

COVID-19 Disability Community Survey Results: Health and Financial Crisis

On March 24 and 25, 2020, National Disability Institute (NDI) held two listening sessions, [*The Impact of Coronavirus on the Disability Community*](#), with more than 17 national disability organizations and a nationwide audience to learn more about the current challenges people with disabilities and chronic conditions are facing from the COVID-19 pandemic. More than 600 individuals responded to an online survey that provides additional insights on the immediate concerns of this population during the current crisis.¹ This report shares what we learned.

Overview

NDI's previous research indicated that people with disabilities are more likely than those without disabilities to live in poverty, more likely to be in low wage jobs if they are employed, less likely to have accumulated savings and less likely to be able to come up with funds if an unexpected need arose.

Although some people with disabilities are able to weather the financial impact of COVID-19, for many, their fragile financial situation makes it more difficult to navigate difficult times.

Based on the survey responses:

- 51 percent have “a lot” or “an extraordinary amount” of concern about their ability to pay bills or meet financial obligations; and
- 49 percent have either already lost their job or fear losing their job or having their hours reduced.

People with disabilities and chronic health conditions are at higher risk of having a severe illness if they contract COVID-19. In addition to their anxiety around contracting the virus, respondents were concerned about related health care issues:

- 68 percent expressed concern about access to medical care referring to both the ongoing medical, mental health and therapies they need to manage their underlying conditions and access to care if they do contract the virus;
- 66 percent were concerned that, if services are rationed, they will be deprioritized; and
- Half were worried about maintaining access to personal care assistance and other supports that enable them to live independently.

¹ NDI conducted the online survey March 24-April 2, 2020. Of the 613 individuals who responded, 55 percent were people with disabilities, 32 percent were family members and 47 percent represented disability or other community-based organizations who were predominantly reporting on the experience of their clients. Respondents ranged in age from 18 to over 65 with 74 between 31 and 65. Respondents were asked to rate a list of issues on a scale of “not a concern,” “a little concern,” “a lot of concern” or “an extraordinary amount of concern” and were given the option to add open-ended comments.

Financial concerns, coupled with the health risk from the virus, affects food and housing security:

- 47 percent are concerned about having enough money to stock up on food;
- 42 percent worry they will have difficulty paying their rent or mortgage; and
- One-third are worried about being evicted.

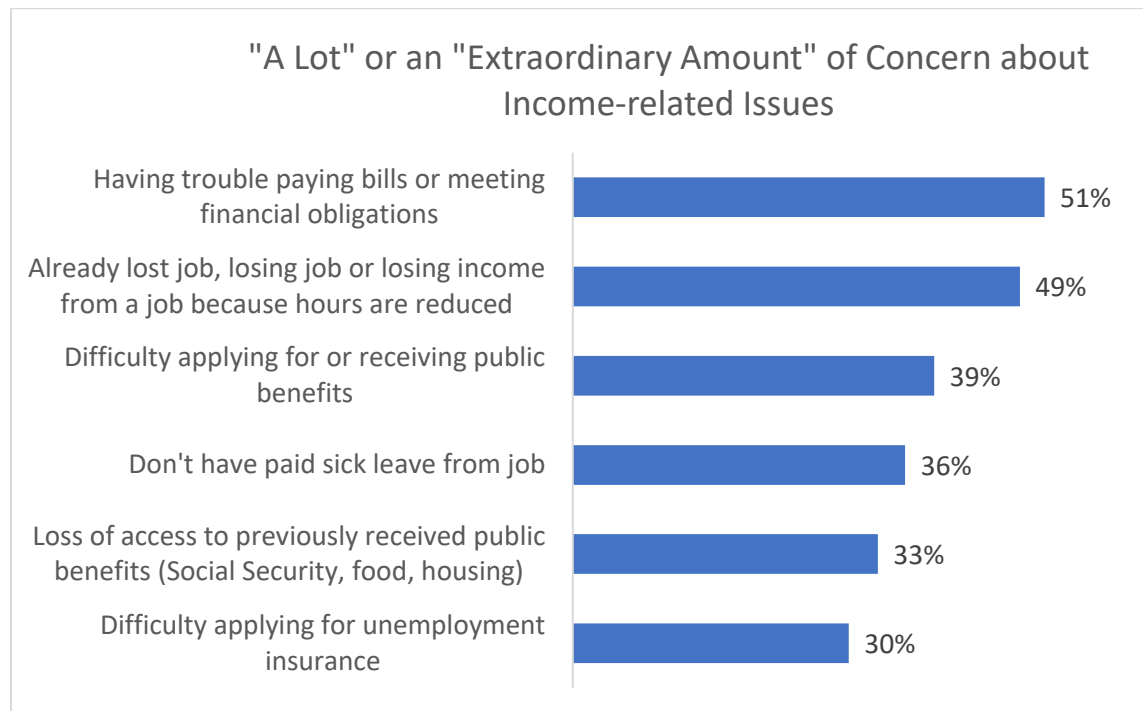
People with disabilities and chronic conditions identified other challenges they face during the crisis:

