

Unmet Needs During COVID-19 Pandemic: Survey of Ohioans with Disabilities

Breaking Silences Advocacy Committee, Access Center for Independent Living,
and The Ability Center of Greater Toledo
March 2021

Suggested Citation: Breaking Silences Advocacy Committee, Access Center for Independent Living, and The Ability Center of Greater Toledo. (2021). *Unmet Needs During COVID-19 Pandemic: Survey of Ohioans with Disabilities*. <https://www.acils.com/news/survey-of-ohioans-with-disabilities>

About the Breaking Silences Advocacy Committee

The Breaking Silences Advocacy Committee was created in response to the COVID-19 pandemic and the lack of emergency preparedness for people with disabilities. The committee brings together community partners to better prepare and plan for future events. The committee is solely focused on issues pertaining to disability rights within our local communities, especially those individuals who have been impacted most by the lack of planning and preparedness around the COVID-19 pandemic. The main goal of the Breaking Silences Advocacy Committee is to create an active space for advocates to work together to develop and create community awareness and change in the communities that we live, work, and participate in. The intent of this committee is to make connections with local and state officials as well as partnering with other organizations. This committee was formed to ensure that our community members with disabilities obtain and maintain a place among those who will make decisions that impact our lives. Topics of discussion include but are not limited to: 1) Community awareness of the disability community, 2) Ensuring equality for the disability community, 3) Regaining rights that have been lost or not recognized, 4) Demanding a place at the table, and 5) Working to ensure an equal income and addressing income disparities.



About the Access Center for Independent Living

The Access Center for Independent Living (ACIL), was founded in 1984 by a group of concerned citizens, the majority of whom were persons with disabilities. Those founding activists had a vision of affecting change that would make the community accessible to any person with a disability who wished to pursue a more independent, self-directed lifestyle. The mission of ACIL is to ensure that people with disabilities have full and complete access to the community in which they reside. ACIL accomplishes this through the following core programs: 1) Advocacy, 2) Information & Referral, 3) Peer Support, 4) Independent Living Skills Training, 5) Transition from Institutional to Community Setting, 6) Pre-Employment Youth Transition Services, and 7) Recycled Equipment Donated for Independence (REDI).

About the Ability Center of Greater Toledo The Ability Center

The Ability Center of Greater Toledo is a Center for Independent Living in Northwest Ohio serving Lucas, Wood, Ottawa, Fulton, Henry, Defiance, and Williams counties. The Ability Center advocates, educates, partners, and provides services supporting people with disabilities to thrive within their community. The Ability Center's programs are designed to help individuals with disabilities gain their independence and engage with their communities and include Advocacy, Assistance Dogs, Community Living, Assistive Technology and Medical Equipment, Home Accessibility, Information and Referral, and Youth and Transition Services.

Executive Summary

Earlier this year, the Breaking Silences Advocacy Committee, Access Center for Independent Living, and The Ability Center of Greater Toledo identified a need for input to Ohio Health Departments on responding to disability needs during the current, COVID-19 Pandemic. We conducted a survey of the needs of people with disabilities, and it was run for approximately two and a half months through our state network of Ohio Centers for Independent Living (CILs). We sought the assistance of the Ohio Disability and Health Program at the Ohio State University Nisonger Center to analyze the survey responses we collected. The majority of people who answered the survey were either a person with a disability (48.2% of respondents) or 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%) but a large number were also recipients of services from ODJFS (21.7%).

A majority of Respondents with disabilities expressed feeling fear for their lives during the Pandemic (60.5%) (Table 15). Anecdotally, it seems the fear was attributed to being high risk, witnessing others not take the Pandemic seriously, and disruptions with in-home caregivers during the Pandemic. 32.5% also reported 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; and 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.”

Overall, the main needs expressed by people with disabilities during this Pandemic were access to food security; access to in-home care; access to socialization; medical supply disruption; and access to medical care.

Methods

Survey Methods

The Breaking Silences Advocacy Committee, the Access Center for Independent Living, and The Ability Center of Greater Toledo composed a survey to understand how the COVID-19 pandemic has impacted Ohioans with disabilities receiving home care supports. The survey was comprised of 3 demographic items, 11 closed-ended items and 13 open-ended items. The Ohio Disability and Health Program provided technical assistance in finalizing the survey items. See Appendix I for a copy of the survey.

The survey was administered by the Access Center for Independent Living. The Access Center for Independent Living sent a link to an online version of the survey (via Qualtrics) and a Word document version of the survey to the Directors of Ohio Centers for Independent Living to disseminate to consumers with disabilities, family members of people with disabilities, community disability advocates, and community partners. The Access Center for Independent Living provided a cover letter to explain the survey's purpose to assist in the distribution of the survey. The survey was open from August 12-October 20, 2020.

Data Analysis

The close-ended survey responses were analyzed using descriptive statistics with SPSS software. All data was cleaned and coded for entry into SPSS. Frequencies and percentages were generated for each close-ended survey and demographic items. Sub-analysis by demographic groups was conducted using crosstabs analysis to generate frequencies and percentages of each survey item by demographic group.

