



COVID-19 & ADULTS WITH SERIOUS
DIFFICULTIES CONCENTRATING,
REMEMBERING, OR MAKING
DECISIONS DUE TO AN
INTELLECTUAL DISABILITY, AUTISM,
EPILEPSY, OR BRAIN INJURY

ONLINE SURVEY REPORT

American Association on Health & Disability

Acknowledgements

This report was produced with funding from the Bristol Myers Squibb Foundation to the American Association on Health and Disability (AAHD). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Bristol Myers Squibb Foundation.

Support Provided by:



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Suggested Citation:

Drum, C.E., Oberg, A., Ditsch, J., Cooper, K., & Carlin, R. (2020). COVID-19 & Adults with Intellectual Disability, Autism, Epilepsy, or Brain Injuries: Health and Health Care Access Online Survey Report. Rockville, MD: American Association on Health and Disability.

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A. Introduction

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, including people with serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injury. Online data-collection technologies permit efficient, rapid assessments that, despite limitations, are useful to begin understanding public health issues. People with disabilities experience unique risks during emergencies, disasters, epidemics, and pandemics that can impact health and health care. *Yet, 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 self-report survey includes demographic questions, including disability identifiers, gender, ethnicity, race, geographic area, and type of health insurance. A Summary Report combining all disability responses was issued by AAHD on May 8, 2020. This report focuses on results among persons with intellectual disability, autism, epilepsy, or brain injuries.

To ease respondent burden, we asked respondents for their *primary* disability, knowing that a substantial minority of respondents experience multiple disabilities. The serious difficulty concentrating, remembering, or making decisions disability identifier used in the survey is based on the US Census Bureau and the Center for Disease Control and Prevention's (CDC) definition:

1. Because of a Physical, Mental, or Emotional Condition, Have Serious Difficulty Concentrating, Remembering, or Making Decisions

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.

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 disabilities on AAHD's dissemination networks. AAHD also distributed the survey through existing partnerships and requested that other organizations and individuals distribute the survey. 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 of which 930 experienced serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injury. The survey completion rate varied by item, ranging from a low of 88% to 100%. The overall completion rate was 94% (exclusive of skip patterns). Specific results are described below. All results are rounded.

Demographics

Main Disability

As displayed in Table 1, 930 of respondents experienced serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injury or 38% of the total sample.

Table 1. Respondents with an Intellectual Disability, Autism, Epilepsy, or Brain Injury (N = 930)

Disability	Number	Percentage
Intellectual Disability, Autism, Epilepsy, or Brain Injury	930	38%

Age

As displayed in Figure 1, respondents with intellectual disability, autism, epilepsy, or brain injury selected from the following age groups: a) 18 to 44; b) 45-64; or c) 65 and above. The majority of the respondents were 18-44 (80%); followed by adults that were 45-64 (17%), and adults 65 and older (3%).

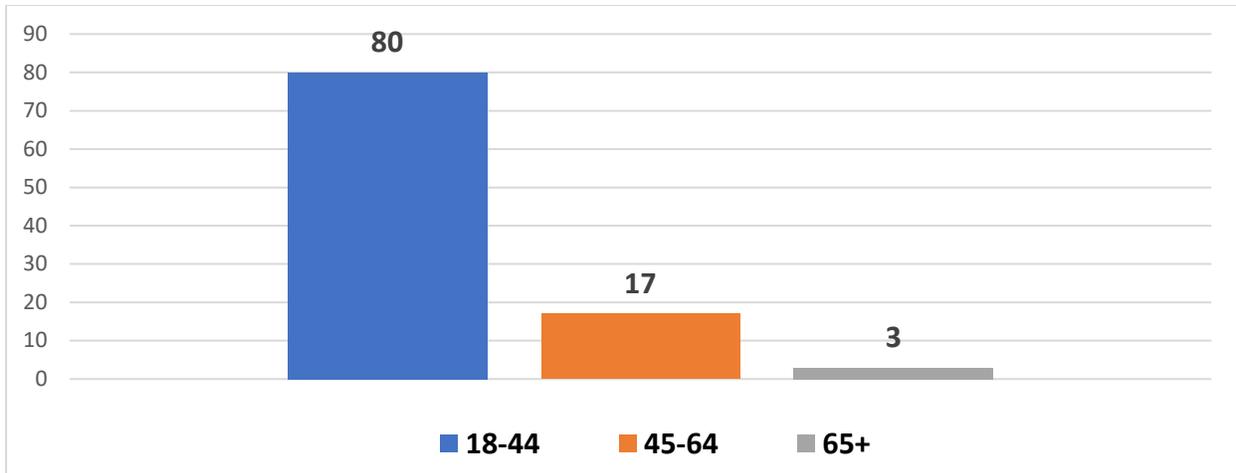


Figure 1. Percentage of Respondents by Age Group (N = 930)

