



COVID-19 & ADULTS WITH DISABILITIES: HEALTH AND HEALTH CARE ACCESS

ONLINE SURVEY SUMMARY REPORT

American Association on Health & Disability

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A. Introduction

People with disabilities experience unique risks during emergencies, disasters, epidemics, and pandemics that can impact health and health care. For example, access to on-going health care or prescriptions may be disrupted by an outbreak or emergency. People with disabilities who experience underlying chronic conditions may be at greater risk for severe illness stemming from an outbreak. Yet, historically persons with disabilities have not been a significant focus of emergency preparedness and surveillance activities (Krahn et al., 2015; White, 2009).

Purpose

The purpose of the COVID-19 & Disability (C-19 & D) Survey was to conduct a rapid, real-time online assessment of the coronavirus pandemic's impact on access to health care and on adults with a range of disabilities. Online data-collection technologies permit efficient, rapid assessments that, despite limitations, are useful to begin understanding public health issues. Online surveys can also provide a safe and anonymous environment for vulnerable populations to express opinions. The C-19 & D Survey is especially important since the Centers for Disease Control and Prevention (CDC) COVID-19 case report forms do not include disability identifiers such as vision, hearing, mobility, or cognition disabilities (see CDC, 2020). *At this time, we do not know the full impact of COVID-19 on people with disabilities.*

Organization of the COVID-19 & Disability Survey

The COVID-19 & Persons with Disabilities Summary Report is the first in a series of publications developed by the American Association on Health and Disability (AAHD) based on our COVID-19 and Disability online survey. The initial Summary Report presents findings combining all disability responses. Subsequent publications will focus on results by specific type of disability, as well as analyzing open-ended responses.

The self-report survey includes demographic questions, including disability identifiers, gender, ethnicity, race, geographic area, and type of health insurance. Because our focus was adults with disabilities, respondents who were 17 or younger were automatically disqualified. However, large numbers of youth with disabilities attempted the survey, indicating a significant unmet need to understand COVID-19 from a youth perspective.

Disability Identifiers

We adopted four of the six disability identifiers used by the CDC's Behavioral Risk Factor Surveillance (BRFSS), the nation's premier public health survey, the US Census Bureau, and other federal agencies. To ease respondent burden, we asked respondents for their

primary disability, knowing that a substantial minority of respondents experience multiple disabilities.

The primary identifiers included:

1. Deaf or serious difficulty (Hearing);
2. Blind or serious difficulty seeing, even when wearing glasses (Vision);
3. Serious difficulty walking or climbing stairs (Mobility); and
4. Because of a physical, mental, or emotional condition, have serious difficulty concentrating, remembering, or making decisions (Cognition).

We were also interested in understanding the disability conditions underlying “serious difficulty concentrating, remembering, or making decisions” (DCRD). For this reason, respondents who chose the cognition identifier as their main disability were asked if this was due to:

- An Emotional, Psychological, or Mental Health Disability;
- An Intellectual Disability, Autism, Epilepsy, or Brain Injury;
- Difficulty Reading, Writing, or Communicating; or
- Another Disability (such as Chronic Pain, Difficulty Sleeping, Medication Side Effects, or Other).

Access to Regular Health Care & Prescriptions

The survey includes a set of questions on access to regular (non-COVID-19) health care and services, including access to needed health care treatment, prescriptions, and the use of direct care workers.

COVID-19 Information and Impact on Persons with Disabilities

The survey also includes questions regarding COVID-19 information and impact, including sources of information about the Coronavirus pandemic, adherence to public health COVID-19 recommendations, testing, and access to emotional supports during the pandemic.

B. Methodology

We reviewed existing COVID-19 surveys and either modified existing items or created new ones consistent with our areas of interest. Print, electronic and social media platforms were used to solicit responses from people with cross disabilities. Within the social media platforms, AAHD “boosted” Facebook posts and engaged LinkedIn Groups. In addition, AAHD distributed the survey through existing partnerships and requested

that other organizations and individuals distribute the survey invitation/link using their list serves, newsletters, social media platforms, and other print and electronic dissemination strategies. The survey was available online from April 17, 2020, until May 1, 2020.

C. Results

A total of 2,469 adults with disabilities responded to the survey and 578 youth 17 or younger attempted to take the survey. Because our survey focus was adults, youth were excluded from the survey after determining their age. The survey completion rate varied by item, ranging from a low of 86% (Question 12) to 100% (Question 1). The overall completion rate was 93% (exclusive of skip patterns). Specific results are described below. All results are rounded.

Demographics

Main Disability

As displayed in Table 1, 58% of respondents were adults with a cognition disability (i.e., the presence of a physical, mental, or emotional condition creating serious difficulty concentrating, remembering, or making decisions). The second largest percentage of respondents were persons with mobility disabilities (serious difficulty walking or climbing stairs) at 27%, followed by persons with vision disabilities (blind or with serious difficulty seeing, even when wearing glasses) at 8%, and persons who are Deaf or have serious difficulty hearing (7%).

Table 1. Main Disability of Respondents (N = 2,469)

Disability	Percentage	Number
Deaf or Have Serious Difficulty Hearing	7%	182
Blind or Have Serious Difficulty Seeing, Even When Wearing Glasses	8%	193
Have Serious Difficulty Walking or Climbing Stairs	27%	663
Because of a Physical, Mental, or Emotional Condition, Have Serious Difficulty Concentrating, Remembering, or Making Decisions	58%	1431

Physical, Mental, or Emotional Conditions Causing Difficulty with Concentrating, Remembering, or Making Decisions

A range of physical, mental, or emotional conditions contribute to difficulty with concentrating, remembering, or making decisions (DCRD). Figure 1 displays the

underlying causes of DCRD, including an Intellectual Disability, Autism, Epilepsy, or Brain Injury (71%), an Emotional, Psychological, or Mental Health Disability (16%), Another Disability such as Chronic Pain, Difficulty Sleeping, Medication Side Effects, or Other (14%), and Difficulty Reading, Writing, or Communicating (2%).

