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. People with disabilities and/or chronic conditions face inequalities in emergency responses that affect health, safety, and wellbeing. It is important to understand the unique needs of this population to address their needs. 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 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. 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 responded 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.

Demographics
A total of 1409 respondents 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 and were included in this report. Of those respondents, 57% identified as a person with a disability and/or chronic condition (n=798) and 43% identified as a family member or caregiver of a person with a disability and/or chronic condition (n = 611).

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.

The following reoccurring needs emerged from open-ended questions:

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

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

“Better access to captions and/or ASL interpreters on videos.”

“Advocacy to ensure that I won’t be denied medical care if I contract COVID-19 during a supply shortage.”
“Financial resources such as bill assistance. Food banks are over booked, and all the cheap generic foods are sold out.”

“I live in a remote rural town. We don't have delivery services which the big [cities] have”

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.