The open-ended survey responses were analyzed using a qualitative thematic analysis by two evaluators, who divided the survey responses equally among them. Each evaluator first read through the assigned responses, then developed codes capturing the content of those responses. After each round of coding by the evaluators, they met to discuss their coding process. During this meeting, evaluators reviewed areas of overlap and disagreement until consensus was reached. Using a constant comparative approach to analysis, evaluators used an iterative process of re-reading responses and deleting, substituting, or expanding upon codes as necessary (Glaser, 1965). This process was repeated for grouping the agreed upon codes into broader categories (groups of similar codes) and overall themes (groups of similar categories). The overall process was inductive in nature, in that categories and themes were developed through codes that were based on the responses themselves, rather than on existing theories (Braun & Clarke, 2006). Finally, when data saturation was reached, a third evaluator familiar with the survey reviewed the original survey responses and confirmed the coding and thematic structure. All three evaluators have experience and expertise on disability and health topics, survey methods, and survey analysis. ATLAS.ti software was used to organize and visualize the qualitative analysis of the open-ended responses. The qualitative analysis of the open-ended questions aimed to describe how the COVID-19 pandemic has impacted people with disabilities and their families.

All data was organized, de-identified, and analyzed by the Ohio Disability and Health Program. The Ohio Disability and Health Program provided the raw results of the analysis to the Breaking Silences Advocacy Committee, the Access Center for Independent Living, and The Ability Center of Greater Toledo for interpretation and composing recommendations based on the results.

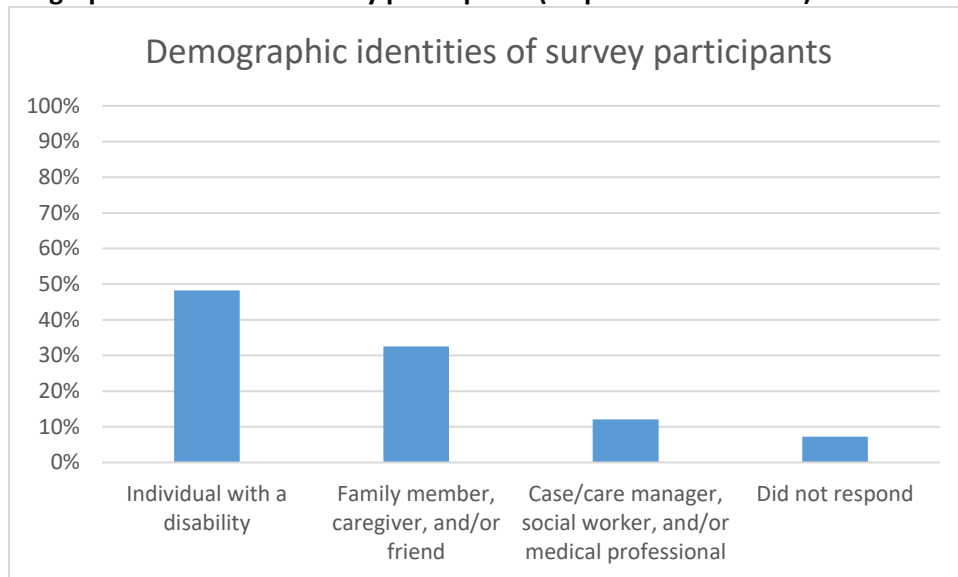
Results

A total of 83 individuals completed the survey. One of those surveys was completed via a word document and the remaining 82 were completed online via Qualtrics. A majority of the survey participants were individuals with disabilities. See Table 1 and Figure 1, which describes the demographic identities of the participants.

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%

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



Participants represented 15 Ohio counties. Montgomery County had the most participant representation. Note that nearly 45% of survey participants skipped or declined to answer this question. See table 2 for complete details.

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%

A majority of participants are currently receiving services from their County Board of Developmental Disabilities and/or Job and Family Services. See table 3 for all organizations that are currently providing services to participants.

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%

Closed-Ended Survey Item Results

Tables 4-14 present the results of all the survey closed-ended questions. Following each table are representative quotes to the open-ended questions accompanying the closed-ended items.

Table 4: Were you able to access proper health care for your physical and mental health needs? (response rate=78.3%)

Response	# of Participants	% of Participants
Yes	43	51.8%
No	22	26.5%
Did not respond to question	18	21.7%
Total	83	100%

Examples of reported barriers experienced to accessing proper health care for participants who answered no above include:

- “We experienced loss of doctors/ therapy appointments which we really needed & now are again on waiting lists after 6 months of waiting as it was.”
- “Afraid to go for any appointment.”
- “Needing to do everything electronically with limited internet.”
- “Getting respiratory supplies. They are very limited to I am reusing supplies more than before pandemic.”
- “Not being able to get to food pantries and extra costs with delivers of rxs and groceries. Televisits audio can be choppy at times to where it's difficult to communicate.”

