COVID-19 and disability services in Upstate New York: A survey of disability organizations
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Introduction/purpose
People with disability, who represent 1 in 4 adults in the U.S., experience a number of health disparities. These disparities have been exacerbated by the recent SARS-CoV-2 pandemic (COVID-19). Individuals with disability may rely on services from organizations for support, and anecdotal evidence suggests that these services have been impacted by COVID-19. The purpose of this study was to understand changes in service provision in a number of categories, organizational priorities related to COVID-19, and the information needs of disability organizations in New York State. We hypothesized that disability services would have decreased and that more services would be offered remotely during COVID-19 compared to prior to COVID-19.

Methods
We conducted a survey of disability organizations, contacting individuals at those organizations via phone, email, and listserv. The survey was developed by the research team and included questions about services offered prior to COVID-19 versus during COVID-19, as well as questions about additional precautions, health information, and organizational priorities. Disability services assessed in the survey included advocacy, caregiver, education, emergency/crisis services, health promotion programming, mental health, and recreational services, among others. Additional precautions included social distancing, use of masks, use of other PPE (face shields, gowns, gloves), reduced hours, reduced staff density, reduced group sizes, increased sanitizing of space/equipment, temperature screenings, other (please specify). The survey was conducted from August to December 2020. Descriptive analyses and paired sample t-test were conducted to compare service provision prior to and during COVID-19.

Results
Fifty-three respondents completed the survey from twenty-two counties in New York State. Organizations represented were of varied size and served a broad range of populations. The majority of organizations indicated that staff and clients had been impacted by COVID-19 positive cases. Overall, there significantly were fewer disability services offered during COVID-19 compared to prior to COVID-19. In addition, there was a significant change to remote disability services during COVID-19. Several disability services were no longer offered by organizations during COVID-19 that had been offered previously, while at the same time some services were initiated by organizations during the pandemic. Many respondents from disability organizations reported use of additional precautions. Disability organizations accessed information and COVID-19 related information from sources including National Center on Health, Physical Activity and Disability (NCHPAD), New York State Department of Health (NYSDOH), and Centers for Disease Control and Prevention (CDC). Almost all of the respondents reported sending COVID-19 health and wellness resources to their consumers and/or stakeholders.

Discussion/Conclusions
As hypothesized, disability services decreased during COVID-19, and more services were offered remotely. The resulting impact of this change on health disparities experienced by people with
disability is not yet clear, and these results represent a starting point for understanding that impact. In addition, the finding that some services were no longer offered, while others were initiated, warrants further investigation. Further research on this topic utilizing clear definitions and investigating the changes in specific services would be valuable, especially related to the effect on people with disability in rural areas and other instances where alternatives might not be available.

Introduction

More than 1 billion people globally, and 61 million individuals the United States (US) live with a disability (Okoro et al. 2018). This minority group that makes up 1 in 4 adults in the United State includes individuals whose disability is related to their mobility, cognition, independent living, hearing, vision, and self-care (Okoro et al. 2018). Comparatively, people with disability experience an excess burden of disease and have also been shown to have lower health status than that of the general United States population (Reichard, Stolzle, and Fox 2011). One in three adults with disability “do not have a healthcare provider” or “have an unmet healthcare need because of cost in the past year,” while one in four “did not have a routine check-up in the past year” (Okoro et al. 2018). Further, people with disability are more likely to be diagnosed with obesity, heart disease, and type II diabetes (Okoro et al. 2018; Emerson et al. 2011). However, despite these pervasive health disparities, people with disability have been largely unrecognized as a population deserving of public health attention. These differences in health status are associated with various individual, social, and systemic factors (Rowland et al. 2014). Individual factors consist of disability, gender, and/or race/ethnicity, while social factors include educational status, occupation, and other indicators or social class and systemic factors include access to a usual source of healthcare. These individual, social, and systemic factors play a role in the health of all people, but people with disability experience the effects of such factors on a larger scale relative to non-disabled individuals (Rowland et al 2014).