- 55 percent were concerned about social isolation
- 54 percent were concerned about access to community supports

Only one in five thought Congress plans to address the immediate needs of people with disabilities and/or chronic health conditions who are adversely impacted by COVID-19.

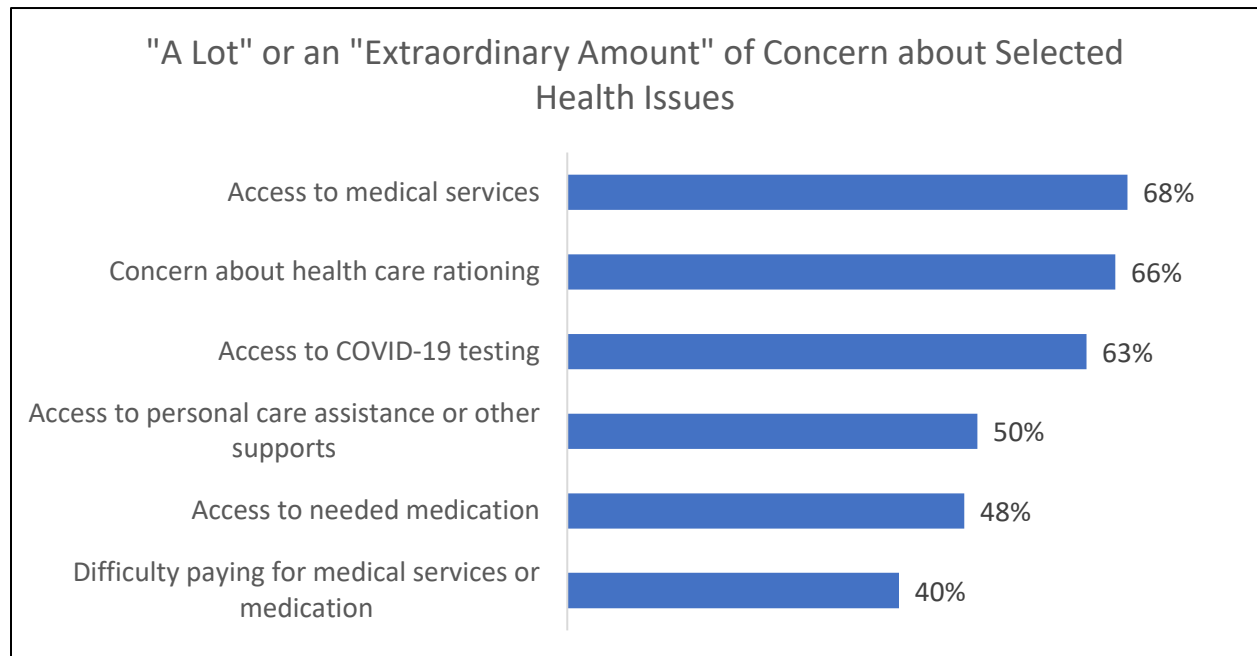
Detailed Findings

Income



Respondents expressed concern about employers terminating job or furloughing employees or reducing hours. Some respondents, especially those who are immunocompromised or have other chronic conditions, were additionally concerned they would need to leave their jobs if their employers could not guarantee their safety.

Health and Health Care



Respondents who were receiving regular care from doctors and physical therapists, prior to the pandemic, had appointments cancelled and are worried about the impact of not being able to access that care. "I will go backwards on progress without my physical therapy," wrote one respondent. Others were concerned that the drugs and supplies they use to maintain their health will be difficult to get because they will be "prioritized" for COVID-19 patients. For example, one respondent uses Hydroxychloroquine (the drug that has been mentioned as a treatment for coronavirus) for lupus and said, "I cannot work or function without that medication."