Table 5: Did you ever feel unsafe or afraid for your life during this pandemic? (response rate=96.4%)

Response	# of Participants	% of Participants
Yes	38	45.8%
No	42	50.6%
Did not respond to question	3	3.6%
Total	83	100%

Examples of reasons for feeling unsafe or afraid for participants who answered yes above include:

- “Other people not taking it seriously and not wearing masks. I am in a high risk category and catching it would place me in the hospital. It could be fatal. But others not following the guidelines puts me and my family at risk and that is terrifying.”
- “No staff showing up. Didn't know how I was going to get groceries.”
- “The government officials caused panic and fear.”
- “I have to rely on untrained caregivers to make sure I'm on the ventilator when I need to be. Which risks suffocation. Also wound care follow-up is difficult to achieve, and creates an additional risk.”
- “Knowing there is a virus out there and no real treatment exists, and people die from it in a horrible way, and I am high risk, scares me.”

Table 6: If you have caregivers, did you have access to PPE for yourself as well as your caregivers? (response rate=91.6%)

Response	# of Participants	% of Participants
Yes	27	32.5%
No	15	18.1%
I do not have caregivers	34	41.0%
Did not respond to question	7	8.4%
Total	83	100%

**Table 7: Are you encountering caregiver issues as a direct impact from the COVID-19 pandemic?
(response rate=93.9%)**

Response	# of Participants	% of Participants
Yes	27	55.1%
No	18	36.7%
I don't know	1	2.0%
Did not respond to question	3	6.1%
Total*	49	100%

*note: 34 of the 83 survey respondents do not have caregivers and thus did not receive this question

Examples of caregiver issues and what is being done about caregiver issues for participants who answered yes above include:

- “Had trouble finding one before, really bad now.”
- “nothing. i have been told that they are running short on help.”
- “The agency I work with promised 9 days ago to find a replacement for the 4th nurse in 5 months to quit with no notice and I haven't heard from them since. This is the 2nd agency I've hired since January.”
- “nothing, there is no way to address it as Ohio ruined the medicaid IP program long beofre the pandemic.”
- “My County DD Department is trying to help me find caregivers, but with not too much luck so far.”

**Table 8: Has the COVID-19 pandemic affected your ability to find and secure necessary caregivers?
(response rate=78.1%)**

Response	# of Participants	% of Participants
Yes	23	71.9%
No	1	3.1%
I don't know	1	3.1%
Did not respond to question	7	21.9%
Total*	32	100%

*note: 51 of the 83 survey respondents do not have caregivers or were not encountering caregiver issues and thus did not receive this question

Examples of how the pandemic has affected ability to secure necessary caregivers for participants who answered yes above include:

- “Individuals are not comfortable picking up new cases and PPE was not available, or provided, early on.”
- “They're just aren't enough. Some have daycare issues. Others don't want to be around a person who is post covid (I've had two negative tests though). Some aren't reliable about wearing masks and changing gloves. They don't get paid enough and if they're car goes down they can't fix it. They need pandemic payments too.”
- “The agency can't find any due to there is none that apply so the staff that I do have have to overwork themselves.”
- “It has not affected us personally.”

- “I’m afraid to bring in new staff because of COVID and my dad had cancer and we don’t want unclean people in our house.”

Table 9: Has the COVID-19 pandemic been cited as a reason why you have not been provided a caregiver for your home care needs? (response rate=83.7%)

Response	# of Participants	% of Participants
Yes	18	36.7%
No	23	46.9%
Did not respond to question	8	16.3%
Total*	49	100%

*note: 34 of the 83 survey respondents do not have caregivers and thus did not receive this question

Examples of reasons why participants have not been provided a caregiver for participants who answered yes above include:

- “I use Independent Providers so there has been a shortage even before the pandemic. I have been seeking nursing coverage for 6 years - the pandemic just makes it harder.”
- “Caregiver illness and loss of Medicaid funding.”
- “General shortage.”
- “I’ve been concerned about exposing my son to someone who may have contact with people that I don’t know who they have been exposed to.”
- “no one shows up.”

Table 10: Has the availability of caregivers changed with the COVID-19 pandemic? (response rate=59.2%)

Response	# of Participants	% of Participants
Yes	23	46.9%
No	6	12.2%
Did not respond to question	20	40.8%
Total*	49	100%

*note: 34 of the 83 survey respondents do not have caregivers and thus did not receive this question

Examples of how the availability of caregivers has changed for participants who answered yes above include:

- “it has become 1,000% harder to find qualified people.”
- “It’s harder because people are afraid and not given appropriate supports.”
- “Caregivers do not feel comfortable coming in because of my health.”
- “There are none. They make more money on unemployment.”
- “Many are parents and have to be home with kids.”

Table 11: Are you able to get needed medications? (response rate=89.2%)

Response	# of Participants	% of Participants
Yes	71	85.5%
No	3	3.6%
Did not respond to question	9	10.8%
Total	83	100%

Examples of barriers to getting needed medications for participants who answered no above include:

- “Med changes have been slow with new specialists. Pharmacy shortages cause me to go to alternate CVS locations.”
- “Insurance needs to pay for it. I can't believe they started denying medications in the middle of the pandemic, especially medications that are needed for conditions to protect against is.”
- “A prior authorization took a month. The people answering the phone with the insurance company are working from home. They did not listen to doctor's office. They gave me great amount of resistance. They said there were no.”