Gender

As displayed in Table 2, the majority of adult respondents reported being either Female (45%) or Male (51%), 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=923)

Gender	Percentage	Number
Female	45	417
Male	51	468
Transgender Female	0	0
Transgender Male	0	1
Gender Variant/Non-Conforming	1	12
Other	1	7
Prefer Not to Answer	2	18

Race and Ethnicity

We combined an ethnicity identifier (Hispanic, Latino, or of Spanish Origin) with race for the results, as shown in Figure 2. The sample was primarily White (79%), followed by Black or African-American (12%), Hispanic (5%), Asian (4%), American Indian or Alaska Native (2%), and Native Hawaiian or Other Pacific Islander (0%). Six percent of respondents preferred not to answer.

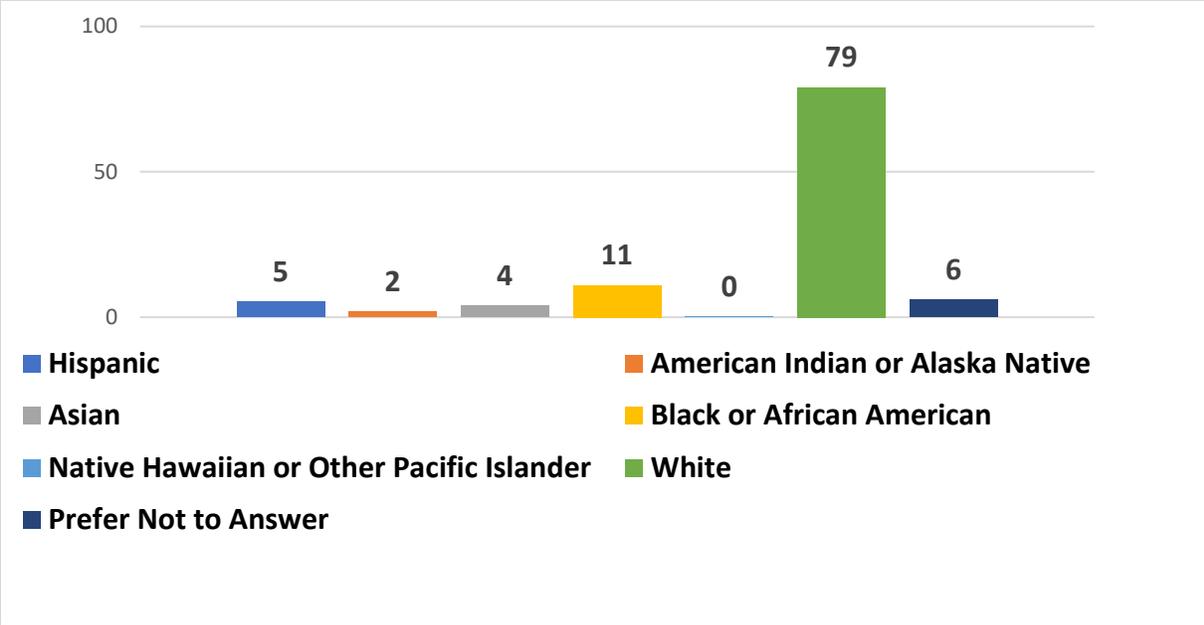


Figure 2. Percentage of Respondents by Ethnicity & Race (N = 912)

Geographic Location

Respondents selected their location as Urban, Suburban, Rural, or Frontier. As shown in Figure 3, the largest percentage of respondents were in Suburban locations (57%), followed by Rural (23%) and Urban (19%), and Frontier (1%) locations.

