



COVID-19 Disability Community Needs Assessment Report

Executive Summary

At the onset of the COVID-19 pandemic, Lakeshore Foundation and the National Center on Health, Physical Activity and Disability (NCHPAD) initiated a survey to gain a better understanding of needs of the disability community during this time. Findings from the national online, COVID-19 survey data identify critical, unmet needs of the disability community from the viewpoint of both people with disabilities and/or chronic health conditions and those who are family members or caregivers of someone with a disability and/or chronic health condition. Over a two-week period, 1409 people who identified as members of the disability community responded to the survey.

The following reoccurring needs emerged from the responses:

- **Financial needs are of major concern.** Many worry about being able to afford items to meet basic needs. Many fear not being able to continue to pay bills such as rent or mortgage, which may result in the loss of their home. Others were concerned that they will not be able to afford food or their medication.
- **There is a lack of access to necessary items including groceries, medication and medical supplies.** Restricted availability of grocery delivery in addition to costs associated with delivery pose a barrier to accessing basic necessities. Current policies and technology prevent the use of benefit programs through online ordering. Some called for policies to include people with disabilities and/or chronic health conditions in the special shopping hours for older adults.
- **Inclusion in all hospital services is of vital importance.** There is a true fear of exclusion and discrimination receiving lifesaving treatments or in policy and guideline development due to a pre-existing disability or health condition.
- **Many also feared that others put them at risk.** By others not being careful and following protective measures, there was a worry that there will be exposure to COVID-19 whenever leaving the home. Additionally, those in essential jobs feared going to work and having unnecessary exposure or bringing the virus home to loved ones.
- **Many reported needing unbiased information about COVID-19 that is available in accessible formats (e.g., sign language interpreters, Spanish).**
- **Broadly, addressing mental health is vital.** Many feel overwhelmed with uncertainty or adjusting to the new routines and protective measures. Others lack social support and feel isolated and lonely. Some lack caregiving help for either their own needs or the needs of their family members, leading to potential caregiver burnout or a need for respite.
- **Finding ways to access healthcare is also important.** Telehealth cannot always be used or is not always available and may not be covered by all insurance providers. Without access to medical professionals and therapists, many fear regression in physical or functional gains or relapse in conditions due to lack of access to medicine or medical equipment.





Introduction

People with disabilities and/or chronic conditions face inequalities in emergency responses that affect health, safety, and wellbeing¹. It is important to understand the unique needs of this population in order to address their needs. Therefore, this survey was conducted to explore current needs of people with disabilities and/or chronic health conditions in response to the COVID-19 pandemic.

Purpose

The purpose of the survey was to identify what people with disabilities and people with chronic conditions need most during the COVID-19 crisis. This survey was exploratory in nature and targeted representatives of the disability community including people with disabilities and/or chronic conditions, family members of people with disabilities and/or chronic conditions, and caregivers of people with disabilities and/or chronic conditions. The survey consisted of closed and open-ended questions focused on assessing the ability to meet daily needs, sources of information, worries or fears, assistance needed during this time, as well as other questions to assess how this population is or is not able to meet their needs.

Methodology

The COVID-19 Disability Community Needs Assessment was available to be completed online from April 2, 2020 through April 17, 2020 through two survey platforms. The survey was distributed initially through networks of disability serving organizations and individual advocates. A survey in Spanish was also available and sent upon request. Overall, 1409 individuals responded to the survey. Respondents identified either as a person with a disability and/or chronic health condition or a family member or caregiver of a person with a disability and/or chronic health condition and provided a response to at least one question.

All survey questions were self-report. Open-ended responses were coded for emerging themes. Two coders were assigned to the open-ended responses to review and code each one. Closed-ended responses were summarized and reported. The number of responses is included to account for varying levels of completeness in the surveys.



Results

Demographics

A total of 1585 began the survey. 798 (50%) identified as a person with a disability and/or chronic condition, 611 (39%) identified as a family member or caregiver of a person with a disability and/or chronic condition, 42 (3%) preferred not to answer and 133 (8%) were none of the above. The survey analysis only includes those who identified as a person with a disability and/or chronic condition or a family member or caregiver of a person with a disability and/or chronic condition (n=1409).

Figure 1: Respondents by self-selected identity:

Respondents identify as...

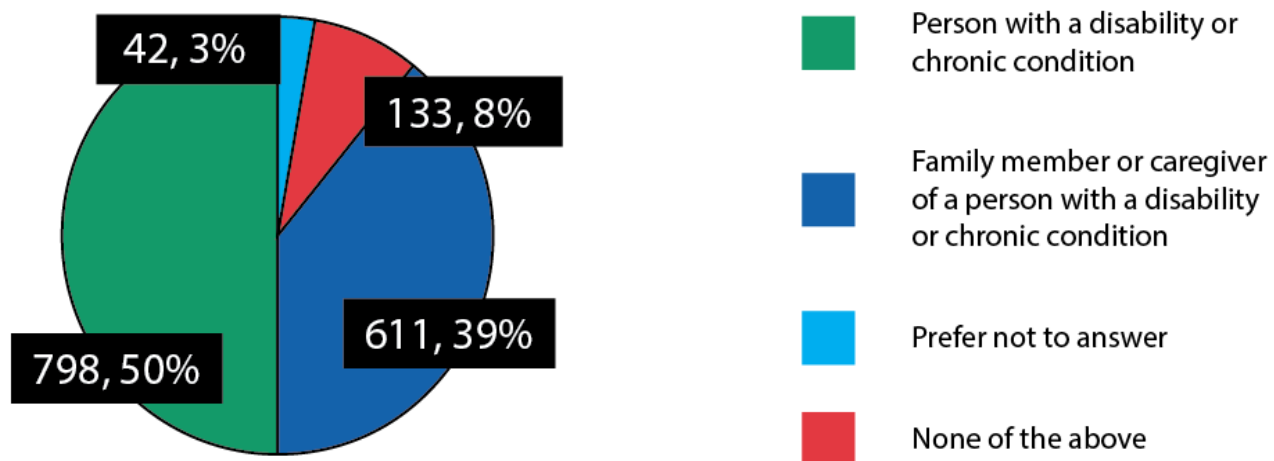


Table 1: Respondents by age and identity

	Total (n=1409)	% of total responses	PWD n=798 (56.6%)	Fam/Care n = 611 (43.4%)
18-25 years	97	6.9%	35 (4.4%)	62 (10.1%)
26-39 years	284	20.2%	156 (19.5%)	128 (20.9%)
40-59 years	757	53.7%	457 (57.3%)	300(49.1%)
60+ years	263	18.7%	146 (18.3%)	117 (19.1%)
No answer	8	.01%		

Most people who participated in the survey were between the ages of 40-59 years (53.7%), followed by 26-39 years (20.2%), 60+ years (18.7%) and 18-25 years (6.9%).