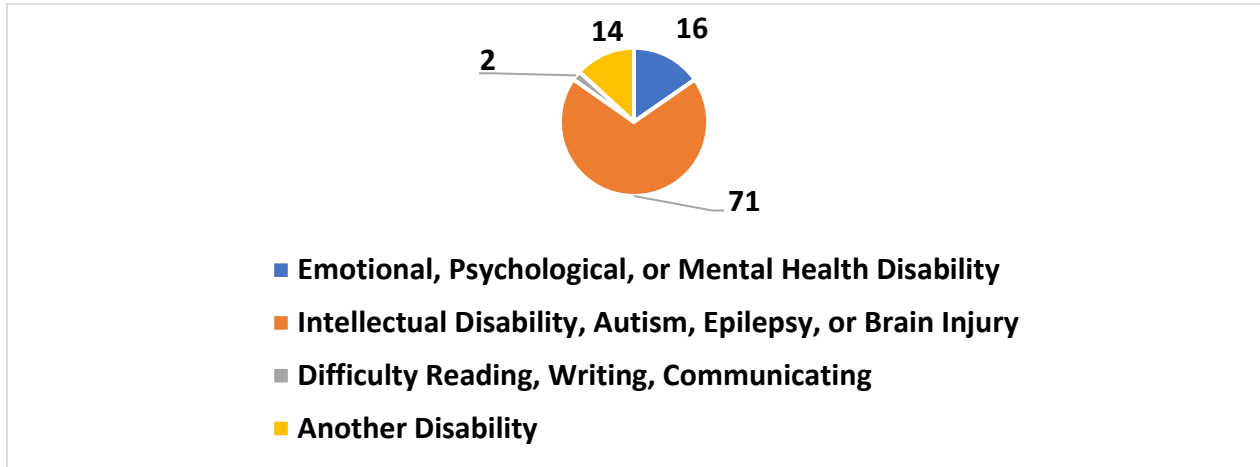


Figure 1. Prevalence of Conditions Causing Serious Difficulty Concentrating, Remembering, or Making Decisions (N = 1,431)

Age

As displayed in Figure 2, respondents selected from the following age groups: a) 18 to 44; b) 45-64; or c) 65 and above. Since the survey was adult-focused, respondents who were 17 and younger were excluded from other survey questions (see also Recommendations). The majority of the respondents were 18-44 (54%), followed by adults that were 45-64 (35%), and adults 65 and older (12%).

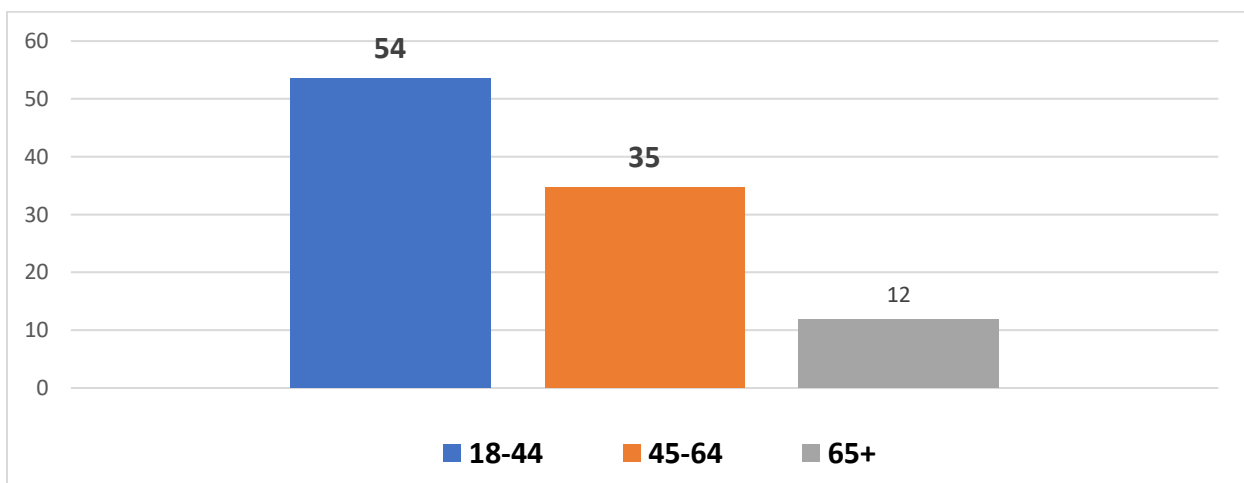


Figure 2. Percentage of Respondents by Age Group (N = 2,469)

Gender

As displayed in Table 2, the majority of adult respondents reported being either Female (59%) or Male (37%), with Gender Variant/Non-Conforming at 1%, Other at 1%, and Transgender Male (0%) and Transgender Female (0%). Two percent of the sample preferred not to answer.

Table 2. Gender of Respondents (N = 2,449)

Gender	Percentage	Number
Female	59	1448
Male	37	911
Transgender Female	0	2
Transgender Male	0	3
Gender Variant/Non-Conforming	1	31
Other	1	13
Prefer Not to Answer	2	41

Race and Ethnicity

We combined an ethnicity identifier (Hispanic, Latino, or of Spanish Origin) with race for the results, as shown in Figure 3. The sample was primarily White (83%), followed by Black or African-American (9%), Hispanic (5%), American Indian or Alaska Native (4%), Asian (3%), and Native Hawaiian or Other Pacific Islander (0%). Five percent of respondents preferred not to answer.