Recognition of People with Disability in Emergency Preparedness Efforts

People with disability may be more vulnerable in emergency situations when compared to non-disabled individuals (Krahn, Klein Walker, and Correa-De-Araujo 2015) suggesting that this population is deserving of greater consideration for emergency preparedness planning. However, people with disability are not often given this additional consideration and often face inadequate health surveillance in times of crisis (Scott D. Landes et al. 2020). Further, planning and response systems are deficient in certain parts of the United States and details about how emergency responders can meet the needs of this population during times of crisis is often overlooked when curating guidelines (Campbell et al. 2009). Notably, many jurisdictions underestimate the required amount of planning and coordination to adequately accommodate individuals with disabilities in emergent situations (Campbell et al. 2009). Because people with disability may live in long term care facilities or group homes, and may also have paid direct support staff who assist with activities of daily living, they also experience increased risk of exposure to communicable disease (Campbell et al. 2009).

Disproportionate Impact of COVID-19 among People with Disability The current SARS-CoV-2 pandemic (COVID-19) has disproportionately impacted people with disability and
exacerbated existing disparities. Although research about the impact of COVID-19 on people with disability is limited, studies have begun to investigate this minority group during the pandemic (Kamalakannan et al. 2021; Scott D. Landes et al. 2020; S. Landes et al. 2020; Turk et al. 2020; Chakraborthy 2021; Morrow, Patel, and Duff 2021; Mills et al. 2020; Espinosa 2020; Jeste et al. 2020; Neece, McIntyre, and Fenning 2020; Wolstencroft et al. 2021). Researchers have begun calling for increased attention to the impact of COVID-19 on people with disability (Sabatello, Landes, and McDonald 2020; Turk and McDermott 2020; Lebrasseur et al. 2021).

Initial studies have shown that people with intellectual and developmental disability (IDD) were more likely to die from COVID-19 (Scott D. Landes et al. 2020; Mills et al. 2020). As a result of increased rates of chronic disease, people with disability may be at increased risk of associated severe outcomes from COVID-19 (Okoro et al. 2018). People with disability whose immune function is decreased may also experience increased risk of COVID-19, including individuals with Down syndrome (Espinosa 2020), Autism Spectrum Disorder (ASD) (Pangrazzi, Balasco, and Bozzi 2020; Al-Beltagi 2021), and some genomic conditions that may have underlying immune problems. Individuals in long term care and group homes also experienced increased rates of COVID-19 compared to the general population (Scott D. Landes et al. 2020).

Access to COVID-19 Vaccines

In addition to these disparities, there have also been disparities for people with disability in access to COVID-19 vaccines. The initial recommendations in the United States for prioritizing and allocating vaccines did not include people with disability. Among people with disability excluded from these recommendations are individuals who report many of the high risk pre-existing conditions described by Centers for Disease Control and Prevention (CDC), those living in congregate settings such as group homes, or those who require support for higher personal or medical care needs (often involving close personal contact) (Hotez et al. 2021). A National Academies of Science, Engineering, and Medicine committee was convened and developed a framework for equitable vaccine allocation in the United States (NASEM) (National Academies of Sciences et al. 2020). These recommendations allowed for people of all ages with comorbid or underlying health conditions putting them at high risk (many people with a variety of disability conditions reported many of the high-risk conditions) to be vaccinated in the second wave of Phase 1, and people with disabilities living in group homes were named as a priority in Phase 2. Included in Phase 2 were staff support who worked in congregate settings. Not all states followed these recommendations, in particular including direct support professionals in the vaccination prioritization (Turk and Landes 2021). Despite prioritizing people with disability, issues were reported related to accessible communication, physical or environmental accessibility, and social and sensory environment accessibility (Rotenberg et al. 2021).

Health information and health literacy play an important role in health, and have been identified by the National Prevention Strategy as a priority for addressing health disparities (“National Prevention Strategy: America’s Plan For Better Health and Wellness” 2011). Health information for people with disability in general is not always readily available (Goss et al. 2019), which may be an issue for health information related to COVID-19 for that audience as well. Furthermore, misinformation related to COVID-19 has become a significant issue (Islam et al. 2020), and has the potential to contribute to health disparities related to
COVID-19. Accessibility of COVID-19 resource pages is also of concern, with existing reports of limited web accessibility of vaccine registration websites in the United States (Alismail and Chipidza 2021).