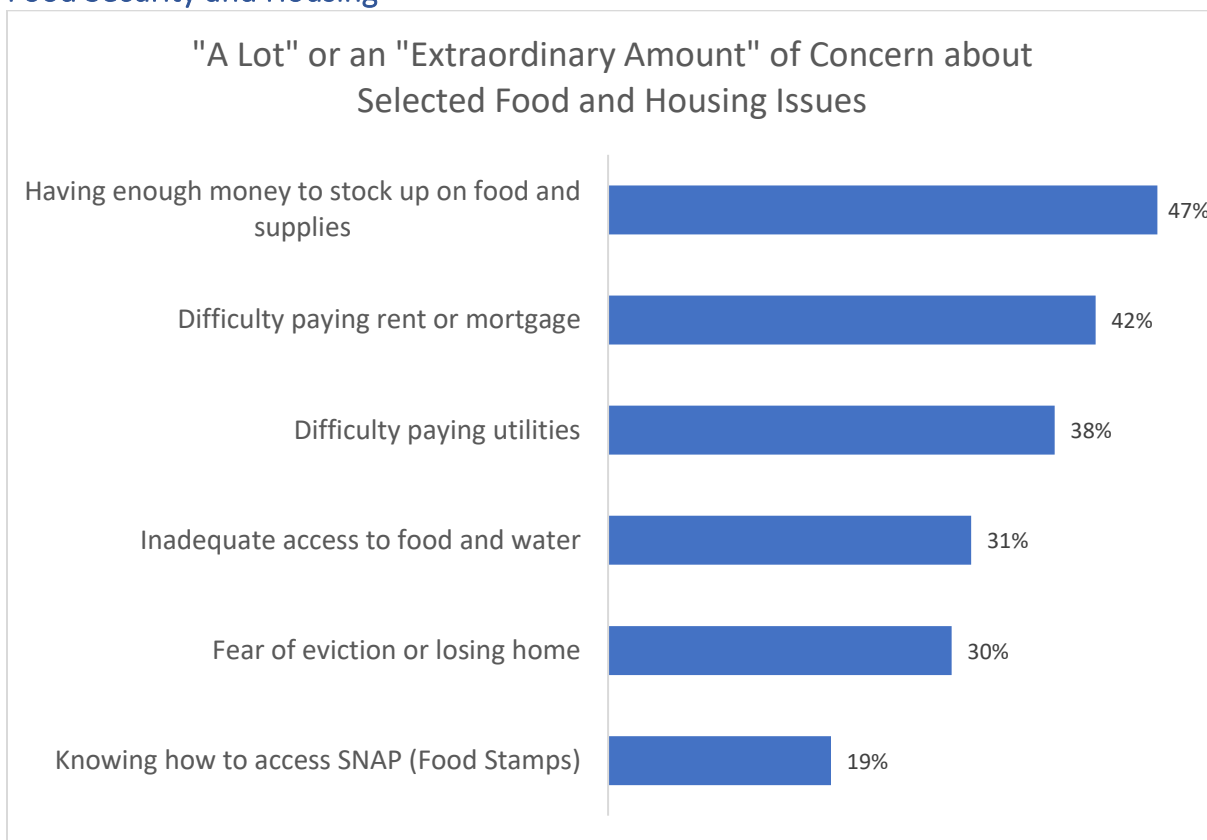
Rationing is a major concern. Another respondent wrote, "Is my 27-year old physically and mentally challenged son, who is otherwise healthy, going to lose out to an income-producing typical 27-year-old when there is just one ventilator between the two of them?" Yet another respondent wrote:

"I heard that as hospitals run out of ventilators, this means they are going to choose who lives and who dies. This means people with disabilities and other conditions are going to die first. I have asthma besides my CP. This means if I get sick, I am going to die. With everything that we have done and continue to do, we are still not valuable to save. I'm not only talking about myself, but people with developmental disabilities and intellectual disabilities in general. Will society see us as valuable or are we the first to die? Does our Government have our back? I'm not sure!
I'M SCARED.

Those who rely on personal care supports expressed concern they will not be able to continue living independently and will be forced into institutions if they don't have reliable supports.