Self-reported characteristics of respondents:

- Most people (94.3%) are currently or planning to “stay at home” during this time. (n=1397)
- Most people (77.8%) have support available through others such as family, friends, or caregivers. (n=1152)
- 66.7% know where to find resources for help if they are feeling anxious (n=923)

Meeting daily needs

The survey presented 10 categories and asked “are you able to meet your daily needs in the following areas”. Responses were ‘yes’ or ‘no’, except for a subset of participants who identified as people with disabilities and/or chronic conditions who were able to respond “yes, by myself”; “yes, with help from other people”; “yes, with help from organizations”; “no” or “does not apply to me”. This allowed for a better understanding of how needs were being met. None of the categories were defined in the survey, so the person taking the survey could respond however they felt it applied to them. The data is first summarized all together, then is broken down graphically by people with a disability or a chronic condition followed by family members or caregivers of people with a disability and/or chronic condition. Overall, the top three areas in which people felt they could not meet their needs were recreation and other health-related activities, home repair, and keeping doctor and/or therapy appointments.

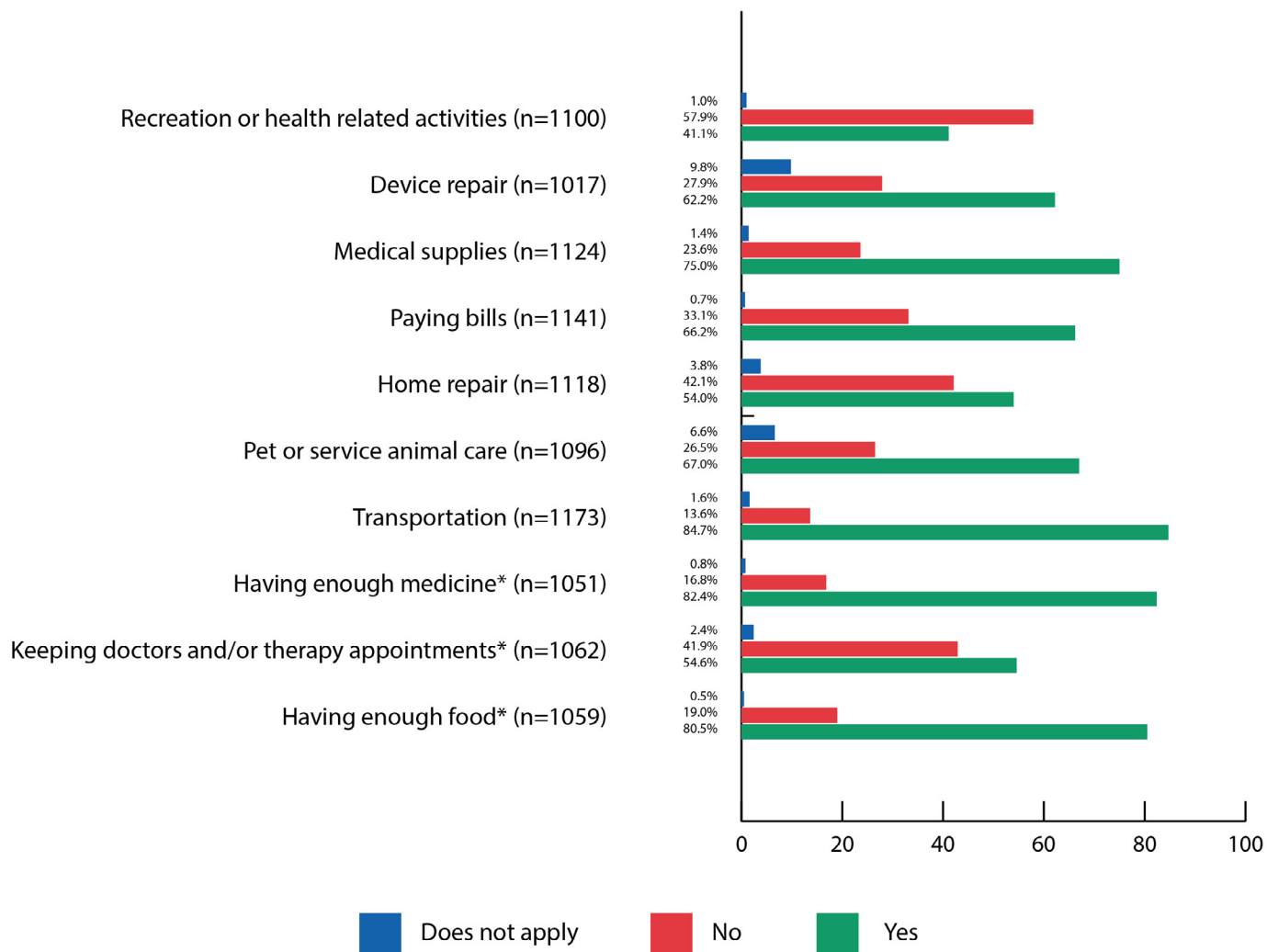
The percentage of respondents reporting needs could not be met were as follows:

- 58% could not meet daily needs in recreation or other health related activities
- 42% could not meet daily needs keeping doctor or therapy appointments
- 42% could not meet daily needs in home repairs
- 33% could not meet daily needs paying bills
- 28% could not meet daily needs in animal care
- 29% could not meet daily needs in wheelchair or assistive device repair
- 27% could not meet daily needs having enough medical supplies
- 19% could not meet daily needs having enough food
- 17% could not meet daily needs having enough medicine
- 14% could not meet daily needs in transportation



Figure 2: Reported ability to meet daily needs in specified categories for all respondents

"Are you able to meet your daily needs in the following areas" combined responses (%)