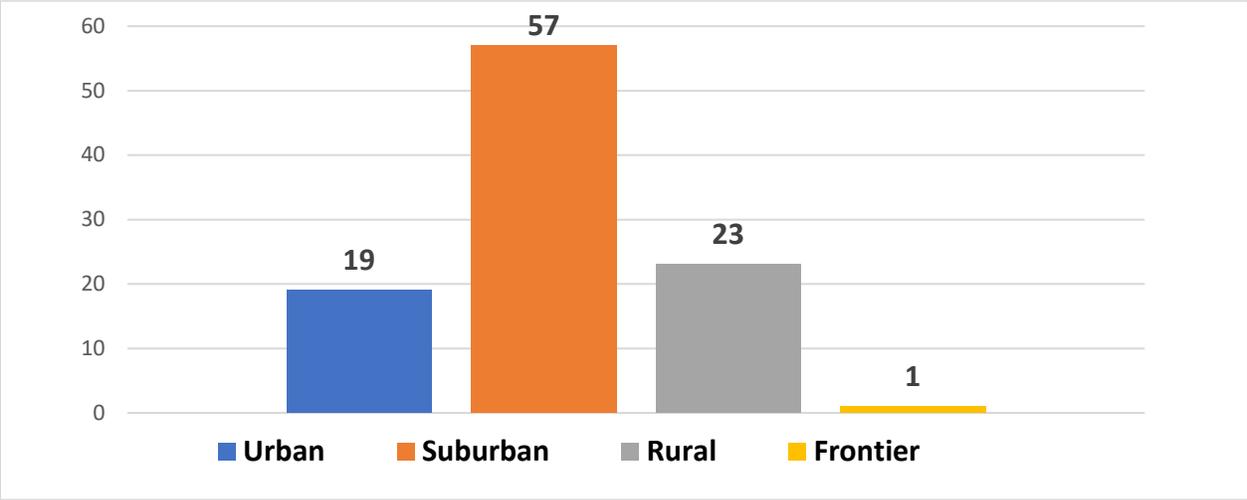


Figure 3. Percentage of Respondents by Geographic Location (N = 908)

Health Insurance

As displayed in Figure 4, the largest percentage of respondents with serious difficulties concentrating, remembering, and making decisions due to intellectual disability, autism, epilepsy, or brain injury reported having Medicaid/CHIP (68%), Medicare (39%), followed by Private Insurance (31%), VA/Government insurance (6%), and Other (5%). Respondents were allowed to select “all that apply.” One percent of respondents had no insurance.

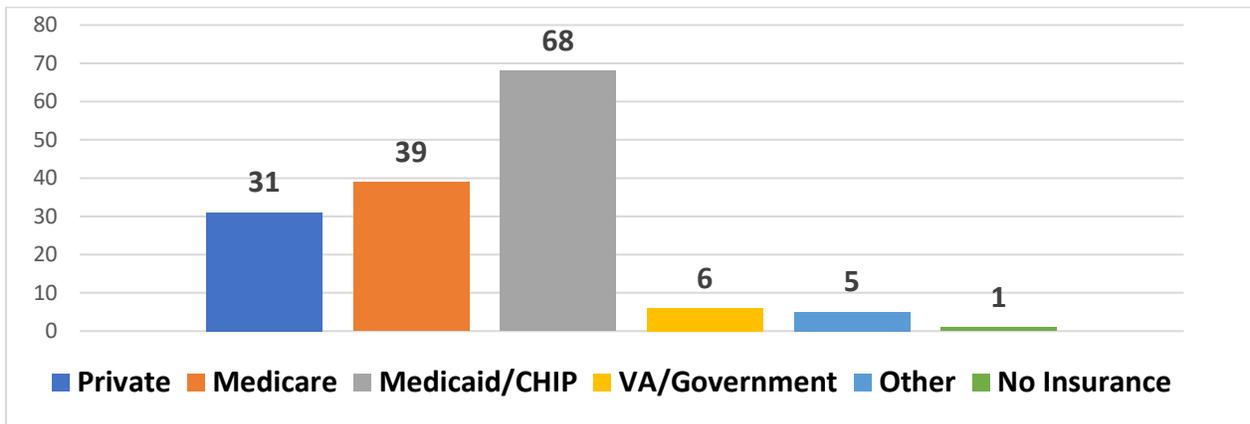


Figure 4. Percentage of Respondents by Type of Health Insurance (N = 901)

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).

Seventy-two percent of respondents reported having a Direct Care Worker in their home, while 28% did not (see Figure 5). As shown in Figure 6, among respondents with a Direct Care Worker, 76% of respondents continued to receive these home services, while 24% of respondents were no longer receiving these services.

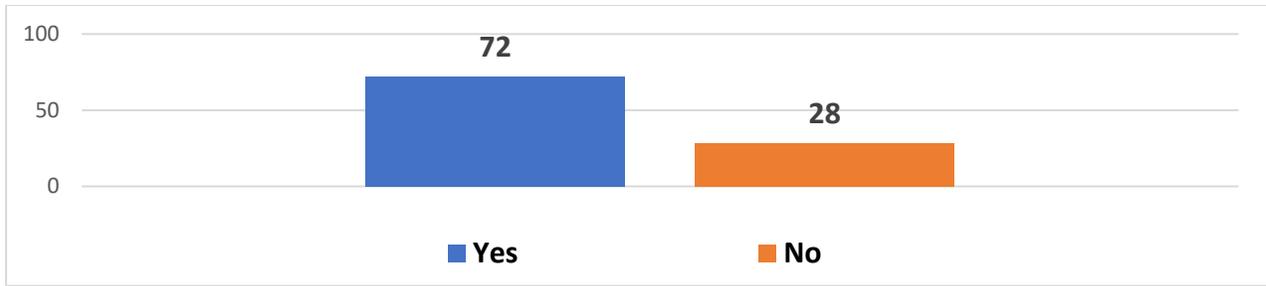


Figure 5. Percentage of Respondents Who Use a Direct Care Worker (N = 597)