Table 12: Are you able to get needed physical therapy? (response rate=86.5%)

Response	# of Participants	% of Participants
Yes	17	45.9%
No	15	40.5%
Did not respond to question	5	13.5%
Total*	37	100%

*note 46 of the 83 survey respondents do not need physical therapy and thus did not receive this question

Examples of barriers to getting needed physical therapy for participants who answered no above include:

- “Had to wait for referral appointment. Doctor appointments spread out due to 6 foot rule so less appointments are available.”
- “I can't allow physical therapist in my home until it is safe.”
- “They are not doing hands on.”
- “transportation they had stop coming to the house. my physical therapy is on hold.”
- “Cannot do virtual PT, not an option for me.”

Table 13: Are you or anyone you know of at risk of losing your/their home or apartment? (response rate=75.9%)

Response	# of Participants	% of Participants
Yes	10	12%
No	53	63.9%
Did not respond to question	20	24.1%
Total	83	100%

Examples of barriers and what is being done for participants who answered yes above include:

- “Loss of work meant loss of income for several family members. As the rent moratorium lifted and people faced eviction they went to other family members homes despite pandemic.”
- “Barriers to housing include increases in rent and lack of public housing.”
- “no response to my complaints.”
- “Cost of rent and I am trying to budget my money to stretch it.”
- “Bigger place within budget and not being able to find any help with this.”

Table 14: Have you or anyone you know had issues navigating an emergency room or hospital admission in a medical crisis during the COVID-19 pandemic? (response rate=74.7%)

Response	# of Participants	% of Participants
Yes	15	18.1%
No	47	56.6%
Did not respond to question	21	25.3%
Total	83	100%

Examples of the issues and what was done to resolve the issues for participants who answered yes above include:

- “I was forced to be at risk multiple times because they would not schedule the multiples procedures needed together.”
- “The care at an emergency room was sub par. My adult son (caregiver at times) was not allowed back at the moment. Was not updated regarding me status. I later found out he was allowed back. I was not offered PPE, once the towel was removed from my face from a bloody nose. That was my PPE when I first came in. They also allowed a man with a blind man's cane (white with red tip) walk unassisted to the triage room. The nurse did not get up and assist the man. She allowed him to walk on by the room before she finally got up. I talked to a supervisor regarding these things.”
- “My brother was denied access to his wife when she was taken to the hospital from a nursing home. He was not allowed to see her.”
- “Staff not allowed to be with individual in the hospital so no relevant information could be shared or was shared. Staff had to wait in their car and had no update on the person's condition, decision about admission or.”
- “I had issue because I use assisted technology to communicate a hospital ER nurses wouldn't wait for me communicate then held me down against my will and self cath me without my permission.”

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.”

Specific examples of how the COVID-19 pandemic has impacted participant’s personal life include:

- “The isolation from family, friends and co-workers.”
- “lost job in a nursing home due to being in a vulnerable age group and unwillingness to risk exposure.”
- “It gets depressing at times having to be home all the time.”
- “Lack of school, lack of interaction, lack of routine.”
- “Lack of aide service has made everything difficult.”

Finally, specific examples on what health officials could have done differently to assist survey participants include:

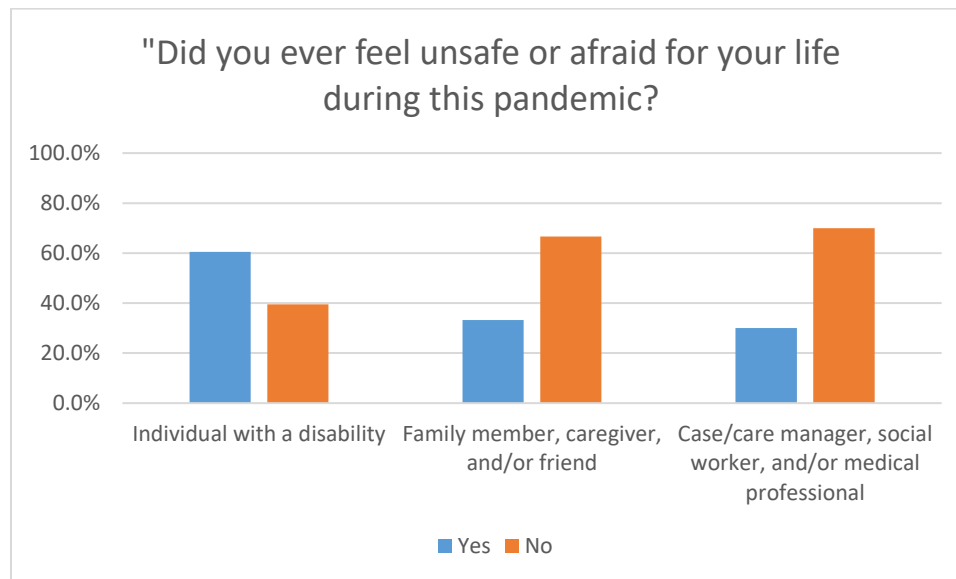
- “the greatest issue if the lack of reliable factual information, particularly at the Federal level.”
- “Gotten PPE to home health agencies during the early shortage so I didn't have to cancel my home health aside for 4 months until they got their act together.”
- “clear rules for safe social interaction that does not just involve staying home.”
- “I believe that they are doing the best that they can with this unusual situation.”
- “I do not believe there were any plans in place in the state of Ohio to plan for assisting the disabled during an emergency, such as a pandemic. No one from the Ohio Home Care Waivers was checking in on clients and were extremely hard to reach (and still are). We have little to no access to necessary repairs to maintain health and safety in the home. Groceries should have been delivered to the doors of the medically fragile and disabled. We had a very difficult time accessing groceries without putting ourselves at risk. Food stamps could not be used for online ordering. No disabled person I know can afford to use cash to purchase groceries, pay delivery fees and then cover a tip. The disabled were less than an afterthought.”