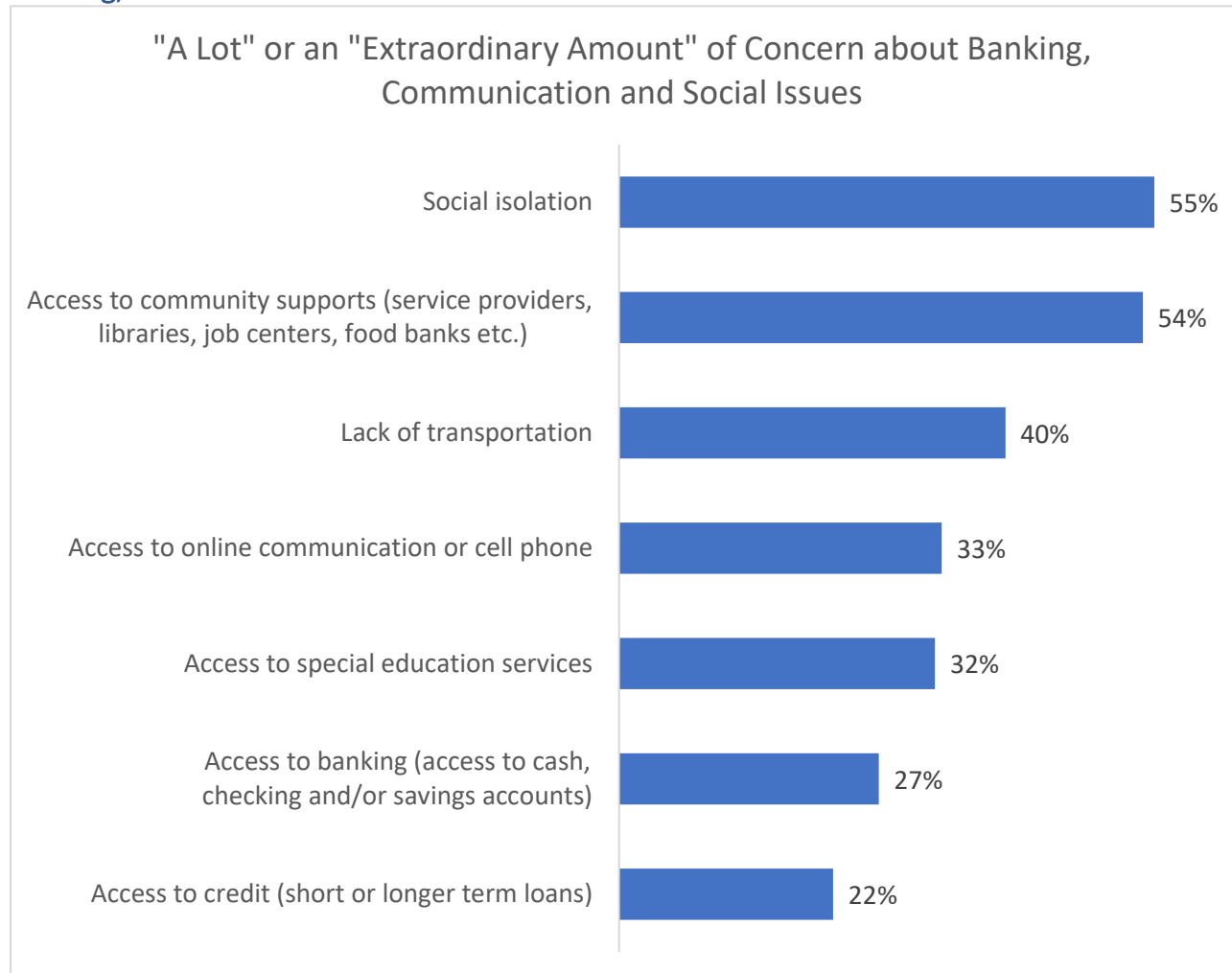
They are concerned that the virus has exacerbated the shortage of personal care attendants (PCA). Increasingly, PCAs are not available because they are either sick from COVID-19, worried about exposing themselves to the virus or needing to stay home to take care of their own families. At the same time, programs that provide day services are not operating. Several respondents from disability service organizations shared the challenge of balancing the rights of the direct care staff with the need to provide quality care that people with disabilities need and are entitled to.

Food Security and Housing



Respondents expressed concern about the impact of COVID-19 on their ability to access food and safe housing. They described the logistical challenges of getting food: Some have a chronic condition that makes it dangerous for them to shop and expose themselves to the virus; others cannot find transportation to get to a store because public transportation and paratransit has been reduced; or delivery is difficult to access because there is so much more demand for the service. Respondents with chronic conditions that put them at elevated risk for the virus identified the challenge of remaining safe in public housing, shared housing and congregate living situations where COVID-19 may spread rapidly.