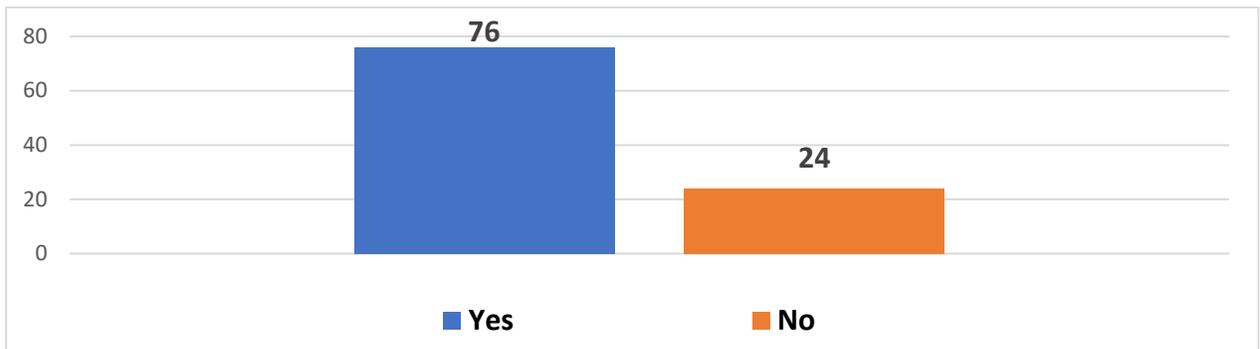


Figure 6. Percentage of Respondents with Direct Care Worker Home Visits During COVID-19 (N = 459)

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 7, 50% of respondents reported that they were unable to maintain a safe distance from their Direct Care Worker, while 50% of respondents were able to maintain a safe distance.

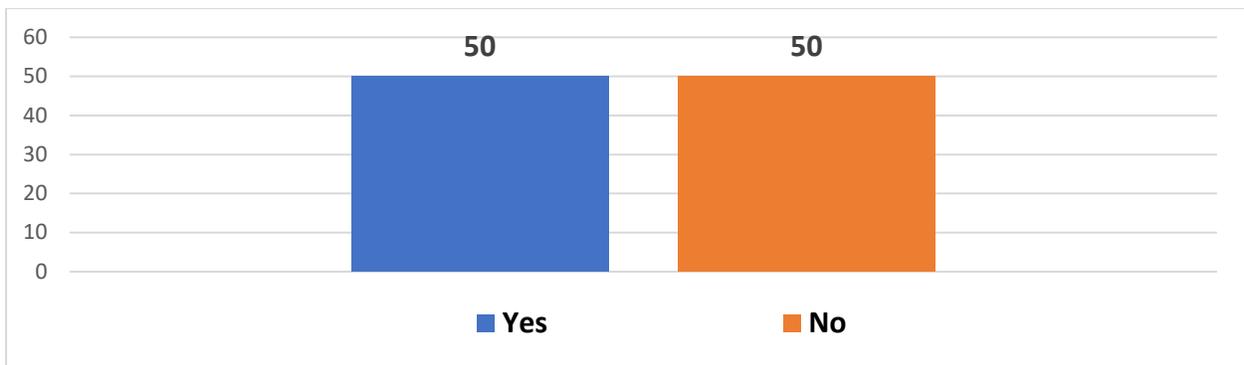


Figure 7. Percentage of Respondents Maintaining A Safe Distance from Direct Care Worker (N = 452)

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. Forty-one percent were not receiving regular care. Among respondents who needed regular health care, 56% reported access had been disrupted and 44% reported that access had not been affected (see Figure 8).