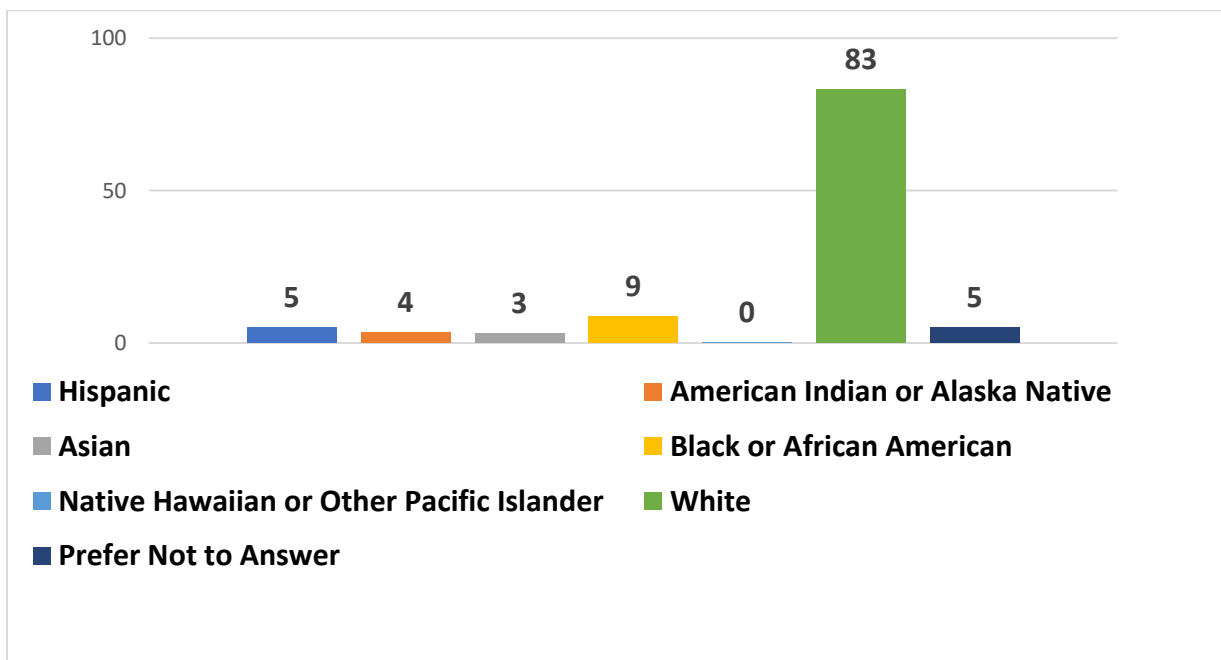


Figure 3. Percentage of Respondents by Ethnicity & Race (N = 2,419)

Geographic Location

Respondents selected their location as Urban, Suburban, Rural, or Frontier (see Figure 4). The largest percentage of respondents were in Suburban locations (47%), followed by Rural (26%) and Urban (26%), and Frontier (1%) locations.

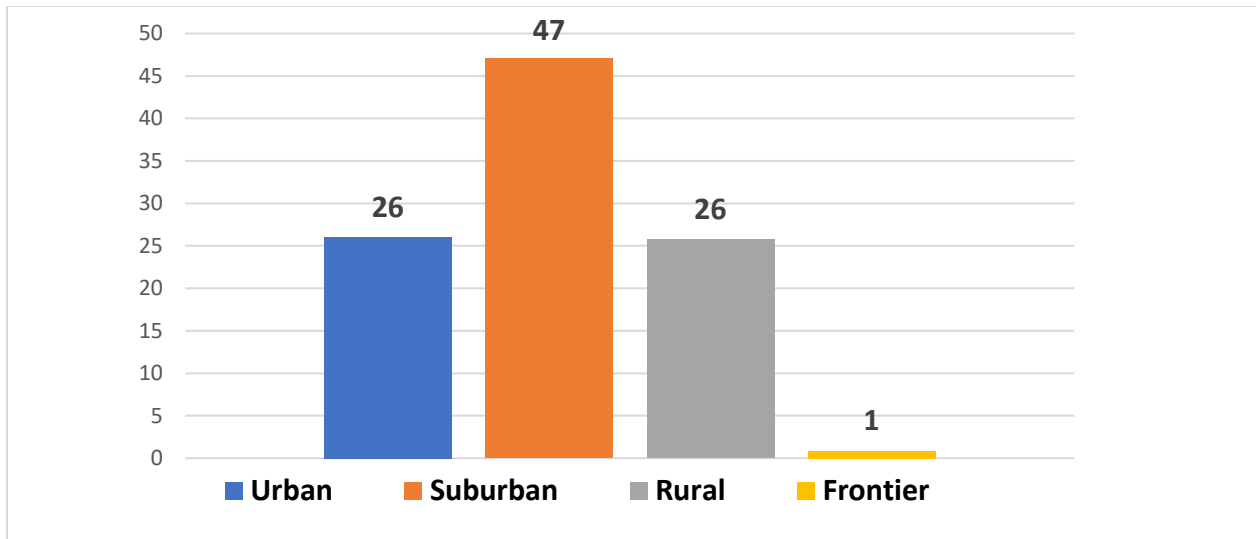


Figure 4. Percentage of Respondents by Geographic Location (N = 2,407)

Health Insurance

As displayed in Figure 5, the largest percentage of respondents reported having Medicaid/CHIP (44%), followed by Medicare (41%), Private Insurance (38%), VA/Government insurance (7%), and Other (6%). Respondents were allowed to select "all that apply." Two percent of respondents reported having no insurance.