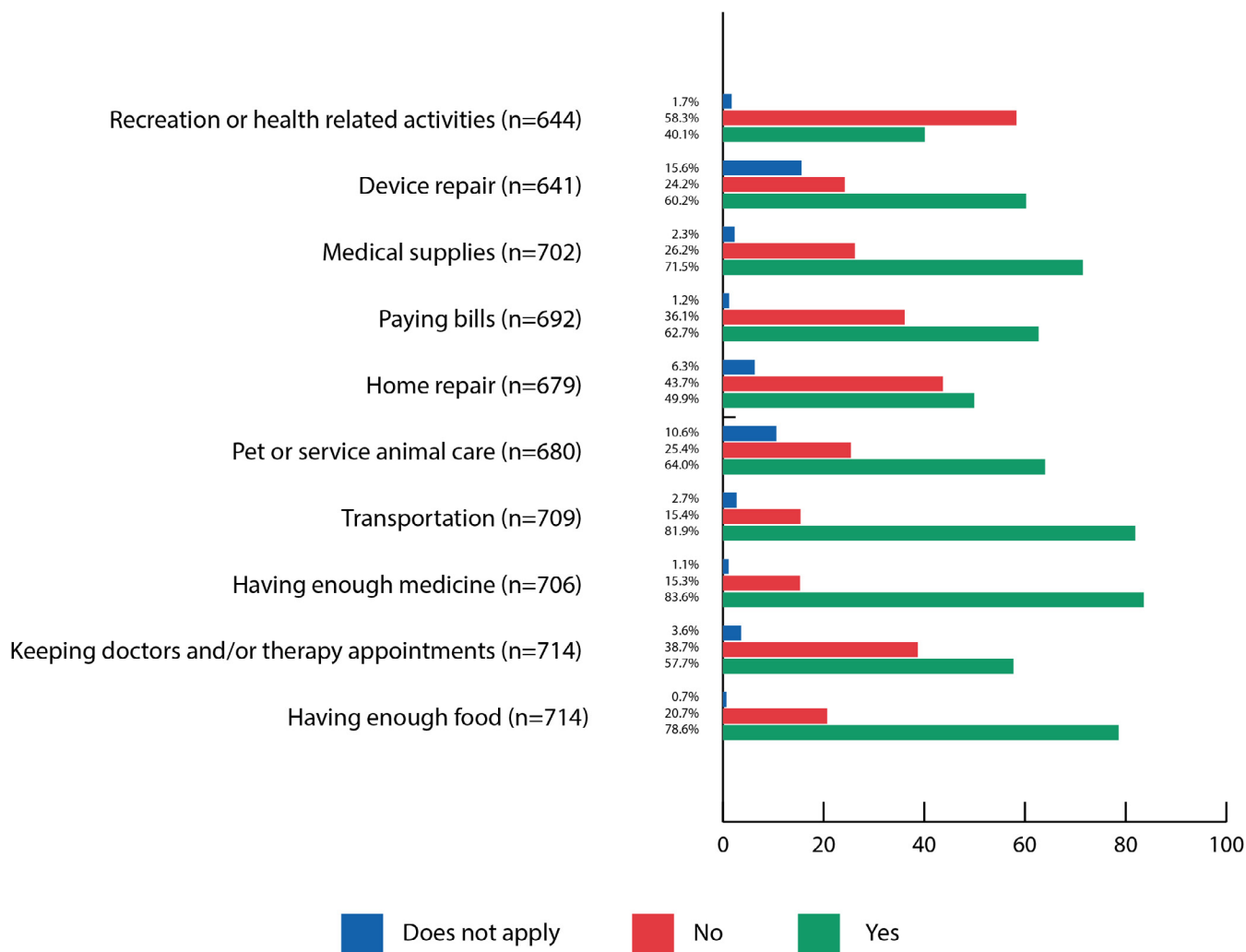


*these answers may be underreported due to a technical difficulty in the survey collection tool.

Note: The response 'does not apply to me' was only available to the subset of people with disabilities and/or chronic health conditions, others may not have responded to the question if it did not apply.

Figure 3: Reported ability to meet daily needs in specified categories for people with disabilities and/or chronic conditions (%)

"Are you able to meet your daily needs in the following areas" people with disabilities or chronic conditions (%)



"Financial resources such as bill assistance. Food banks are over booked and all the cheap generic foods are sold out."
– Survey Respondent

Figure 4: Reported ability to meet daily needs independently or with assistance in specified categories for the subset people with disabilities and/or chronic conditions (%).

Ability to meet daily needs independently or with assistance (%)