Table 15 and figure 2 present a sub-group analysis of feelings of safety during the pandemic by demographic identity group. As the table demonstrates, individuals with disabilities overall felt more unsafe or afraid for their life than the two other groups. There were no other differences in trends with any other sub-group analysis by demographic identity, types of organization services, or county for any of the other survey items.

Table 15: “Did you ever feel unsafe or afraid for your life during this pandemic?” by demographic identity

Identity	# of Yes (%)	# of No (%)
Individual with a disability (n=38)	23 (60.5%)	15 (39.5%)
Family member, caregiver, and/or friend of an individual with a disability (n=27)	9 (33.3%)	18 (66.7%)
Case/care manager, social worker, and/or medical professional (n=10)	3 (30%)	7 (70%)

Figure 2: “Did you ever feel unsafe or afraid for your life during this pandemic?” by demographic identity



Open-Ended Survey Item Thematic Analysis Results

Our open-ended analysis produced **six overall themes** to explain how COVID-19 has impacted people with disabilities and their families. From initial independent coding evaluator 1 created 229 unique coded quotes that were combined into 24 categories (groups of similar codes) and evaluator 2 created 166 unique coded quotes that were combined into 40 categories. After two meetings between evaluator 1 and evaluator 2 to revise and confirm each other’s coding and categorizing, themes emerged from the agreed upon categories. After the final consensus building meeting with the third independent evaluator, all three evaluators agreed upon a final set of **399 codes** (relevant quotes) that formed **48 total categories** and **six overall themes**.

The six themes that emerged from the analysis in order of participant discussion frequency were: 1) disruption in daily activities and life situations due to COVID-19, 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 due to COVID-19, 5) issues in how the healthcare system interfaces with people with disabilities, and 6) perceptions on the health department’s response to COVID-19. Each theme is described in more detail below.

Theme 1: Disruption in daily activities and life situations due to COVID-19

Fourteen categories define this theme comprised of 129 codes. See table 16 for a complete list of the categories in order of frequency of participant discussion (density of the codes) and representative quotes for each category. The five most frequently discussed categories for this theme include:

- Changes in socialization/social opportunities
- Transition to telehealth challenges
- Social isolation

- Food insecurity
- Financial concerns

Respondents discussed the disruption in daily activities from COVID-19 mostly in terms of fewer social opportunities. Individuals felt COVID-19 “limited [their] social activities,” which seemed to engender feeling “isolated and disconnected” from others. Beyond restricting their social world, respondents also described the challenges in moving to telehealth, in terms of providing appropriate accommodations and feeling their health needs were met. On a more basic level, individuals discussed difficulty in accessing food, housing concerns, and employment changes, all of which contributed to financial concerns.

Table 16: Theme 1 categories, code density, and quotes

Theme 1: Disruption in daily activities and life situations due to COVID-19		
Category	# of Codes	Representative Quote
1. Changes in socialization/social opportunities	19	“[I am] not able to enjoy everyday activities. Mostly been restricted to my home.”
2. Transition to telehealth challenges	17	“I didn’t have a smart phone and so it was hard to do telehealth and because I only had a flip phone and so I actually had to buy a smart phone and learn how to use it and that was really difficult for me.”
3. Social isolation	16	“I have been more isolated socially and have not been able to get out in my community as much as I would like.”
4. Food insecurity	12	“How do I ask for food I need in an environment where you're looked down on if you're ‘beggars and choosers’ or ‘if you really needed it you would take whatever’? Thanks, but I like to be able to breathe, and to eat without throwing up or being in pain for days.”
5. Financial concerns	10	“Financial assistance (utilities, food, rent).”
6. Changes in employment	9	“Was off work for a few months due to my daughter's health condition, still haven't received my unemployment nor was I paid cause of fmla. So I had no choice but to ask to be released back to work despite my daughter's condition cause I couldn't support my family and I'm a single mother.”
7. Disruption in daily routine	9	“A schedule so chaotic that it changed radically every 7 days, making appointments difficult to schedule/attend. No free time due to no caregivers besides myself.”
8. Virtual learning challenges	8	“Simultaneously my minor child with a severe disability lost access to her school, her friends, her in-person therapies, the teachers for the deaf and the visually impaired, her respite weekends away, her summer day camp, her week-long summer camp.”
9. Transportation issues	8	“No viable transportation in my area...Greene Cats Hasn't ever provided a transportation option.”