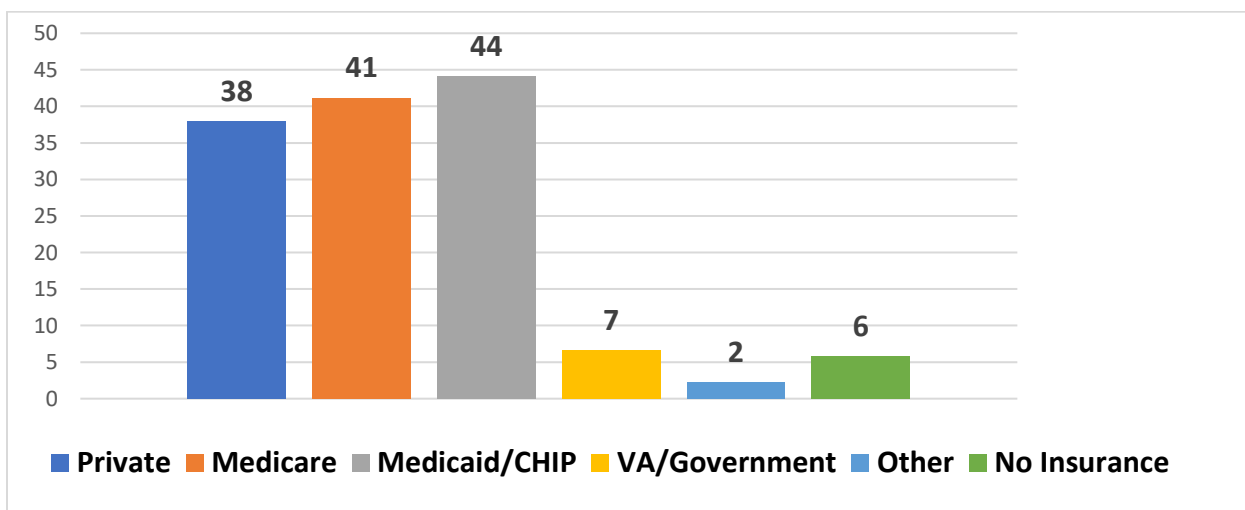


Figure 5. Percentage of Respondents by Type of Health Insurance (N = 2,389)

Access to Regular Health Care & Services

We developed a set of questions to determine if the coronavirus pandemic was impacting access to non-COVID-19 (regular) health care and services, including access to needed health care treatment, prescriptions, and the use of direct care workers.

Use of Direct Care Workers & Impact of COVID-19

Respondents were asked if they used a Direct Care Worker (e.g., Home Health Aide, Personal Care Aide, or Unpaid Family Caregiver), if their Direct Care Worker was continuing to provide care, and if respondents had been able to maintain a safe distance from their Direct Care Worker (e.g., six feet).

Forty-seven percent of respondents reported having a Direct Care Worker in their home, while 53% did not (see Figure 6). As shown in Figure 7, among respondents with a Direct Care Worker, 77% of respondents continued to receive these home services, while 23% of respondents were no longer receiving these services.

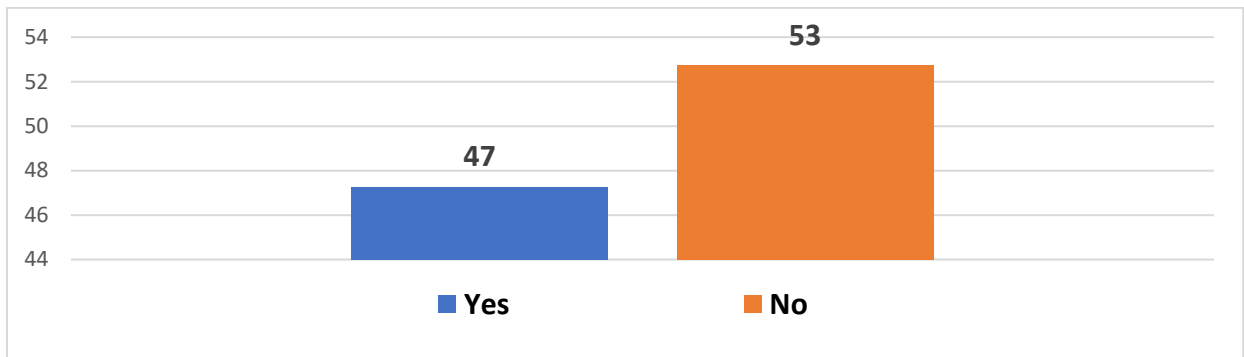


Figure 6. Percentage of Respondents Who Use a Direct Care Worker (N = 2,183)

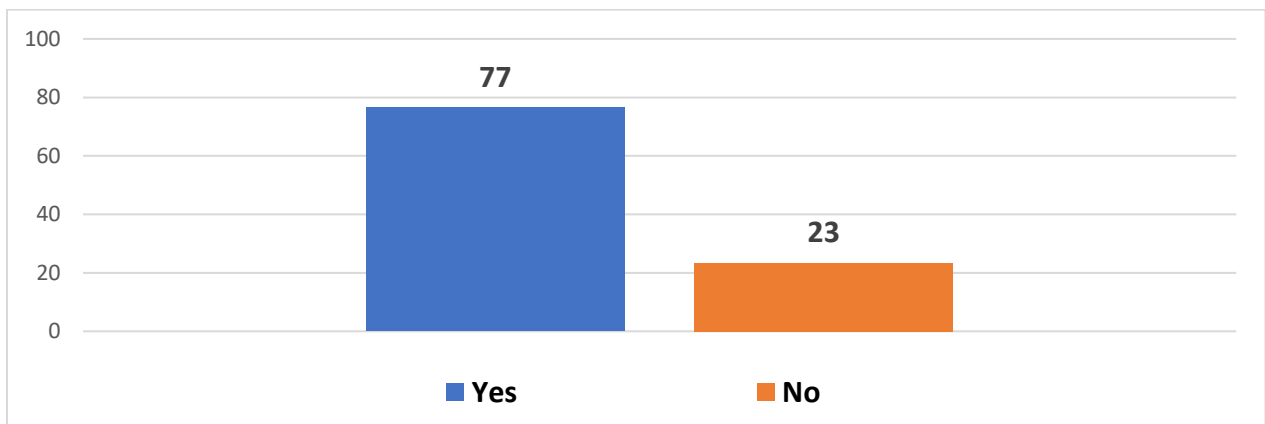


Figure 7. Percentage of Respondents with Direct Care Worker Home Visits During COVID-19 (N = 1,045)

Safe Distance Practices and Direct Care Workers

Respondents receiving Direct Care Worker services during the COVID-19 pandemic were asked if they were able to maintain a safe distance from their provider. As displayed in Figure 8, 54% of respondents reported that they were unable to maintain a safe distance from their Direct Care Worker, while 46% of respondents were able to maintain a safe distance.