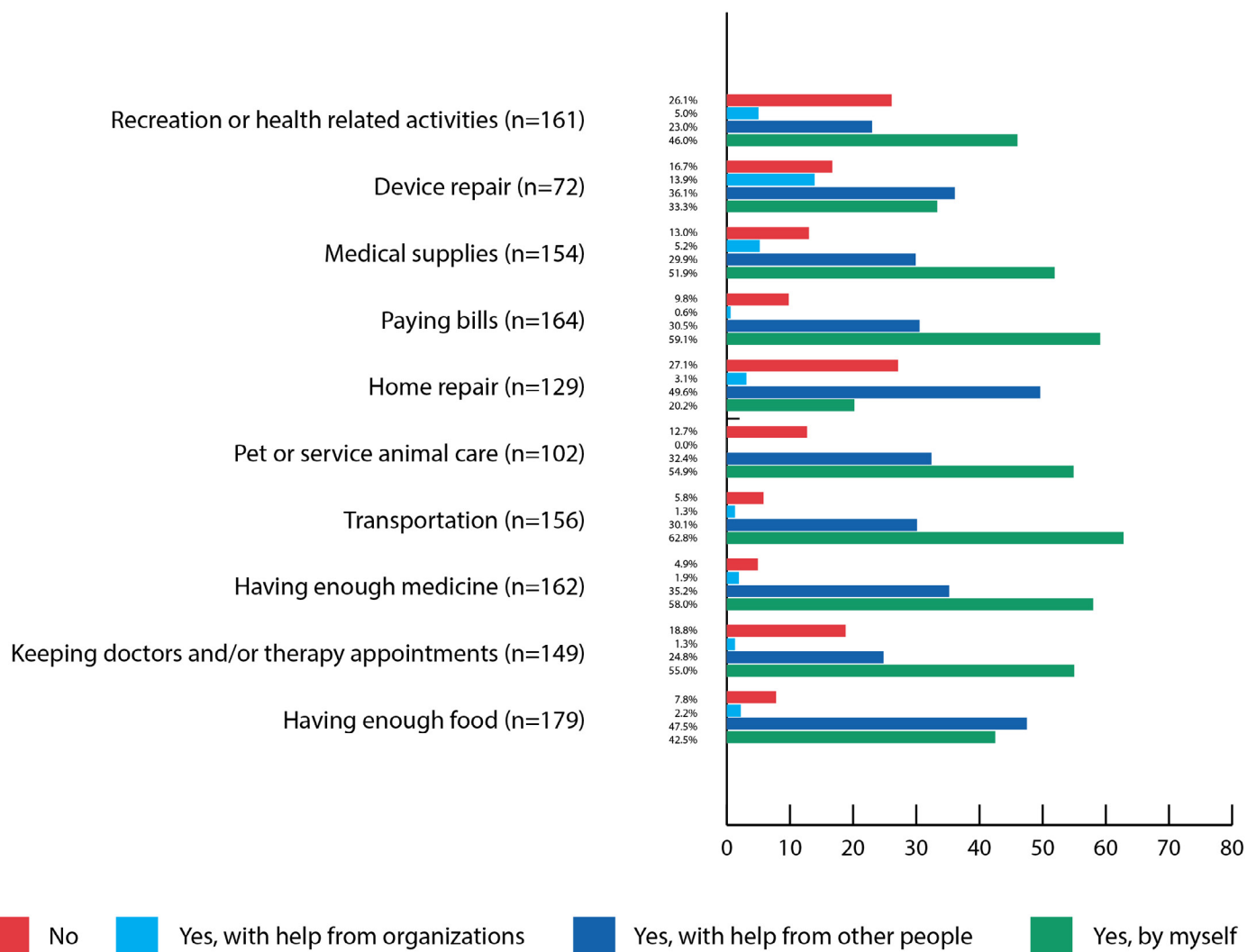
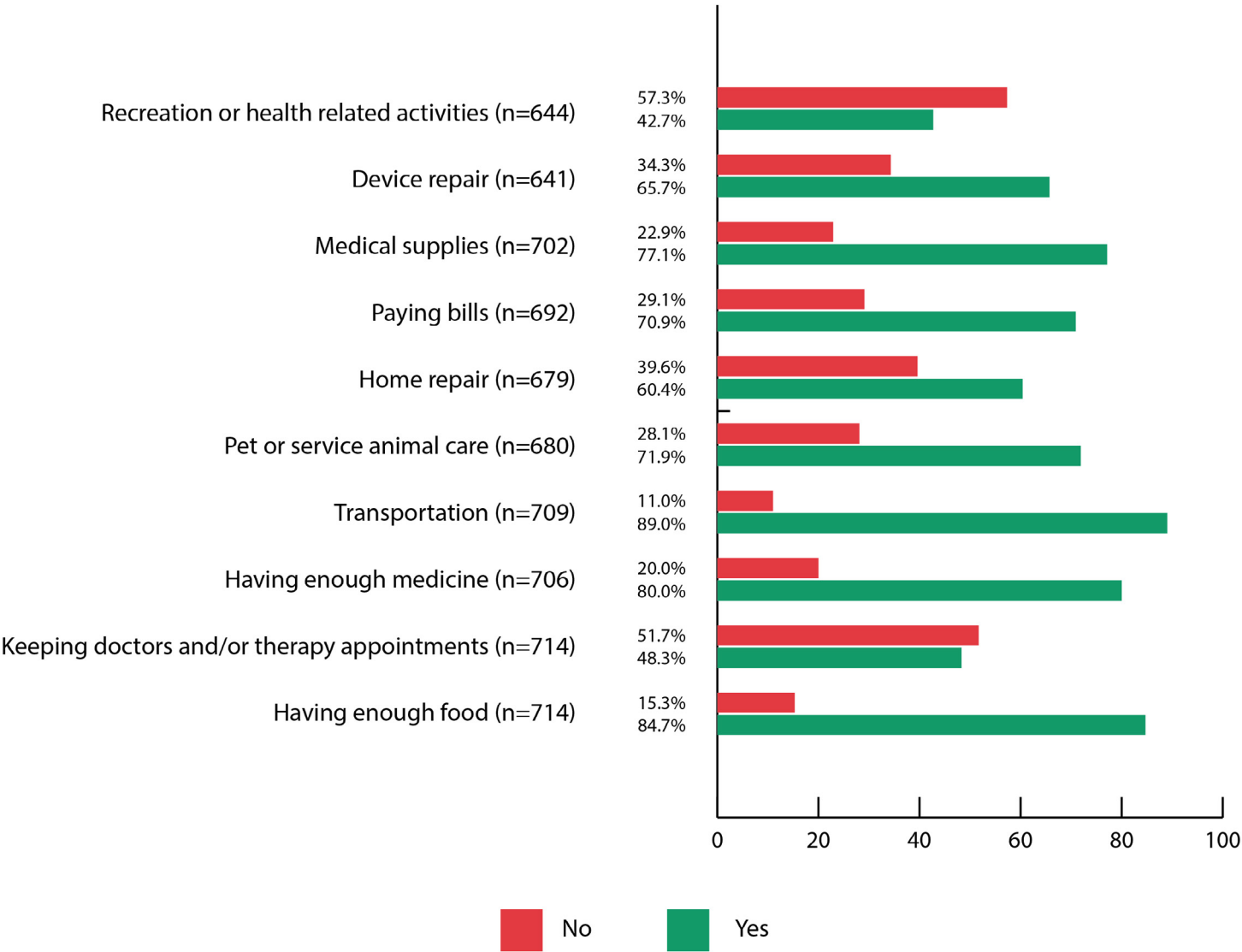


Figure 5: Reported ability to meet daily needs in specified categories for family members or caregivers of people with disabilities and/or chronic conditions (%)

"Are you able to meet your daily needs in the following areas" Family members or caregivers (%)



Organizational help meeting needs

Only 23.7% of 1138 respondents reported reaching out to an organization for help during this time. Of those who reached out, only 12% reported that all of their needs were met and the majority (57%) reported that some of their needs were met (Figure 6).