10. Limitations in recreation and leisure	6	"No location in which to go to exercise. Parkinson's disease is my diagnosis and I am so much better off if I have a structured place with a leader to do exercise."
11. Taking health precautions due to not wanting to contract COVID-19	6	"I haven't been able to go anywhere because I am high risk. It's made me stay home even more than I used to and I only went to the store before. Now I can't even do that."
12. Disruption in participating in faith communities	4	"I normally attend church every Sunday. I have been viewing it via live stream."
13. No support with housing issues	3	"No response to my complaints."
14. Issues with landlords	2	"This affects my friends, not me. so my comments are from me looking into other people's situations and what they are telling me. Several are concerned that the landlord is going to use this corona virus situation to get rid of tenants that they are just tired of anyway and will refuse to make any accommodation to tenants they don't like."
Total Density of Codes	129 codes	

Theme 2: Issues in finding or securing qualified caregivers

Twelve categories define this theme comprised of 83 codes. See table 17 for a complete list of the categories in order of frequency of participant discussion (density of the codes) and representative quotes for each category. The five most frequently discussed categories for this theme include:

- Caregiver shortage made worse by COVID-19
- In need of a caregiver
- Lack of funding for caregivers
- Family as caregiver
- Nothing being done about caregiver issues

Respondents discussed that the caregiver shortage in Ohio has been made worse by the pandemic. As one described, "There was already a shortage, and now everyone is stretched even more thin." Respondents cited staffing shortages for caregivers due to a lack of funding, noting in order to increase the number of caregivers, the position needs to "[pay] more than unemployment." Due to few caregivers available, and the need for caregiving services, respondents described turning to others for support. Some discussed using their family as their caregiver, while others were continuing to try to find help through local agencies. Others expressed how nothing is being done about caregivers and that in some instances case managers are not returning calls.

Table 17: Theme 2 categories, code density, and quotes

Theme 2: Issues in finding or securing qualified caregivers		
Category	# of Codes	Representative Quote
1. Caregiver shortage made worse by COVID-19	27	"It has become 1,000% harder to find qualified people."
2. In need of a caregiver	16	"My greatest need during the pandemic have been related being able to find reliable providers."
3. Lack of funding for caregivers	8	"There is an extreme shortage and nobody is addressing the fact that it's harder to get providers on the Medicaid waivers and it is the Dodd waivers because the pay is so low."
4. Family as caregiver	8	"Meetings that I need to attend during the day are stressful for me, due to the fact that my son has had seizures during the video conference calls. Generally, I have less time to handle many of the important things I usually handle due to having less help."
5. Nothing being done about caregiver issues	6	"Nothing. Case manager doesn't return calls."
6. Receiving support from agency to find a caregiver	4	"The aide agency is sending their administrative assistance to cover a few of the hours. That's the best they can do."
7. Caregivers afraid of contracting COVID-19	4	"They are afraid to go into other people's homes."
8. Caregivers have to stay home with own children	3	"Many are parents and have to be home with kids."
9. Caregivers cannot work due to having COVID-19 or exposure to COVID-19	3	"[Caregivers] sick with the virus."
10. Family afraid of contracting COVID-19 from caregivers	2	"I've been concerned about exposing my son to someone who may have contact with people that I don't know who they have been exposed to."
11. Caregivers that are available are low quality	1	"There are few available. The ones available have been low quality or not in physical shape to do the actual job."
12. Virtual caregiver visits are not sufficient for caregiving needs	1	"Everything medical is very virtually based now, and a caregiver isn't really a caregiver on ZOOM. It's more like being checked up on, not cared for."
Total Density of Codes	83 codes	

Theme 3: Concerns, fears, and behavioral health issues during COVID-19

Nine categories define this theme comprised of 69 codes. See table 18 for a complete list of the categories in order of frequency of participant discussion (density of the codes) and representative quotes for each category. The five most frequently discussed categories for this theme include:

- Mental health concerns
- Fearful of self and/or family/friends getting COVID-19 and negative consequences
- Concern to not have caregivers or proper caregiver support during pandemic
- Fear of people not following public health guidelines during pandemic
- Fearful to engage in typical daily activities due to pandemic and government messaging

Most notably, respondents described mental health concerns during COVID-19. For some, the “extra stress” of COVID-19 exacerbated existing mental health problems, such as bipolar disorder or social anxiety. Respondents also discussed at length their fears of getting COVID-19 or someone they love getting COVID-19. Many were specifically fearful of dying or someone they love dying from COVID-19 or having long-term complications as a result of COVID-19. A couple individuals were also worried about being forced into a nursing home or not receiving care because of their disability if they contract COVID-19. Respondents also expressed fears that they would not receive needed caregiving and support during COVID-19 resulting in situations such as not being able to eat, not able get groceries, having regression of mobility, and having to lay in urine for hours. Individuals were also very concerned about people in society who refuse to wear masks, refuse to follow social distancing guidelines, and who think the virus is a hoax or do not take it seriously. Because of all these concerns, individuals also discussed fears to leave their homes and engage in their activities of daily living because they felt unsafe and also felt that government officials caused panic and fear.

