

**Public Health - Unmet Needs of
People with Disabilities
*during and after the COVID-19
Pandemic***

Collaboration between: The Breaking Silences Advocacy
Committee, The Access Center for Independent Living in Dayton,
The Ability Center of Toledo, and The Ohio Disability and Health
Program at the Ohio State University Nisonger Center

Who are we?

- 12 Centers for Independent Living in Ohio
- consumer-controlled
- cross-disability
- provide services for people with disabilities

Centers for Independent Living (CILs) are a one-stop resource for Ohioans with disabilities, providing a variety of programs and services. Our collective goal is to assist these citizens to live independently in their community of choice. CILs provide the following services: Advocacy; Information & Referral; Peer Support; Skills Training; Nursing Home and Institution Transition to the Community; Youth Transition; and Diversion from Nursing Home or Institution.

Reason for Project:

To assist local health departments and emergency management agencies to respond to these needs:

- the CILs collected data of a small sample of Ohioans with disabilities through a survey of disability needs.
- The Ohio Disability and Health Program at the Ohio State University Nisonger Center analyzed the survey responses and presented us with the raw results.
- We then reviewed the results shared by the Ohio Disability and Health Program and interpreted the findings based on our personal experiences and conversations with Ohioans with disabilities during this pandemic to formulate our recommendations.

What is this project and why?

The needs of people with disabilities have been front and center during the COVID-19 Pandemic

People with disabilities have been more likely to experience significant complications from COVID-19

People with disabilities have been disproportionately impacted:

- by isolation and a sense of being trapped in their homes
- job loss or unsafe job conditions
- lack of access to public transit
- faced with increased barriers to accessing healthcare

- Many people with disabilities rely on the healthcare system for activities of daily living.
- The barriers to accessing the health care system affect not just health but also independence and self-determination.
- The fall- out from the COVID-19 Pandemic will be felt for a long time in our community.

The survey ran for approximately two and a half months throughout our state network of Ohio Centers for Independent Living (CILs).

- The majority of people who answered the survey were either a person with a disability (48.2% of respondents)
- a family member of a person with a disability (32.5% of respondents)
- the remainder were professionals who work with people with disabilities.

Respondents were from 15 counties in Ohio, with the majority of responses coming from Montgomery County.

- Most Respondents were recipients of services from their County Board of Developmental Disabilities (22.9%)
- A large number were also recipients of services from ODJFS (21.7%).

Results:

A total of 83 individuals completed the survey. One survey was completed via a word document. The remaining 82 were completed online via Qualtrics.

A majority of the survey participants were individuals with disabilities.

Table 1: Demographic identities of survey participants (response rate=92.8%)

- Identity # of Participants % of Participants Individual with a disability 40 - 48.2%
- Family member, caregiver, and/or friend of an individual with a disability 27 - 32.5%
- Case/care manager, social worker, and/or medical professional 10 - 12.1%
- Did not respond to question 6 - 7.2%

Total 83 100%

Table 2: Counties where survey participants live (response rate=55.4%)

Ohio County # of Participants % of Participants

- Montgomery 15 - 18.1%
- Greene 7 - 8.4%
- Lucas 5 - 6.0%
- Wood 4 - 4.8%
- Williams 3 - 3.6%
- Cuyahoga 2 - 2.4%
- Warren 2 - 2.4%
- Clark 1 - 1.2%
- Clinton 1 - 1.2%
- Delaware 1 - 1.2%
- Franklin 1 - 1.2%
- Fulton 1 - 1.2%
- Hamilton 1 - 1.2%
- Lake 1 - 1.2%
- Stark 1 - 1.2%
- Did not respond to question 37 - 44.6%

Total 83 100%

Table 3: Current organizations where participants are receiving services Organization Providing

Services # of Participants % of Participants

- County Board of Developmental Disabilities 19 22.9%
- Job and Family Services 18 21.7%
- Centers for Independent Living 6 7.2%
- Area Agency on Aging 5 6.0%
- Public Transit Authority 3 3.6%
- Public Housing Authority 1 1.2%
- Homeless Service 1 1.2%
- Other 11 13.3%

About half of respondents expressed feeling fear for their lives during the Pandemic (45.8%).

Anecdotally, the fear was attributed to being:

- high risk
- witnessing others not take the Pandemic seriously
- disruptions with in-home caregivers during the Pandemic
- not having PPE for themselves or their caregivers

Over half of Respondents (55.1%) reported encountering caregiver issues as a direct result of the COVID-19 Pandemic: (“Had trouble finding one before, really bad now”).

Worded differently, 71.9 % of respondents’ ability to find necessary caregivers were affected by the COVID-19 Pandemic.

And according to 36.7% of Respondents, COVID-19 was cited as a reason that there were no caregivers available.