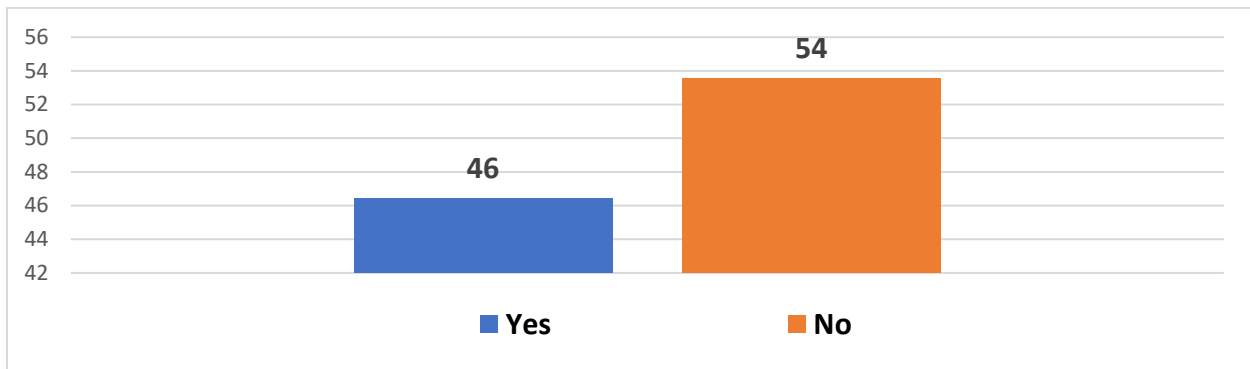


Figure 8. Percentage of Respondents Maintaining A Safe Distance from Direct Care Worker (N = 786)

Access to Regular Health Care Treatment

Respondents were asked if they were able to get regular health care treatment (such as physical therapy, dialysis, bloodwork, etc.) during the COVID-19 outbreak. Thirty-six percent of respondents did not receive regular health care. Among respondents who did, 56% reported access had been disrupted and 44% reported that access had not been affected (see Figure 9).

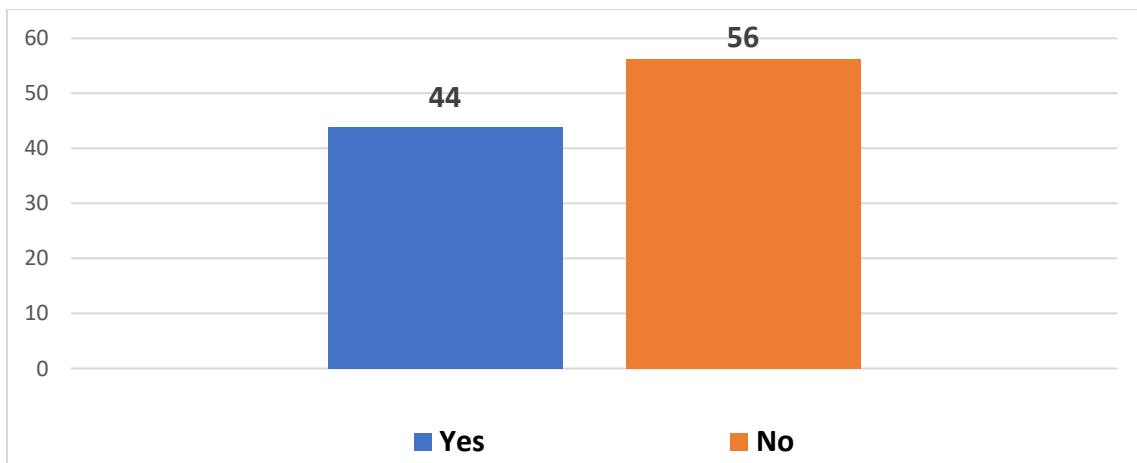


Figure 9. Percentage of Respondents Able to Access Regular Health Care (N = 1,375)

Access to Prescription Medications

Respondents were asked if they were able to obtain prescription medications during the COVID-19 outbreak. Ten percent of respondents were not taking any prescriptions. Among respondents taking prescriptions, 96% reported that access had not been affected and 4% reported access had been disrupted (see Figure 10).

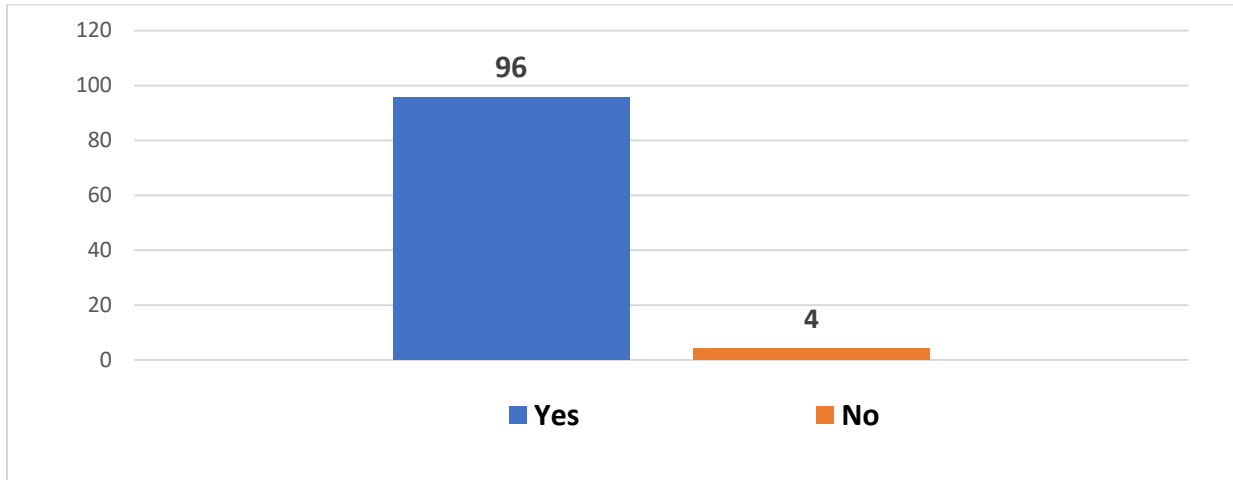


Figure 10. Percentage of Respondents Able to Access Prescriptions (N = 1,946)

New Challenges to Health

Respondents were asked if they were experiencing new challenges to obtaining health care treatment, health care access, and/or prescriptions during the COVID-19 outbreak. Forty-four percent of respondents reported experiencing new challenges, while 56% reported that they had not experienced new challenges.