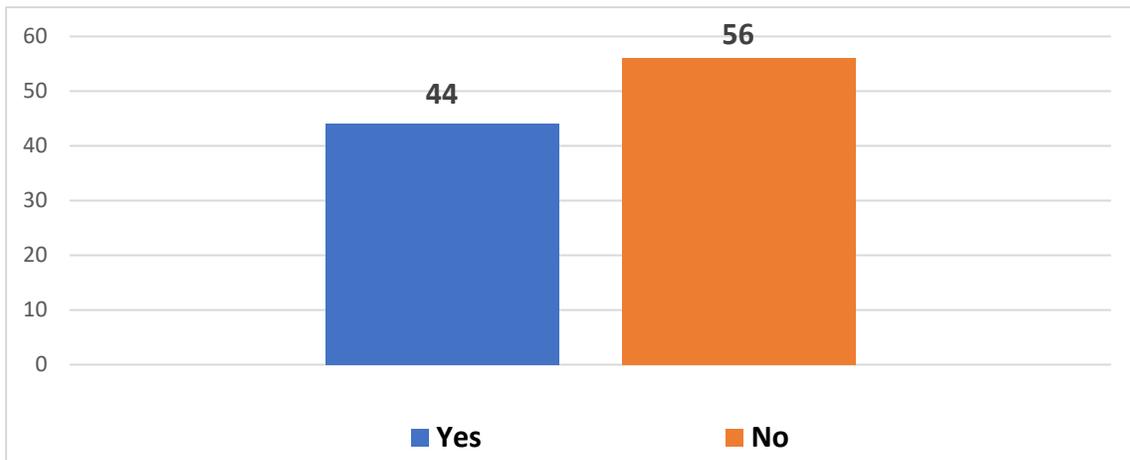


Figure 8. Percentage of Respondents Able to Access Regular Health Care (N = 269)

Access to Prescription Medications

Respondents were asked if they were able to obtain prescription medications during the COVID-19 outbreak. Among respondents taking prescriptions, 98% reported that access had not been affected and 2% reported access had been disrupted (see Figure 9).

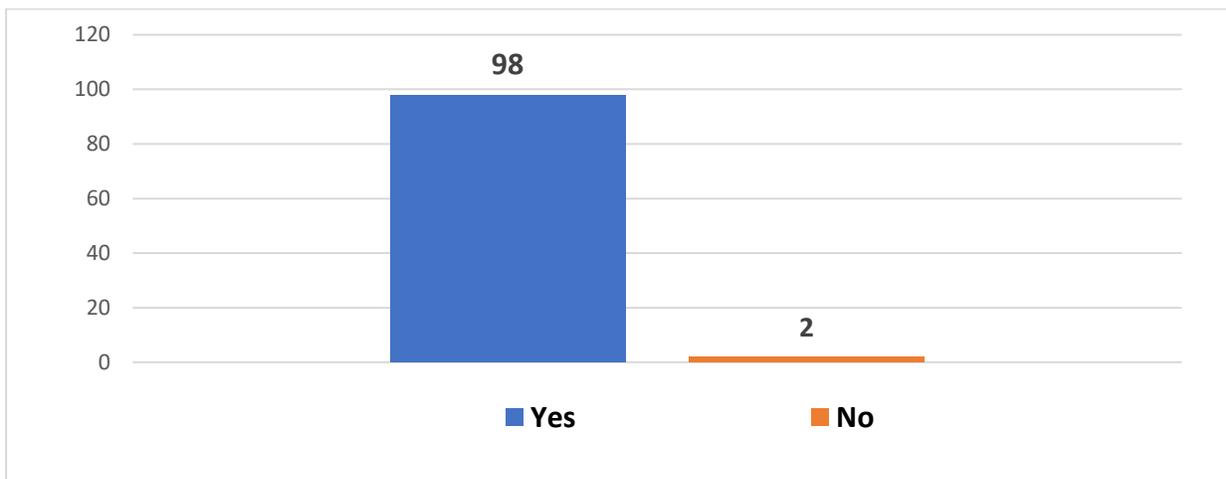


Figure 9. Percentage of Respondents Able to Access Prescriptions (N = 706)

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. 38% percent of respondents reported experiencing new challenges, while 62% reported that they had not experienced new challenges (See Figure 10).