Respondents also had additional trouble accessing other medical needs. For example, 40.5% of Respondents were unable to get physical therapy.

In an analysis of open-ended results regarding Pandemic needs, six main themes emerged in response to that survey:

- 1) Disruption in daily activities and life situations
- 2) Issues in finding or securing qualified caregivers
- 3) Concerns, fears, and behavioral health issues during COVID-19
- 4) Barriers and issues in meeting healthcare needs
- 5) Issues in how the healthcare system interfaces with people with disabilities
- 6) Perceptions of the health department's response.

Examples of participant self-reported greatest needs during the COVID-19 pandemic include:

- “Staff to provide me care, financial assistance and physical socialization.”
- “socialization, routine, connecting outside the house; feeling safe in dayhab and at work.”
- “Getting groceries, rx and general non- medical transportation. Also, getting supplies - masks, sanitizer, clorox wipes etc.”
- “Financial support and access to mental health treatment.”
- “Food access, access to PPE, access to technology, and accommodations in Doctor appts.”

Recommendations

Lack of Clear Communication/ Messaging to the Disability Community:

Health Departments should be the main source of information on the COVID-19 Pandemic for people with disabilities. To do so, they need to have a variety of different methods of communicating with people with disabilities including via website; social media; a call-line; e-mails; texts; television; public service mailings, and outreach to the full network of disability services and agencies within their community, including 211. Town halls and webinars with clear information are also large scale efforts that could inform marginalized communities, not just those with disabilities, about current and everchanging states of emergency.

In-Home Provider Shortage and Unreliability:

Health Departments should plan for disruption of in-home care during public health emergencies by coordinating with local hospitals, agencies, and local nursing and STNA programs to find back-up caregivers. It is not appropriate to place a person in a nursing home or long-term care facility as a response to a shortage or unreliability of in-home care providers. Additionally, Health Departments should ensure that in-home agency, independent providers, and family and friend providers have access to PPE, COVID-19 testing, and vaccinations in order to minimize service disruptions and shortages.

Lack of Access to Transportation:

Testing and vaccination sites are difficult to access for people with disabilities who have no method of transportation. Health departments need to ensure that Pandemic response programs are accessible to people without transportation. Also, there needs to be a mobile program that goes to individuals' homes, shuttles, or some sort of arranged transportation to these sites.

Access to Healthcare:

People with disabilities have had difficulty accessing healthcare during the Pandemic, which affects their ability to be independent and engage in Activities of Daily Living. Several areas of concern are:

- Lack of internet connectivity or ability to afford internet has affected access to telehealth services
- Medical Setting Visitation Policies
- Lack of Communication Accommodations
- Issues navigating an Emergency Room or hospital admission and staying safe
- Rude, unprofessional doctors or staff

Pandemic guidelines for businesses should take disability access into account:

Many health department guidelines for social distancing and other Pandemic safety developed for businesses and health care facilities did not consider wheelchair dimensions or other disability access. Guidelines should be revised to ensure that people who use mobility aids are considered and appropriately accommodated and that businesses are aware that people with disabilities are entitled to reasonable modifications of policies.

Food Insecurity:

It is clear from our survey results that food insecurity is affecting people with disabilities, especially those who are isolated in their homes due to health fears, unemployment, increased barriers to health care, and lack of public transportation. Health departments need to work with local agencies and providers to ensure that food can be delivered to individuals' homes.

In the shift from in-person to virtual provision of services, doctors' and therapy appointments were cancelled or difficult to schedule:

Health departments should work with doctors and therapists in their region to ensure that they are able to continue to provide services if services need to shift to virtual service in the future. In-person services should resume as quickly as possible for individuals who experience barriers that prevent the effective use of virtual services. Additionally, virtual services should continue to be an option for folks who need it even after the Pandemic protocols are no longer necessary.

Resource Shortages (Medical Equipment, Medications):

People with disabilities who rely on medical equipment and medications that are also being used by hospitals to treat COVID-19 patients had difficulty getting ahold of needed equipment and medication. Health departments should work to ensure that this equipment and medications are available to individuals who need them for other health conditions.

Feeling Unsafe or Afraid for their Life:

- The lack of accurate information of the Pandemic instilled a lot of fear in people.
- The lack of clear information about how the virus is transmitted, i.e. via surfaces, packages and mail.
- Risk in taking a vaccine.
- Mixed information about how the virus is transmitted and how to stay safe caused a lot of fear.
- Multiple methods of communicating information, as outlined above, would be beneficial to mitigating some fear.

Overall, the main needs expressed by people with disabilities during this Pandemic were:

- **access to food**
- **access to in-home care**
- **access to socialization**
- **medical supply disruption**
- **access to medical care**

For more information
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