Table 18: Theme 3 categories, code density, and quotes

Theme 3: Concerns, fears, and behavioral health issues during COVID-19		
Category	# of Codes	Representative Quote
1. Mental health concerns	18	“I am bipolar and the isolation has exacerbated some of my symptoms.”
2. Fearful of self and/or family/friends getting COVID-19 and negative consequences	17	“As a person with a disability, I was worried that if I were to catch COVID-19, would co-morbidity make it harder for me to successfully combat the virus, and if it got so bad that I was hospitalized, would rationing of care be an issue because providers would not see my life with a disability as a life worth living?”
3. Concern to not have caregivers or proper caregiver support during pandemic	11	“Felt afraid and still do at times because of lack of home care staff that can come help.”
4. Fear of people not following public health guidelines during pandemic	7	“Other people not taking it seriously and not wearing masks. I am in a high-risk category and catching it would place me in the hospital. It could be fatal. But others not following the guidelines puts me and my family at risk and that is terrifying.”

5. Fearful to engage in typical daily activities due to pandemic and government messaging	7	"In the beginning with all of the news coverage of the pandemic I was very uneasy of going out to get groceries or any type of supplies needed."
6. Fear of the unknown during the pandemic	3	"Just the unknown."
7. Fearful because do not have access to needed healthcare services	2	"Wound care follow-up is difficult to achieve, and creates an additional risk."
8. Fearful could not get needed supplies	2	"I could not get hold of cleaning products or help in cleaning my house."
9. Fearful no treatment or vaccine for COVID-19	2	"No vaccine, no cure, no medications known to help treat the symptoms. Anyone who is not afraid is fooling themselves."
Total Density of Codes	69 codes	

Theme 4: Barriers and issues in meeting healthcare needs due to COVID-19

Five categories define this theme comprised of 68 codes. See table 19 for a complete list of the categories in order of frequency of participant discussion (density of the codes) and representative quotes for each category. The three most frequently discussed categories for this theme include:

- Disruption in access to healthcare, supplies, and medication
- Access to PPE
- Emergency services and hospitals did not make proper accommodations for accessibility to quality care

Respondents described the healthcare barriers they experienced due to COVID-19. Individuals "had difficulty getting medical supplies," including requisite equipment and medication to manage health conditions. A number of individuals also described not being able to access needed physical therapy services causing concerns for regression of mobility and not being fitted properly for new wheelchairs and receiving needed transfer training. Beyond individual medical needs, respondents also lacked access to PPE, either for themselves or for those providing them in-home care. There were also several instances where proper accommodations were not made in healthcare settings such as not allowing direct service providers, caregivers, or family in with the patient during examinations to assist with communication, refusing to provide sign-language interpreter for a patient who becomes non-verbal under stress, and not providing a pen to write when non-verbal.

Table 19: Theme 4 categories, code density, and quotes

Theme 4: Barriers and issues in meeting healthcare needs due to COVID-19		
Category	# of Codes	Representative Quote
1. Disruption in access to healthcare, supplies, and medication	34	“Had to wait for referral appointment. Doctor appointments spread out due to 6 foot rule so less appointments are available.”
2. Lack of access to PPE	16	“We have had zero access to proper PPE.”
3. Emergency services and hospitals did not make proper accommodations for accessibility to quality care	11	“I needed an interpreter because I go nonverbal for a few reasons and my cognitive issues get overwhelmed. They refused an interpreter.”
4. Problems with insurance	5	“Insurance needs to pay for [medications]. I can't believe they started denying medications in the middle of the pandemic, especially medications that are needed for conditions to protect against is.”
5. Sensory issues related to COVID-19 protocols	2	“Sensory issues cause him to not wear face protection so they [healthcare providers refuse to see him.”
Total Density of Codes	68 codes	

Theme 5: Issues in how the healthcare system interfaces with people with disabilities

Five categories define this theme comprised of 26 codes. See table 20 for a complete list of the categories in order of frequency of participant discussion (density of the codes) and representative quotes for each category. The three most frequently discussed categories for this theme include:

- Communication challenges with healthcare providers
- Unprofessionalism of EMS/ER/hospital staff/providers and lack of respect for people with disabilities
- Rights of people with disabilities ignored in healthcare setting

In this theme, respondents discussed in detail about incidents of communication challenges with healthcare providers and issues related to unprofessionalism, lack of respect, and the rights of people with disabilities being ignored during the pandemic. Individuals reported feeling “degraded and humiliated” after interactions with hospital staff and repeated examples of healthcare professionals not listening to patients with disabilities. Some specific examples of unprofessionalism and lack of respect for people include ambulance staff mocking an individual with a disability for not driving self to the hospital and ER staff ignoring the call button because individual was non-verbal. There were also examples of rights being ignored by holding patients down against their will to insert catheters, having to argue for ADA accommodations, not providing interpreters, and patients filing complaints but nothing being done to resolve the issues.