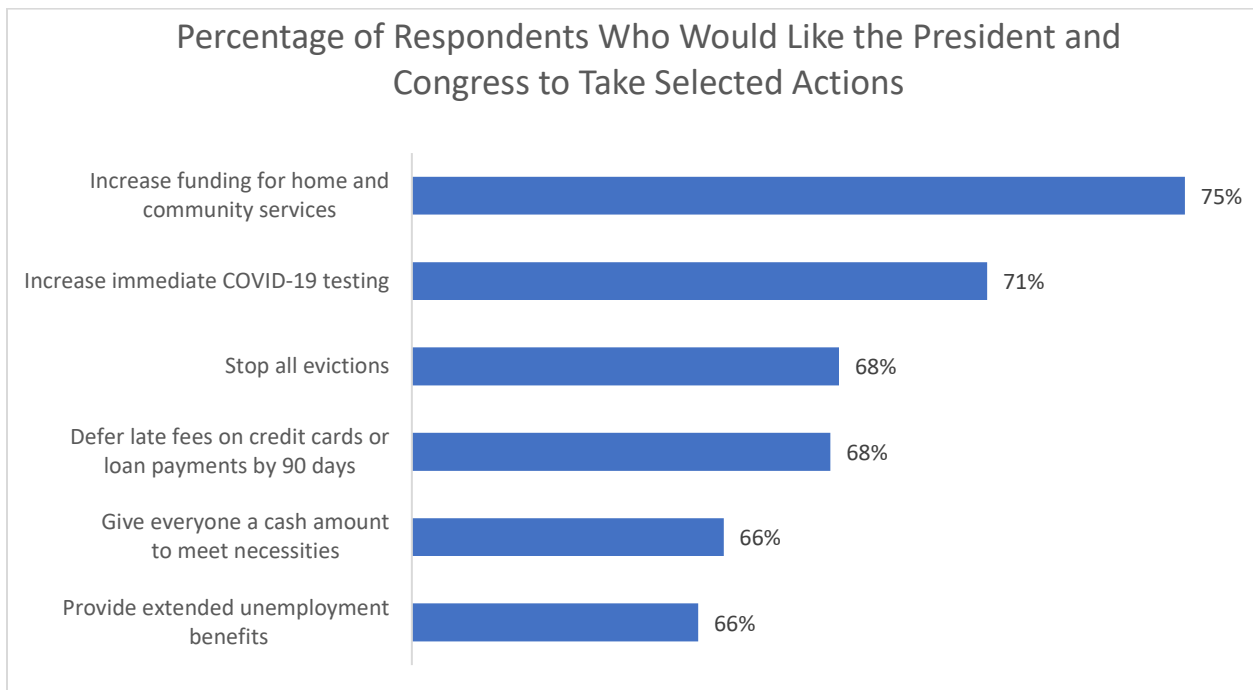
Banking, Communication and Social Issues



Many respondents wrote about the emotional toll of isolation. For those with mental health conditions, losing access to in-person human interaction due to social distancing could exacerbate their anxiety and depression. One respondent shared, “My support meetings have been cancelled. My greatest source of comfort is gone now.” Others wrote about the challenge of not being able to see loved ones who are in congregate living situations. “I have a young adult son with autism who is in a state-run facility and I’m not able to visit him due to restrictions,” wrote another respondent. “He is nonverbal and at a level of development which prevents him from understanding why we can’t see him. This is very upsetting for us and I imagine it is for him as well.” Others have more general concerns about isolation from their usual support circles.

Next Steps

We presented respondents with a list of proposed actions the President and Congress could take. Seventy-five percent believed funding should be increased for home and community-based services; 71 percent believed they should immediately increase COVID-19 testing. Over 65 percent believe Congress and the President should help people address the financial impact of the virus by stopping evictions, deferring late payments on credit cards, providing a cash benefit and extending unemployment benefits.



Respondents urged the government to listen to the needs of the disability community. One respondent wrote that policy makers should “become aware of, acknowledge and address the real needs of people with disabilities; including them in full (positively) in the ‘conversation,’ making explicit the expectation (and associated action) that people with disabilities deserve equitable support during this crisis (and beyond).”

Conclusion

This group of respondents, representing the disability community, presents a stark picture of the immediate needs of people with disabilities and chronic health conditions nationwide during the COVID-19 pandemic. The identification of these needs should inform responses from federal, state and local policy makers.

However, respondents revealed little faith in the government. Only one in five thought Congress plans to address the immediate needs of people with disabilities and/or chronic health conditions who are adversely impacted by COVID-19.

National Disability Institute will continue to identify challenges that face the disability community, develop resources to help the community address those needs and share the issues with policy makers and other organizations. At the same time, we will monitor how organizations and government are responding to the challenges. Follow NDI's response at: <https://www.nationaldisabilityinstitute.org/financial-resilience-center/>.