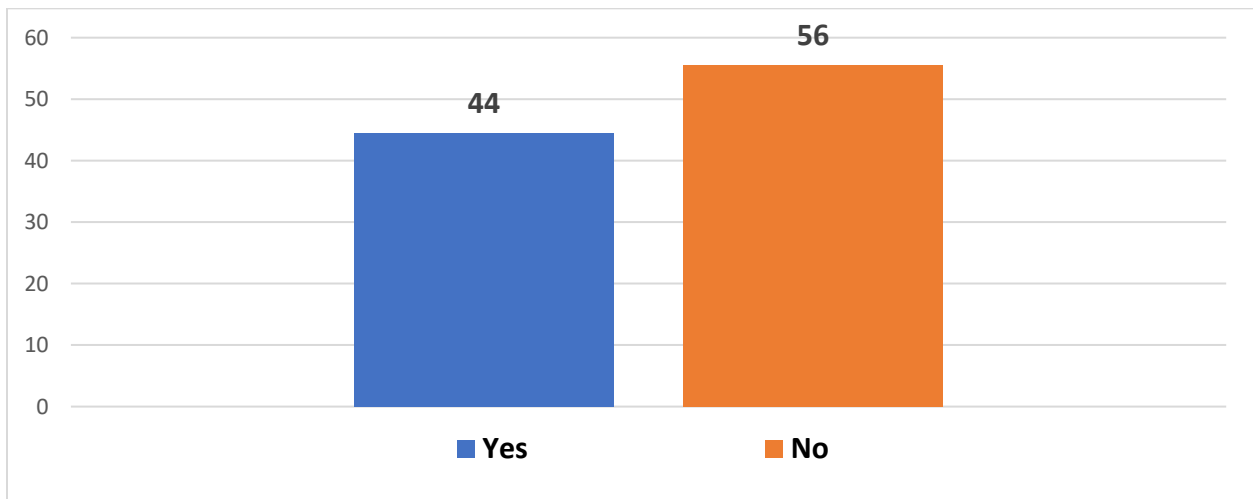


Figure 11. Percentage of Respondents Experiencing New Challenges to Accessing Health Care (N = 2,150)

COVID-19 Information & Impact

The survey includes a number of questions about the impact of COVID-19, including where respondents obtained information about the Coronavirus pandemic, adherence to COVID-19 public health recommendations, testing, and access to emotional supports during the pandemic.

COVID-19 Information Sources

Respondents were asked to rank their three most important sources of information about COVID-19 out of nine options. As displayed in Table 3, among the nine information sources, 31% of respondents identified the most important source as Television, followed by the Internet (24%), and Health Care Providers / Health Systems (HCP/HS) and Relatives, both at 15%. Social Media was at 5%, Other was at 4%, Radio at 2%, Print Media at 2%, and Friends at 1%.

Respondents identified Television (25%) and the Internet (25%) as the second-most important sources of information, followed by Social Media (13%). Other second-most important sources of information were Relatives (9%), Print Media (6%), Radio (5%), and Friends (5%).

Respondents also identified Social Media (16%) as the third-most important source of information, followed by Television (14%) and the Internet (13%). Several other sources were endorsed as the third-most important, including Health Care Providers/Health Systems (12%), Friends (11%), and Relatives (11%). Other sources included Relatives and Friends (both at 11%), Print Media and Other (both at 8%), and Radio (6%).

Table 3. Most Important Sources of COVID-19 Information (N = 2,239)

	HCP/HS	Internet	TV	Radio	Social Media	Print Media	Friends	Relatives	Other
Most Important	15%	24%	31%	2%	5%	2%	1%	15%	4%
Second Most Important	9%	25%	25%	5%	13%	6%	5%	9%	4%
Third Most Important	12%	13%	14%	6%	16%	8%	11%	11%	8%

Following COVID-19 Recommendations

Respondents reported high levels of compliance with COVID-19 public health recommendations. As shown in Figure 12, 95% of respondents reported following recommendations and 5% reported they were not following recommendations.

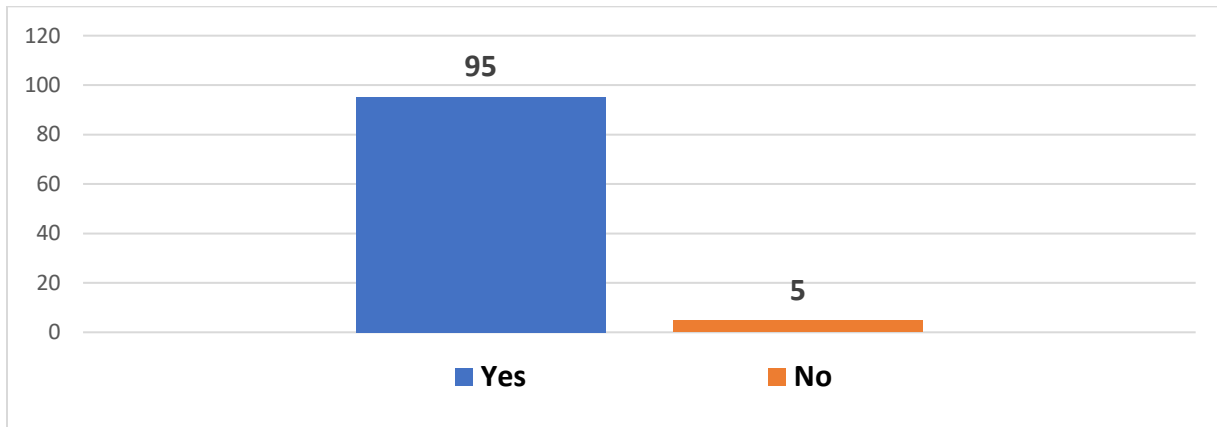


Figure 12. Percentage of Respondents Following COVID-19 Recommendations (N = 2,222)

COVID-19 Testing

We were interested in whether people with disabilities were being tested for COVID-19, if not, why not, and if insurance was covering testing. As shown in Figure 13, 4% of respondents had received a test for COVID-19 and 96% had not received testing. Among respondents that had been tested, 49% reported the test had been covered by insurance, 8% reported it had not, and 44% were not sure if the test was covered (see Figure 14).