Table 20: Theme 5 categories, code density, and quotes

Theme 5: Issues in how the healthcare system interfaces with people with disabilities		
Category	# of Codes	Representative Quote
1. Communication challenges with healthcare providers	8	"I had issue because I use assisted technology to communicate a hospital ER nurses wouldn't wait for me [to] communicate."
2. Unprofessionalism of EMS/ER/hospital staff/providers and lack of respect for people with disabilities	6	"[I] was signing and the hospital nurse yelled at me not to sign at her because she doesn't sign and then said she doesn't have to be treated like this and stomped out."
3. Rights of people with disabilities ignored in healthcare setting	5	"I went to the emergency room and because they weren't taking like regular urine samples and I'm in a wheelchair and they won't let me use a bedpan they just straight cath me against my will it was awful."
4. Lack of trust and feelings of stress and disempowerment with hospital system	4	"I am really stressed out about asking for interpreters or seeking care at area hospitals or facilities because they don't seem to understand communication issues."
5. Hospitals need new policies on how to work with people with disabilities	3	"[need] a new policy on how they interact with people with disabilities that you can't just take somebody's urine without their permission and that people with autism may take longer to respond but do have a choice in their care."
Total Density of Codes	26 codes	

Theme 6: Perceptions on the health department's response to COVID-19

Three categories define this theme comprised of 24 codes. See table 21 for a complete list of the categories in order of frequency of participant discussion (density of the codes) and representative quotes for each category.

The most frequently discussed category for this theme was that the health department responded adequately. Many individuals believed the health department responded appropriately given the situation and were "doing the best they can with what they have." However, others noted the need for better dissemination of information by the health department. Individuals felt that health officials, at the state and federal level, could have done a better job, particularly at press conferences, in disseminating information to the public. Even with appropriate dissemination, individuals still described inconsistencies in the public adhering to safety measures, such as mask-wearing. One respondent expressed that the health department should have made "sure social distancing and masks were worn."

Table 21: Theme 6 categories, code density, and quotes

Theme 6: Perceptions on the health department's response to COVID-19		
Category	# of Codes	Representative Quote
1. Health department responded adequately	14	"I felt that health officials have done well with providing information and resources for testing."
2. Need better dissemination of information	6	"The greatest issue is the lack of reliable factual information, particularly at the Federal level."
3. Need better enforcement of mask wearing	4	"The state says that employers are following appropriate health guidelines - but a lot aren't and when they are its the people literally making it unsafe."
Total Density of Codes	24 codes	

Limitations

There are several limitations to interpreting the results of this survey. Firstly, this survey used a convenience sample and thus, was non-random. Using a convenience sample can be problematic in a number of ways. Convenience samples may be susceptible to response bias, meaning people with certain characteristics may be more likely to respond to the survey, such as those with strong positive or negative opinions, which may not accurately represent the experiences of the larger population of Ohioans with disabilities. Since the results only represent the self-report and opinions of the participants in this survey, they cannot be generalized to all Ohioans with disabilities. Secondly, there was variability in the response rates of individual questions (i.e., the proportion of the sample who responded). Thus, questions with low response rates, as defined by less than 80%, should be interpreted with caution. Finally, though the analysis of the open-ended responses was as rigorous as possible, the qualitative analysis was still subjective in nature and could have been influenced by implicit biases of the evaluators. This limitation was reduced through achieving consensus of the coding and thematic analysis among three evaluators who all independently reviewed the survey responses and analysis. Given the limitations of this analysis, all results must be interpreted with caution.

Appendix I: Survey

Unmet Needs Survey During COVID 19 Pandemic:

Thank you for answering this brief survey. We are using this information to find gaps in emergency response plans for individuals with disabilities and those receiving home care supports by caregivers (paid and unpaid).

Advocates are working with some local health departments to make sure that emergency response plans include the disability community. Your answers inform local health officials about disability needs and encourages them to make needed changes

All responses are confidential. Your names and identifying information will not be seen in the analysis or reporting of results.

Thank you for your time and help!

What have been your greatest need(s) during the COVID-19 pandemic?

How has the COVID-19 pandemic impacted your personal life?

What could health officials have done differently to assist you?

Were you able to access proper health care for your physical and mental health needs? If not, what were the barriers?

Did you ever feel unsafe or afraid for your life during this pandemic? If so, please explain what caused you to feel this way?

If you have caregivers, did you have access to personal protective equipment (PPE) for yourself as well as your caregivers?

Are you encountering caregiver issues as a direct impact from the COVID-19 pandemic? If so, what is being done about your caregiver issues?

Has COVID19 effected your ability to find and secure necessary caregivers? If so, how?

Has the COVID-19 pandemic been cited as a reason why you have not been provided a caregiver for your home care needs? If so, what was the reason?

Has the availability of caregivers changed with COVID-19 pandemic? If so, how?

**Are you able to get needed medications or physical therapy? Are there barriers?
What is being done to overcome those?**

Are you or anyone you know of anyone at risk of losing your/their home or apartment? If so, what are the barriers and what is being done?

Have you or has anyone you know had issues navigating an emergency room or hospital admission in a medical crisis during the COVID-19 pandemic? If so, what are the barriers and what is / was being done?

How would you identify yourself? Select all that apply.

- Individual with a Disability
- Family Member
- Medical Professional
- Case / Care Manager
- Social Worker
- Caregiver
- Friend
- Other (please specify): _____

What County in Ohio do you reside in? _____

What organizations are giving you services now? (Check all that apply)

- Center for Independent Living
- County Board of Developmental Disabilities
- Jobs and Family Services
- Public Housing Authority
- Area Agency on Aging
- Public Transit Authority

- Community Action Partnership
- Homeless Service Providers
- Other (please specify): _____

May we contact you for clarification or follow up questions? Yes or No

If yes, how would you like to be contacted?

Name: _____

Email: _____

Phone Number: _____