If the person responded that they had contacted an organization for assistance, they were asked which organization. Those answers were categorized by type of organization. Some answers were not categorized because there was not enough information to identify the exact organization. In the case where there was a government sponsored program that had a focus in one of the other categories, it was categorized as a governmental organization. Types of organizations contacted are listed in table 2.

Figure 6: Respondents reporting organization's ability to meet their needs (%) (n=270).

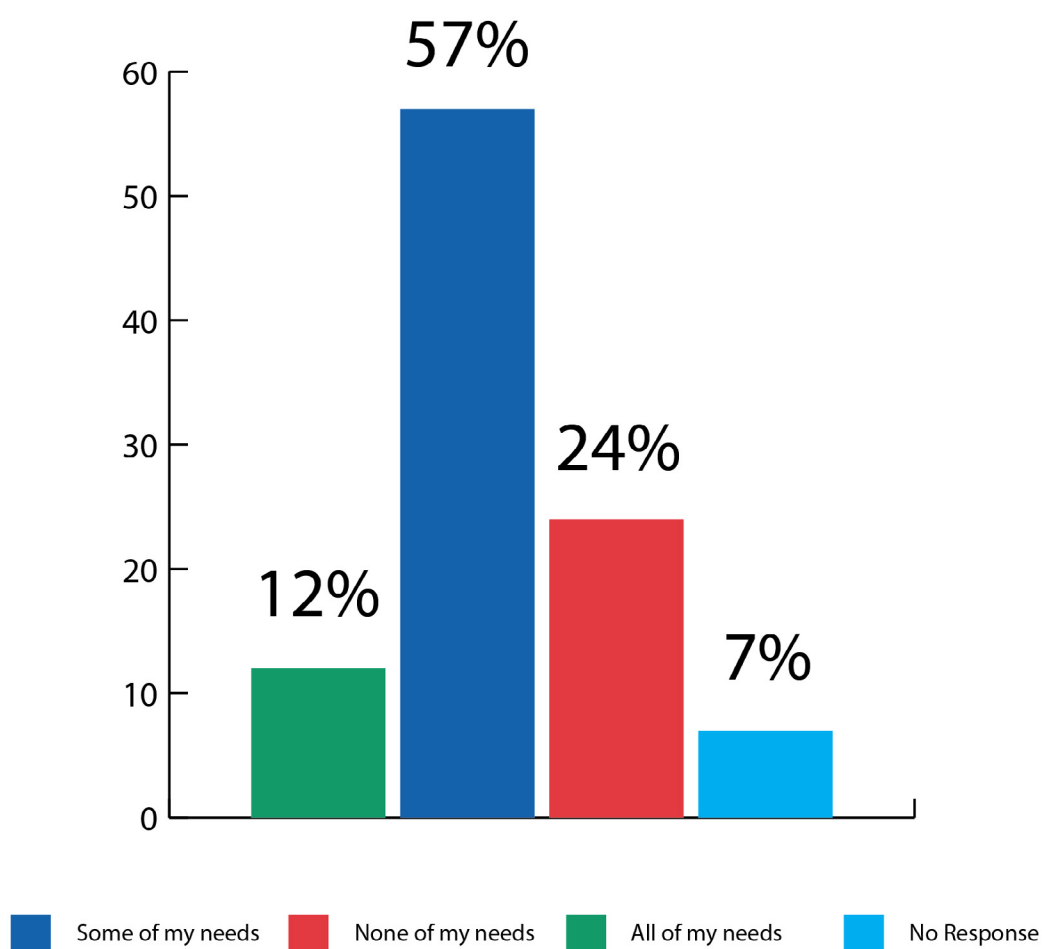


Table 2: Types of organizations contacted for assistance during the COVID-19 crisis in order of number of individuals reporting that type of organization.

Type of organization	Reported Example Organizations
Healthcare	Mental health, hospitals
Organizations that provide various types of assistance (often not-for-profits)	Food banks, United Way, 211, Salvation Army
Disability focused mission	Autism Speaks, Easter Seals
Government	FEMA, government sponsored disability programs (e.g. Office for People With Developmental Disabilities), elected officials
Faith based	Catholic Church Services, local church outreach
Schools or universities	School districts, university centers
Local response	Crisis centers
Financial or insurance	Medicaid
Sport or activity based	Special Olympics
Advocacy organizations	Alabama Disabilities Advocacy Program (ADAP)

*Example organizations are based on those reported

Assistance requested during COVID-19 crisis

Respondents were given the opportunity to identify what they thought would be most helpful to assist them at this time. This question was open ended. The most common responses are summarized below:

Access to groceries and necessities:

Many people reported needing assistance getting food and other necessities (such as hygiene, cleaning, and paper products). A common request was to expand the special shopping hours to include people with disability along with older adults. Additionally, the morning hours can be difficult for this population, so there were requests for alternate special shopping hours. Another issue was delivery of groceries. Many live outside of delivery areas or could not afford the additional delivery fees.

Financial needs:

Most are experiencing financial hardships and expressed a need for assistance in order to pay for their basic needs.

Support help:

Due to the protective measures in place, many have had to go without help that they normally have and have had to take on more daily tasks. Specific examples of needs reported are assistance with cooking, cleaning, respite, access to resources, activities of daily living, and transportation.

Social support:

Many asked for ways to better connect with others during this time or to be able to better reach their loved ones.

Governmental or policy level enforcement of inclusive practices:

Many asked for policies that ensured inclusive practices such as information in accessible formats of information, clear masks for those who are deaf, better captioning or ASL interpreters for videos and live news, and continued assistance for those on disability or social security.

COVID-19 Information:

More information was requested regarding a variety of topics related to COVID-19 including public awareness of safety precautions, testing access for both the virus and the antibodies, and consistent information about the counts of cases.