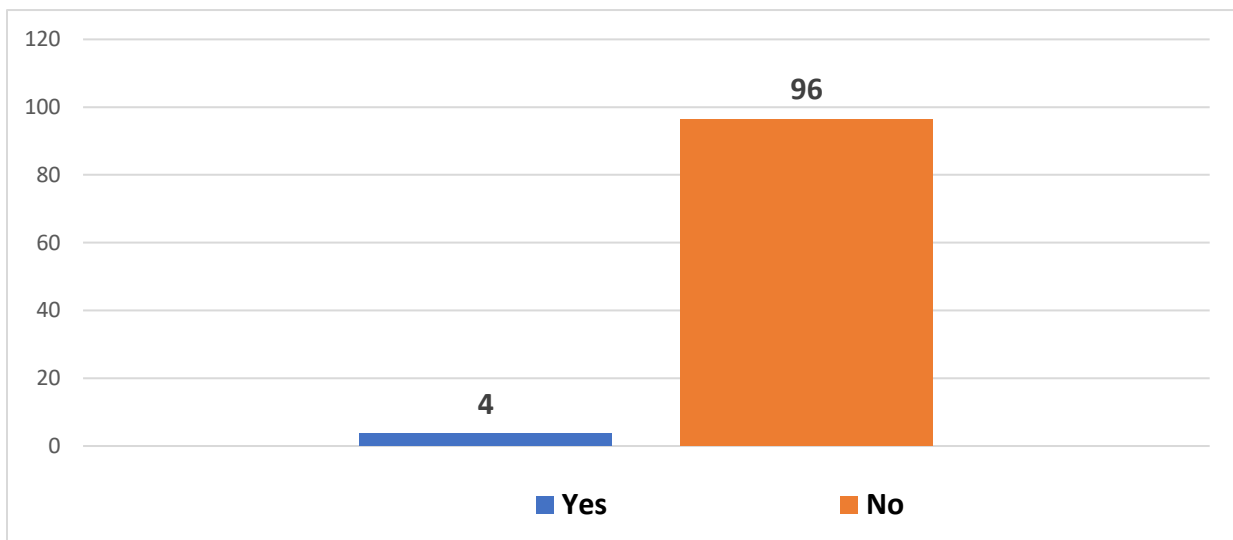


Figure 13. Percentage of Respondents Receiving COVID-19 Testing (N = 2,215)

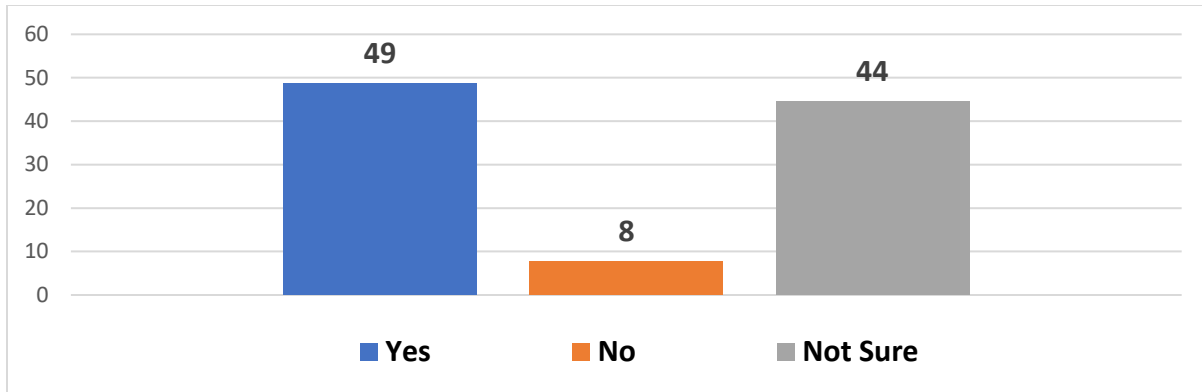


Figure 14. Percentage of COVID-19 Test Takers Covered by Insurance (N = 78)

Why No COVID-19 Testing?

Respondents who had not received a COVID-19 test identified a range of reasons why they were not tested. As shown in Table 4, the largest percentage was among respondents who said they didn't need a test (81%). Among respondents who did need a test, reasons for not receiving the test included the test was unavailable (13%), followed by Other (5%), Health Care Provider would not approve the test (4%), lacking transportation to the test site (3%), cost or concern that insurance wouldn't provide coverage (2%), information about testing was not accessible or available in alternate formats (2%), site did not have sign language interpreters (1%), the testing site was physically inaccessible (1%), and the site lacked accessible parking (0%).

Table 4. Reasons for Not Obtaining COVID-19 Test

Reason	Percentage
Didn't Need Test	81
Test Was Unavailable	13
Other	5
Health Care Provider Would Not Approve Testing	4
Lacked Transportation to Site	3
Cost/Insurance Wouldn't Cover	2
Information About Testing Not in Accessible Formats	2
Site Had No Sign Language Interpreters	1
Site Was Physically Inaccessible	1
Site Had No Accessible Parking	0

Anxiety & Depression

We asked respondents that were feeling anxiety or depression as a result of COVID-19 if they were able to access emotional support or services. Thirty-one percent of

respondents were not experiencing anxiety or depression. As displayed in Figure 15, among respondents feeling anxiety or depression, 76% reported having access to emotional support or services and 24% reported not having access.