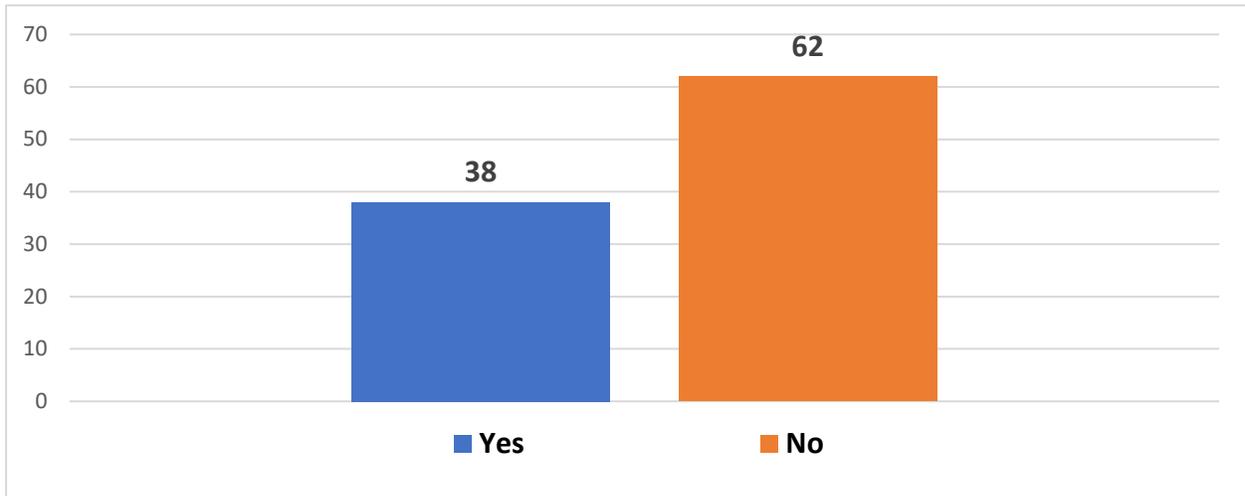


Figure 10. Percentage of Respondents Experiencing New Challenges to Accessing Health Care (N = 813)

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, 32% of respondents identified the most important source as Relatives, followed by the Television (29%), and Internet (15%). HCP/HS was at 14%, other was at 5%, Social Media at 3%, followed by Print Media (2%), Friends (1%), and Radio (0%).

Most respondents identified the Television (27%), Internet (20%), and Relatives (14%) as the second-most important sources of information, followed by Health Care Providers

(10%). Other second-most important sources of information were Social Media (10%), Friends (6%), Other (5%), and Radio and Print Media (both at 4%).

Most respondents identified Television (15%) as the third-most important source of information, followed by Friends, Relatives, and Social Media (13%), and the Internet and Health Care Providers (12%). Other sources endorsed as the third-most important source of information, included Print Media and Other (8%), and Radio (6%).

Table 3. Most Important Sources of COVID-19 Information (N=849)

	HCP/HS	Internet	TV	Radio	Social Media	Print Media	Friends	Relatives	Other
Most Important	14%	15%	29%	0%	3%	2%	1%	32%	5%
Second Most Important	10%	20%	27%	4%	10%	4%	6%	14%	5%
Third Most Important	12%	12%	15%	6%	13%	8%	13%	13%	8%

Following COVID-19 Recommendations

Respondents reported high levels of compliance with COVID-19 public health recommendations. As shown in Figure 12, 93% of respondents reported following recommendations and 7% reported they were not following recommendations.

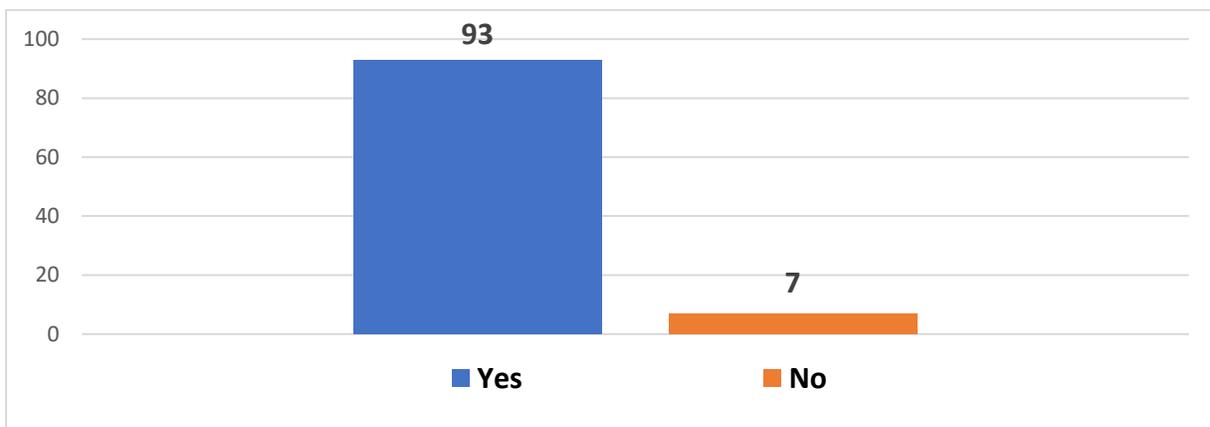


Figure 11. Percentage of Respondents Following COVID-19 Recommendations (N=840)

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 12, 2% of respondents had received a test for COVID-19 and 98% had not received testing. Among respondents that had been tested, 56% reported the test had been covered by insurance, 13% reported it had not, and 31% were not sure if the test was covered (see Figure 13).