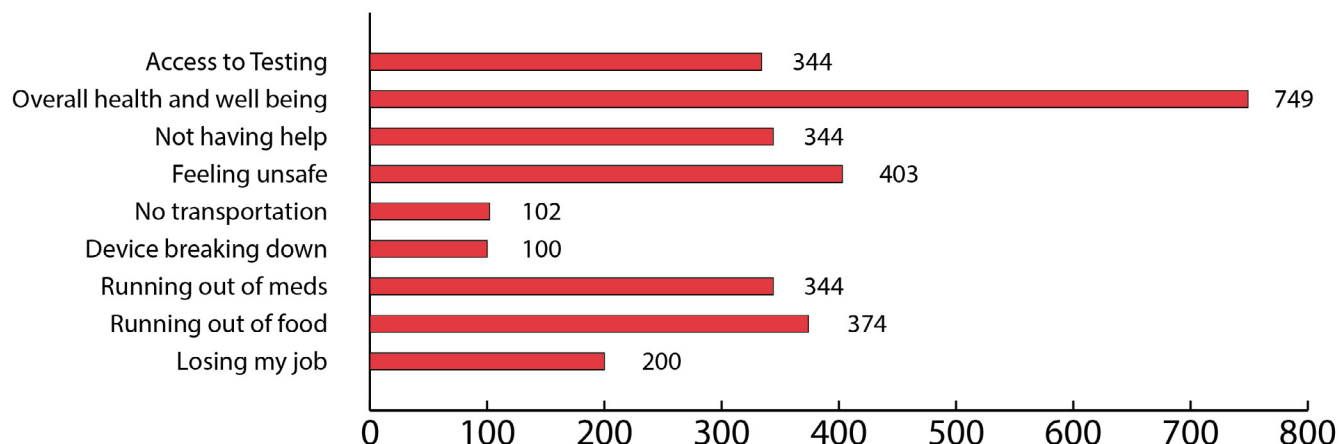
Other Needs:

Other needs reported regarding what would be most helpful at this time included mental health support, increased access to medicine and medical supplies, access to healthcare, safety in accessing healthcare, access to recreational activities, technology assistance in the form of helplines and help with specific applications, finding employment, and maintaining work from home to calm concerns about exposure to COVID-19.

Sources of worry during COVID-19 crisis:

Respondents were given 9 categories of things they might be most worried about and were given an open-ended option to include other things they were worried about. These were not defined for the respondent, so the person taking the survey could select any and all that they felt applied to them as a worry during this time. The most common worry selected was overall health and wellbeing (n=749). Other categories individuals selected were feeling unsafe (n=403), running out of food (n=374), running out of medication (n=344), access to testing (n=344), not having help (n=344), losing my job (n=200), no transportation (n=102), and wheelchair or assistive device breaking down (n=100).

Figure 7: Respondent reported worries during the COVID-19 crisis



Respondents were also given an opportunity to describe anything else they were worried about during this time. This was open-ended and answered by 468 respondents. The most common responses are summarized below:

Becoming infected/a loved one or caregiver becoming infected:

Most responses revolved around being infected with the virus themselves, a loved one being infected, or an essential care giver being infected. Some were worried that due to being deemed an essential worker, and either more vulnerable to exposure and sickness due to an existing health condition or disability. Some worried that they or a family member or caregiver would bring the virus home and infect other members of the household. Some worried that if they were to get sick, they would no longer be able to provide care to family members.

Financial needs:

Many were worried about finances. Common financial worries included paying utility bills and the mortgage or rent, not being able to afford necessities or basic needs, and maintaining insurance coverage. Others were waiting to for governmental funding programs, such as the stimulus money, social security, or other assistance programs. Some feared the financial impacts would result in losing their homes. Additionally, some were worried about being able to afford care and necessities for their support animals.

Mental health:

Many worried about their own mental health, including the contributing factors of social isolation and a lack of social support. Many expressed feeling stressed or overwhelmed.

Healthcare or therapy needs:

Many are also worried about medical or therapy needs at this time. There are required routine healthcare treatments or medications that are not currently accessible, or treatments that have been considered elective care that have been rescheduled. When people are able to receive treatments, the risk of exposure to the virus associated with going out to or entering the hospital causes additional stress. People were also worried about their mental and physical health regressing due to lack of therapy treatments.

Discrimination due to disability:

The fear of being considered a low priority for care due to an existing diagnosis or disability added stress to many people with disabilities and/or chronic conditions and their families and caregivers.

Other people not being careful:

The lack of concern regarding the seriousness of COVID-19 and practicing safety measures caused additional fears. Many chose not to go out or felt additional worry if they needed to go out for essential items due to the lack of protective measures by others putting them or their loved ones at risk of infection.

Uncertainty:

The general uncertainty associated with the current situation caused worry in multiple areas including worry about the future, the length of precautions, and the effects of the virus.

Personal Safety:

A small group of people reported concern that the uncertainty affects personal safety, observing an increase in crime in their area.

Other causes of worry are supplies running out or not being able to find the supplies that are needed, not being able to work, lack of accessible information about the virus or measures to be taken, disrupted routines causing confusion of individuals with specific disabilities or being overwhelmed with managing a new routine, lack of access to testing, access to services or activities, and maintaining education.

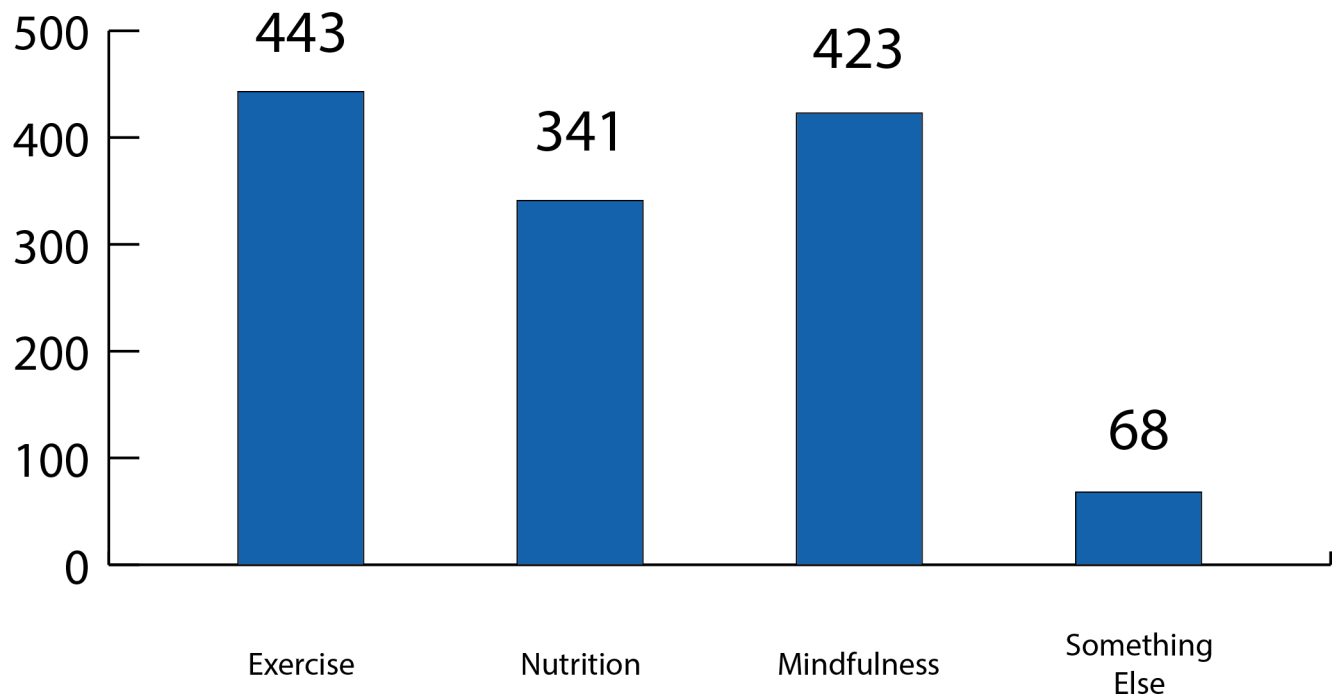
“Advocacy to ensure that I won’t be denied medical care if I contract COVID-19 during a supply shortage.”
– Survey Respondent



