitals have a history of mistreating people with disabilities. Since some medical workers think that disabled people’s lives matter less than those of nondisabled people, they may take longer to give disabled people lifesaving COVID treatments.

The virus wasn’t participants’ only concern. Social distancing, stay-at-home orders, and other COVID rules added extra stress to their lives:

**“ It’s been very stressful—very stressful—and very isolating. I feel very isolated because I’ve just basically had to stay inside, stay away from the population. And I’m at very high risk for COVID—and I just didn’t know what else to do but to stay at home and stay away from most of my family.**

Some participants talked with their workers about ways to support their mental health and well-being:

**“ So, the pandemic kind of made us housebound for a while and very, very boring and just depressing at times. But my worker, we found ways around it, just the two of us. But we had to be very selective on where we went, and that really bothered me because we used to be able to jump in the vehicle. But the pandemic slowed that down for a while. My depression set in really bad... But like I said, my worker found ways to help deal with that part and keep me going, and we found new ways to venture out without venturing out.**

SELF-DIRECTION

## *Putting off healthcare visits*



“I was supposed to go for a repeat scan on my breast back in March. And because of the pandemic I put off the appointment. And I kept putting it off, but I should not have done that. I was just diagnosed this week with breast cancer.”

### Using technology and telehealth

Many participants said that telehealth—meeting doctors, therapists, and other healthcare workers over video calls or the phone—made it easier for them to make their appointments.

“ I’ve been really grateful for telehealth mental health services. You know, I see my therapist once a week over Zoom and that’s really kept me together. I think I would’ve fallen apart a while ago if I didn’t have her and if I didn’t have the ability to have that face-to-face contact.

Some participants told us that they wanted to keep telehealth after the pandemic, too:

“ I have telehealth appointments with the doctors, and I do therapy that way, and in all honesty, that is the best way for me, period. Because for me, traveling is very difficult. I have a lot of health issues that make it really hard to get in and out of the van and wait out in the cold and whatever the elements are.

Telehealth appointments weren’t the only benefit for the study participants. Being able to connect with others through technology helped them stay in touch with their family and

friends, shop for groceries, go to church or other houses of worship, run errands, and take care of other daily-living tasks:

- “ I’m a very social person. And staying home has been really hard, you know. I can order what I need and what I want off of Amazon but it’s not the same as like going to Target, you know, and being able to peruse the aisles.
- “ I’m a member of a church and so everything went online. Everybody’s Zooming and things. So now I can tune into the coffee hour and different things like that which I didn’t really do before because it was too early in the morning, I had to get it all together and get down. So that’s been a real positive thing.

## SELF-DIRECTION

### *Using technology and telehealth*



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## Study Summary

In this study, we learned a lot about the ways self-direction helped people who need LTSS manage during the pandemic. Here’s a list of the things we learned:

## Self-Directing Services and Supports during the COVID-19 Pandemic

- ▶ Some people had a hard time keeping and finding workers during COVID, but most participants were glad that they could hire their own workers to help them during the pandemic.
- ▶ People were able to keep themselves safe from COVID by setting rules for their workers.
- ▶ Most participants struggled to get masks, COVID tests, vaccinations, and other resources.
- ▶ Technology helped people stay connected to family, friends, community members, and healthcare workers.
- ▶ People who direct their own services didn't work as much with formal agencies, so they had a harder time getting support and resources.

## Next Steps

Although the changes in self-direction policies have helped HCBS users stay connected and get the support they need, many of these changes are only temporary and will end after the COVID-19 emergency is over. To make sure that people continue to receive these services, state and federal policymakers should consider making long-term changes to HCBS systems. Congress has already provided over \$12 billion in extra funding in January 2021, and the Biden Administration is considering adding another \$400 billion. This money will help states make their HCBS programs better for people who want to self-direct their services.

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## Self-Directing Services and Supports during the COVID-19 Pandemic

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