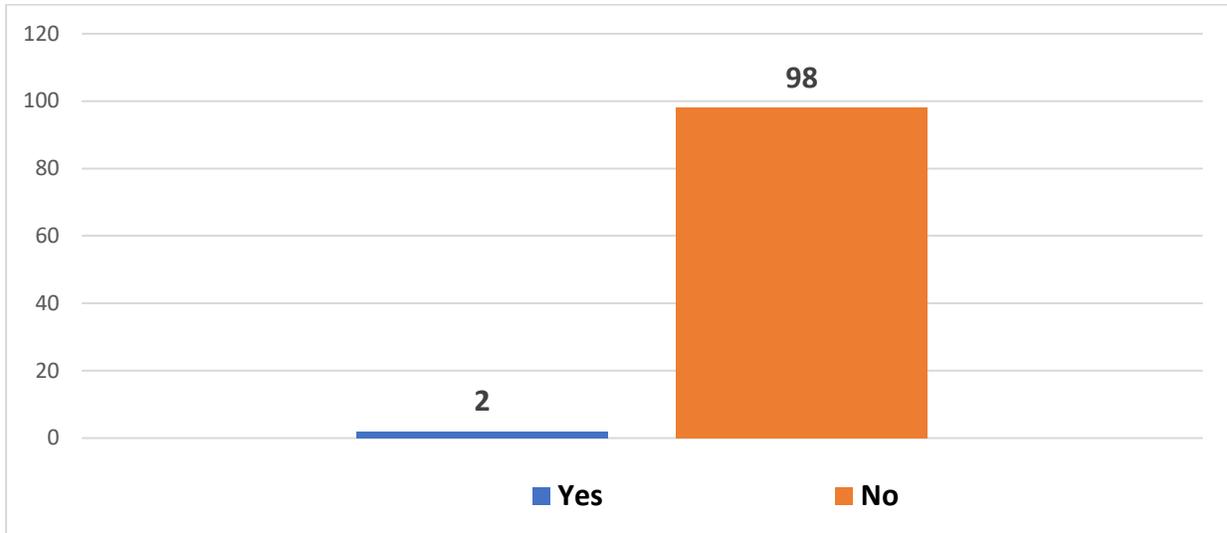


Figure 12. Percentage of Respondents Receiving COVID-19 Testing (N = 836)

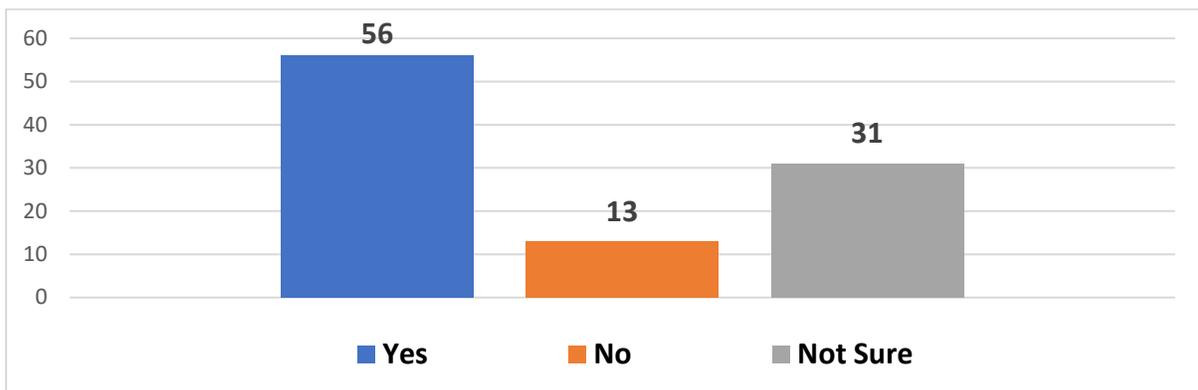


Figure 13. Percentage of COVID-19 Test Takers Covered by Insurance (N=16)

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 (84%). Among respondents who did need a test, reasons for not receiving the test included the test was unavailable (13%), followed by Other (4%), Health Care Provider would not approve the test (4%), lacking

transportation to the test site (2%), cost or concern that insurance wouldn't provide coverage (2%), information about testing was not accessible or available in alternate formats (2%), the testing site was physically inaccessible (1%), site did not have sign language interpreters (0%), and the site lacked accessible parking (0%). Respondents were able to identify multiple reasons.

Table 4. Reasons for Not Obtaining COVID-19 Test (N = 815)

Reason	Percentage
Didn't Need Test	84%
Test Was Unavailable	13%
Other	4%
Health Care Provider Would Not Approve Testing	4%
Lacked Transportation to Site	2%
Cost/Insurance Wouldn't Cover	2%
Information About Testing Not in Accessible Formats	2%
Site Was Physically Inaccessible	1%
Site Had No Accessible Parking	0%
Site Had No Sign Language Interpreters	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-four percent of respondents were not feeling anxiety or depression. As displayed in Figure 14, among respondents feeling anxiety or depression, 80% reported having access to emotional support or services and 20% reported not having access.