Online health-related content

Staying at home has increased the need to utilize online resources and videos. Respondents were asked to ID if they would like access to online content in the areas of exercise, nutrition, and mindfulness. Responses are summarized in figure 8. They had an opportunity to fill in a different option, if there was other online health-related resources they wanted, which is summarized below.

Figure 8: Number of respondents desiring specific online content in exercise, nutrition, or mindfulness during this time



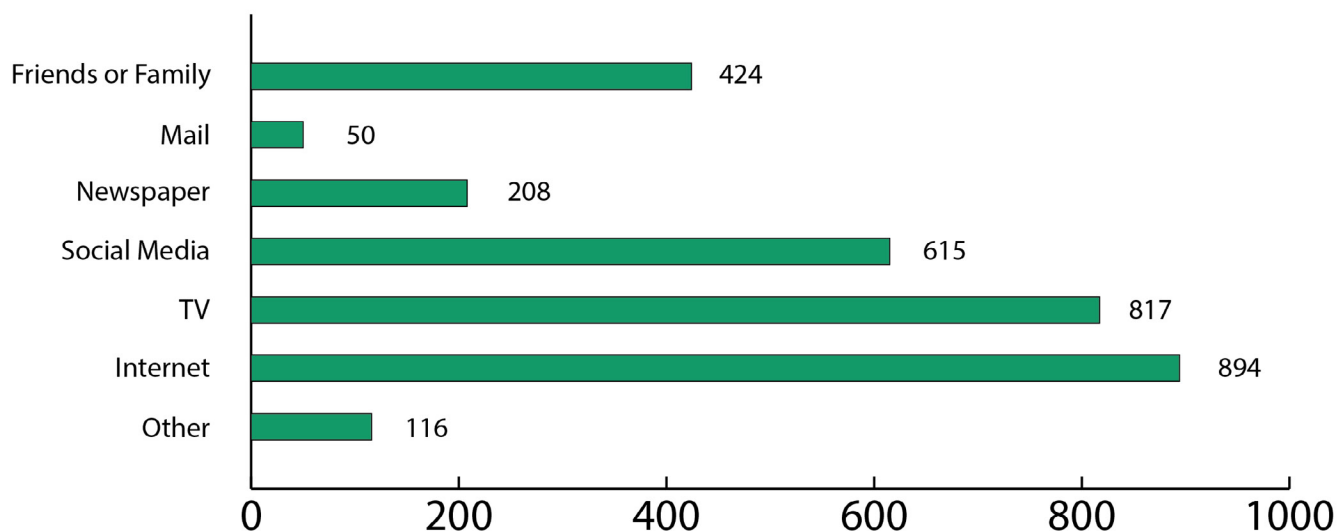
Other suggested online content areas:

- Activities (things to do at home, gardening, creative, fun, singing)
- Mental Health (coping, meditation, yoga, respite care)
- Social opportunities
- Teaching or virtual learning
- At home therapy treatments
- Adapted sports highlights
- Closed captioned videos (including COVID-19 info)
- Spiritual

Information about COVID-19

There are many sources and an overwhelming amount of COVID-19 information. Respondents were first asked where they get their information about COVID-19, selecting all that applied to them. The most common source of information is the internet (n=894), followed by television (n=817), social media (n=615), friends or family (n=424), and newspaper (n=208). Very few respondents reported receiving information from the mail (n=50). These responses are summarized in figure 9.

Figure 9: Sources of information about COVID-19



**“Better access to captions
and/or ASL interpreters
on videos.”
– Survey Respondent**

They were then asked what topics they would like more information about. This was an open-ended question answered by 260 respondents. The topics reported are summarized below.

Financial:

The most requested topic was financial. Respondents requested information on stimulus checks, social security checks, and resources for meeting financial needs (i.e. bills, mortgage, purchasing basic necessities).

Of vital importance is information regarding the use of government benefits online or using grocery delivery platforms. Many reported that they were not able to use benefit programs (e.g., food stamps, SNAP) to buy groceries without entering the stores. Additionally, if eligible products are sold out, they are not able to determine the alternative products that are available.

News about COVID-19:

There was a range of information requested about COVID-19 in general.


First, many wanted up-to-date COVID-19 facts and information that was unbiased and easy to understand. Many expressed a need to explain the pandemic to children or individuals with cognitive impairments or disabilities, so easy-to-understand language and accessible formats is important.

Information was requested on the effects of the virus on specific populations including disability populations, racial or ethnic subgroups, uninsured, specific diagnoses or conditions, and comorbidities. There was a desire to know both the specific risks in these groups as well as disease course.

Many wanted positive stories including stories of recovery either from the view of facts and figures or from personal stories of recovery. Facts pertaining to advances that are being made on vaccines or treatments were also requested.

Finally, many wanted information about testing including both access to and advances in viral and antibody testing. The timeline for COVID-19 testing availability was also requested.