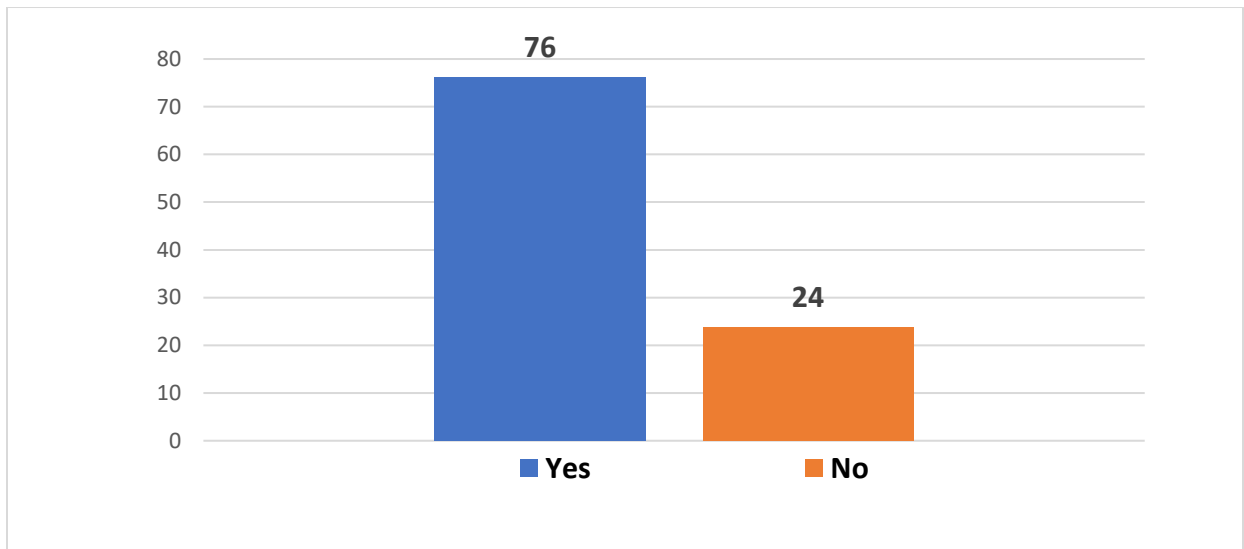


Figure 15. Percentage of Respondents with Access to Emotional Support/Services (N = 1,507)

D. Discussion

One of the limits of using a convenience sample is that results cannot be generalized to a larger population, although they can be informative (Bethell, et al, 2004). Below, we discuss observations about the survey results in relation to the sample's demographics and responses to the COVID-19 Information and Impact and Access to Health Care and Prescriptions sections.

Demographics

The COVID-19 and Disability (C-19 & D) Survey sample is atypical from population-based disability samples on a number of dimensions. For example, the highest percentage of disability (64%) derives from persons reporting a physical, mental, or emotional condition that creates serious difficulty concentrating, remembering, or making decisions (DCRD). Similarly, the high prevalence (71%) of Intellectual Disability, Autism, Epilepsy, or Brain Injury as the underlying condition contributing to DCRD is of note. Overall, the sample differs from many population-based results in age (43% of the sample are persons 18-44), predominately female (59%), White (83%), and Suburban (47%), and have some type of insurance (only two percent of respondents reported not

insurance). Notably, there were a high number of young people who attempted to take the survey but were excluded by age.

Access to Regular Health Care & Services

A high proportion of the sample used Direct Care Worker services (47%), particularly considering that 89% of the adult sample were 18-44 (54%) and 45-64 (35%). While a majority of respondents (77%) continued to receive these services during the pandemic, nearly one-quarter of the sample (23%) had lost critical care services. For the fortunate respondents maintaining their Direct Care Worker services, maintaining safe distances was impossible for over half of the sample (54%).

Of concern is that 56% of respondents who were scheduled to receive regular health care treatment services had those services disrupted during the coronavirus pandemic. In contrast, 96% of respondents taking medications reported that they could access their prescriptions. Yet, for the 4% of the sample who had prescription medication access disrupted, this represents a potentially life-threatening situation.

New Challenges to Health

In many ways, the novel coronavirus pandemic is presenting unfamiliar and unanticipated challenges for persons with and without disabilities. A key difference is that persons with disabilities already encounter documented disparities in accessing health care treatment and services and involvement in emergency planning programs and activities. Of considerable concern is that 44% of the sample reported experiencing new challenges to obtaining health care treatment, health care access, and/or prescriptions. A careful analysis of the open-ended responses as to why these new barriers exist is underway.

COVID-19 Information & Impact

Several unexpected findings emerged from the information and impact survey questions. Despite the relatively young age of the sample, Television is an important information source whether as the most important, second-most important or third-most important source, as well as the Internet. Interestingly, Health Care Providers and Health Systems are playing a less significant information role to the sample, and, to a lesser degree, Social Media.

While several national polls report varying levels of endorsement for COVID-19 guidelines, the C-19 & D sample overwhelmingly reported high levels of compliance with these guidelines at 95%. This suggests that this sample are taking the risks of the

coronavirus pandemic very seriously. Echoing national findings, only a small percentage (4%) of respondents had received a COVID-19 test and there was significant uncertainty if health insurance would cover this cost. Notable, 13% of persons not receiving a COVID-19 test reported that the test was unavailable (13%) and, to a lesser extent, that health care providers would not authorize the test (4%). Importantly, relatively small percentages report that they had not received a test because of general accessibility problems.

Nearly one-third of the sample were not experiencing anxiety or depression during the pandemic. But among persons that were experiencing anxiety or depression, nearly one-quarter (24%) were not receiving emotional support or services.

Limitations

The findings in this report are subject to at least seven limitations. First, the survey data are self-reported and may be subject to reporting or recall bias. Second, the responses represent a snap shot between April 17, 2020, until May 1, 2020, and the coronavirus pandemic situation may have changed since these responses were given. Third, persons without internet access were unable to access and complete the survey introducing a systematic bias in the sample. Fourth, the survey completion rate among adults ranged among items (86% - 100%), suggesting the presence of some response bias. Fifth, because of the use of a convenience sample, the results are not generalizable to the overall population of persons with disabilities. Sixth, persons with multiple disabilities may not be accurately identified since we asked for a person's "main" disability. Seventh, the Report combines all disability group responses for summary purposes; subsequent publications will examine specific disability populations to conduct more precise analysis.

E. Conclusion

The results of this survey provide insights into a moment in time during the coronavirus pandemic. The challenges contained within the results both need to be examined by specific disability groups within the sample and with population-based efforts, including longitudinally. Moreover, the intricacies and changing dynamics of the pandemic establish a critical need for deeper and ongoing surveillance and policy and programmatic responses to this extraordinary health and public health challenge.

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