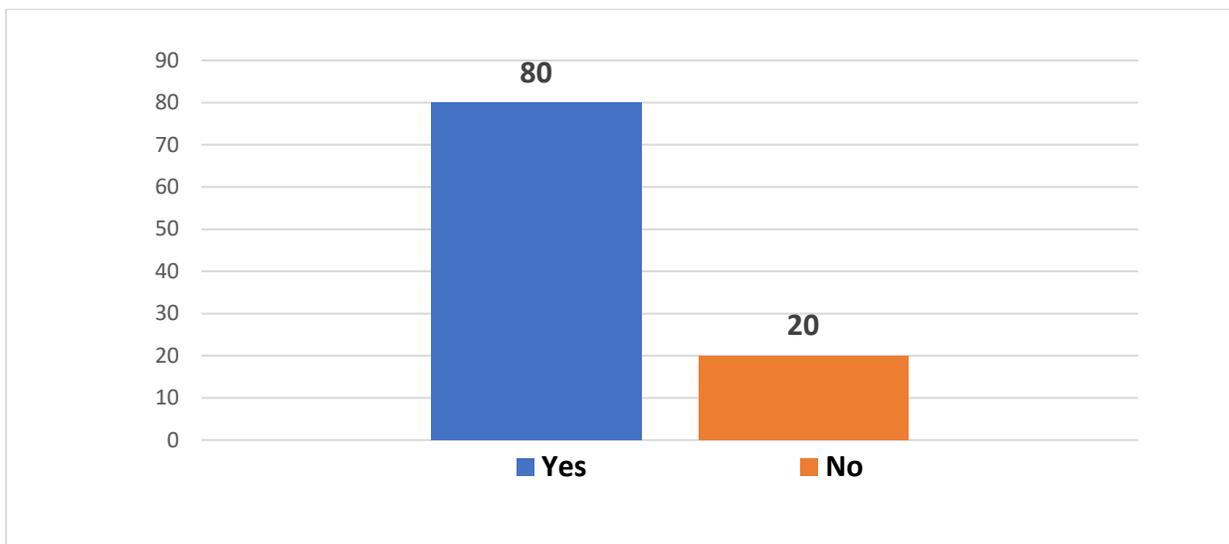


Figure 14. Percentage of Respondents with Access to Emotional Support/Services (N = 436)

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 for planning purposes (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 overall sample includes a higher than typical proportion of persons with Intellectual Disability, Autism, Epilepsy, or Brain Injury (as the underlying condition contributing to difficulty concentrating, remembering, or making decisions, is younger, majority male, White, and Suburban (57%), and has some type of insurance.

Access to Regular Health Care & Services

A high proportion of the sample used Direct Care Worker services (72%), particularly considering that 80% of the adult sample were 18-44 and 18% of the adult sample were 45-64. While a majority of respondents (76%) continued to receive these services during the pandemic, nearly one-quarter of the sample (24%) had lost critical care services. For the fortunate respondents maintaining their Direct Care Worker services, maintaining safe distances was impossible for half of the sample (50%).

A high proportion of the sample used Direct Care Worker services (72%). While a majority of respondents (76%) continued to receive these services during the pandemic, the loss of these services among 24% of the sample could contribute to major care issues. Moreover, the lack of safe distancing among 50% of respondents receiving Direct Care Work services could increase pandemic infection rates. Strategies for developing safeguarding information for both the sample and their care providers is needed.

Of concern is that 55% of respondents who were scheduled to receive regular health care treatment services had those services disrupted during the coronavirus pandemic. In contrast, 98% of respondents taking medications reported that they could access their prescriptions. Yet, for the 2% 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 (Krahn et al., 2015). Of considerable concern is that 38% 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. Relatives were an important information source whether as the most important, second-most important or third-most important source, as well as Television and, to a lesser extent, the Internet. This suggests an important role for parents and families in communicating pandemic information about the pandemic and how public health and health care professionals need to be represented on television in order to provide credible information on how to respond to the pandemic.

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 93%. This suggests that this sample is taking the risks of the coronavirus pandemic very seriously. Echoing national findings, only a small percentage (2%) 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 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. These may become more acute issues (at least for this sample) as the impact of the pandemic continues over time.

Similarly, 66% of respondents were experiencing anxiety or depression as a result of the pandemic and 20% lacked access to emotional supports/services. Emotional issues could grow among respondents over time as the pandemic continues and lack of services/supports make these problems more acute.

Limitations

The findings in this report are subject to at least six 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 (88% - 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.

E. Conclusion

The results of this survey provide insights into a moment in time during the coronavirus pandemic. The challenges revealed for this sample need to be examined with population-based research, and tracked over time. Moreover, the intricacies and changing dynamics of the pandemic establish a critical need for policy and programmatic responses to this extraordinary health and public health challenge.

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