Other topics that were requested related to the following:

- Mental health and coping
 - Identifying disability services
 - Resources for autism
 - Advocacy for people with disabilities receiving services and care
 - Resources for assisting with education
 - Services available for acquiring basic supplies, medical supplies and PPE
 - Options for meeting healthcare or therapy needs
 - Activities that can be done at home
- 

Additional comments:

Respondents were able to leave additional comments about their experiences during the COVID-19 pandemic. Many of the responses reiterated the themes that emerged in other question. New or reoccurring concerns that presented in response to this question included 1) policies to address discrimination or exclusion of people with disabilities from accessing services or information; 2) feeling that extra time or energy required to do things (i.e. shopping) compounded existing problems; 3) support help is requested (cooking, cleaning, respite, resource help, ADLs, etc.); 4) supports for mental health are needed to address anxiety, fear, added worry, understanding the current situation (self or child), caregiver stress, feeling overwhelmed; 5) many have concerns related to work. Some feared they were at risk for exposure because they or a family member or caregiver were considered essential workers. Some fear that they will return to work and become sick; and 6) technical assistance would be helpful in this time in the form of helplines or for specific applications for access to recreation, socializing, and healthcare needs.



**“More importantly,
I wish there were
online meetings to
stay in touch with
other hearing loss
folks to get the social
support I need.”
– Survey Respondent**

Discussion

This survey explored the needs, worries, and potential gaps in the pandemic response to be addressed for the population with disabilities and/or chronic conditions and their family members or caregivers. The data suggests that, over half of respondents with disabilities and/or chronic conditions and their family members or caregivers struggled to meet daily needs in recreation and other health related activities. Additionally, over 40% of respondents could not meet daily needs in keeping doctor or therapy appointments and over 40% could not meet daily needs in home repair. The inability to meet needs tended to align with the self-report of what they were worried about at this time. The primary source of worry was overall health and wellbeing. The data also show that very few individuals reached out to organizations for assistance, highlighting a need to better connect individuals with organizations that can meet their needs. Furthermore, support may be required in order to help organizations meet the challenge of helping more people in need of assistance.

Consistent reoccurring themes emerged through the open-ended questions which helps to further understand or expand upon the responses to the close ended survey questions (summarized below).

- Financial needs are of major concern for people with disabilities and/or chronic conditions. Many worry about being able to afford items to meet basic needs as well as medical needs. Many fear not being able to continue to pay bills such as the rent or mortgage may result in the loss of their home. Others were concerned that they may not receive benefits such as disability or social security
- There is a continued need for ensuring access to necessary items including groceries, medication and medical supplies, basic goods. Those on programs to assist with groceries are limited by the products that they can purchase as well as unsure how to continue to utilize those programs amidst the current protective measures. Others ask for policies to include special shopping hours for those with disabilities and/or chronic health conditions or increased availability for delivery of groceries.
- Inclusion is of vital importance in all hospital and service programs. There was a consistent fear of exclusion from receiving help from service organizations, being discriminated against in receiving lifesaving treatments, or being forgotten as a vulnerable population in policy and guideline development. Additionally, some called for more testing availability to those in nursing homes or group homes.
- Many also feared that others put them at risk. By others not being careful and following protective measures, there was a worry that there would be exposure whenever leaving the home. Additionally, those in essential working jobs feared going to work and having unnecessary exposure or bringing the virus home to loved ones.
- Another important piece was a call for consistent, unbiased information about COVID-19 that was available in accessible formats. This included information about the virus itself, progress in the fight against the virus (i.e. vaccine, treatments), access to testing, and up-to-date information about the pandemic.

- Broadly, addressing mental health is important at this time as well. Many feel overwhelmed with uncertainty or adjusting to the new routines and protective measures. Others lacked social support and felt isolated and lonely. Some lacked help to address caregiving and meeting their own needs or the needs of their family members, leading to potential caregiver burnout or a desire for respite. Additionally, some felt they lacked access to activities and professionals that would typically address their mental health needs.
- Finding ways to continue accessing healthcare was also important. Telehealth cannot always be used or is not always available and may not be covered by all insurance providers. Without access to medical professionals and therapists, many fear regression in physical or functional gains or relapse in conditions due to lack of access to medicine or medical equipment.

There were some limitations in conducting this survey. The only required question was identifying as a person with a disability and/or chronic condition or as a family member or caregiver of a person with a disability and/or chronic condition. This was to ensure that the data was representative of the disability community's needs. This could have resulted in data being missed from those who chose not to identify within one of those categories. There were also limitations and potential bias due to the survey being offered online only. If requested, paper versions were available and supplied. However, restrictions due to COVID-19 and the required short timeframe made it difficult to collect surveys in person, by mail, or by telephone. Consequently, only those with access to both internet and a device were able to complete the survey.

It is important to note that the purpose of the survey was exploratory, intended to quickly identify needs such that responses to those needs could be initiated, and it was not intended for research purposes, more rigorous and in depth analysis is needed to further explore the data for any other purposes.

Responses from this survey help to identify gaps in service provisions, unmet needs, and areas in which the community of people with disabilities and/or chronic conditions feel assistance is needed. This may help inform priorities of responding to the needs of the disability community during the COVID-19 pandemic as well as in future crises.

**“More knowledge of keeping my
wheelchair clean after public outings.
ie: after grocery shopping!”
– Survey Respondent**

Acknowledgements

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A special thanks to the teams from both organizations to build, disseminate, and summarize the information in this survey.

Notes and limitations about the data

Each question includes a number of answers (n =number of survey responses) and each question may have a different amount of responses. This is due in large part to a lack of required questions resulting in incomplete surveys, differences in survey platforms which restricted some survey respondents, and a technical difficulty on one survey platform affected the retention of a small amount of responses for a very limited amount of questions. Due to the urgency of collecting the data, these limitations were accepted.

Data from the 2 survey platforms was exported and compiled. Responses were removed from analysis if the person did not answer any questions beyond age and zip code. A total of 288 responses were removed for this reason. Remaining respondents represented individuals from across the United States as well as a small number of international respondents.

References

1. Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons With Disabilities as an Unrecognized Health Disparity Population. *American Journal of Public Health*, 105(Suppl 2), S198–S206. <https://doi.org/10.2105/AJPH.2014.302182>





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