Support Services for People with Disability

While health differences and disparities have been exacerbated or introduced by the COVID-19 pandemic for people with disability, this group may be further disproportionately impacted by a potential disruption to support services. Various organizations offer services for people with disability, including day programs, group homes, mental health facilities, varied medical services, and others. Anecdotal evidence indicates that services offered by these organizations have been directly impacted by COVID-19, including in New York State specifically, ("First Out, Last Back: The Economic Impact of the COVID Crisis on New Yorkers With Disabilities | Center for an Urban Future (CUF)" n.d.) and have a systemic effect on people with disability (“People With Disabilities Find Coronavirus Has Cut Them Off From Their Caregivers” 2020; “Caregivers Brace For The Spread Of Coronavirus : NPR” n.d.; Ma et al. 2015; “Independent Living Centers Call For Full Funding | CTNewsJunkie” n.d.). New York State policy implemented to maintain a safe environment during the pandemic has also required additional cost to provide services – including cost of equipment to provide remote services, cost of PPE, and requirements for decreased indoor capacity for employees (Cuomo 2020). Following this anecdotal evidence, a number of qualitative studies and surveys have investigated the experiences of people with disability with disability during COVID-19, and have identified changes in service provision (Jeste et al. 2020; Schwartz et al. 2021). Several studies examining experiences of children with IDD and other disabilities have noted the decrease of services and changes to remote provision of services (Neece, McIntyre, and Fenning 2020; Wolstencroft et al. 2021). There have not been studies of changes in disability services specific to New York State, though there have been studies of people with IDD that included data from New York State (Turk et al. 2020; Scott D. Landes et al. 2020; S. Landes et al. 2020; S. D. Landes, Stevens, and Turk 2021).

Goals of the Current Study

The purpose of this survey was to understand changes in service provision in a number of categories, organizational priorities related to COVID-19, and the information needs of New York State disability organizations. A secondary aim of this study was to gather initial data on the disability organizations’ interactions with health information and health information related to COVID-19. This aim was developed in collaboration with the New York State Disability and Health Program, and specific questions related to health information were added.

We hypothesized that there would be an overall decrease in services available during COVID-19, and that, if offered, more services would be provided remotely and/or with additional precautions.

Methods

Sampling Strategy

Initially we employed a sampling strategy using only a modified snowball sample (respondents are asked to refer additional participants) via phone contact. However, after difficulty contacting disability organizations via phone, the sampling strategy was revised to include email and was expanded in partnership with the New York State Disability and Health
Program. This expansion included sending the survey to the Disability and Health Program email listserv, which includes both individuals from disability service organizations and other stakeholders who do not provide disability services. At this time, the study was also expanded to include disability organizations in New York State rather than only Onondaga county. Data collection began for Onondaga County in August 2020 and was expanded to all of New York State in October 2020. Data collection ended in December 2020.

**Survey Design**

The survey was comprised of three sections, organizational information, Prior to COVID-19, and During COVID-19 (complete list of survey items available on request). The survey began with a consent, and directions for the survey including that the intended audience was individuals at organizations providing disability services. This project was deemed exempt by the SUNY Upstate Medical University IRB.

**Organizational Information**

The organizational information section included questions about the city, county, and zip code of the organization, counties served, number of employees and the type of medical staff employed by the organization. Other demographic information included number of clients served, the types of disability served, and age range of clients. Also in this section were questions about information seeking, including “Which of the following methods does your organization utilize to receive information about recent research?” (only data related to accessing information question reported here).

**Prior to COVID-19**

In this section, representatives of disability organizations were asked to consider the organization before COVID-19. Respondents were asked to select if services were offered in person, remote or not applicable (N/A). The services listed were advocacy, assistive equipment/technology/devices, caregiver (education/training, respite), education (early childhood, special education, etc.), emergency/crisis services, employment/job skills, financial/legal planning, food assistance, health promotion programing, home/general assistance in the home (non-medical), mental health/counseling services, nursing (home nursing, center based), recreational, and other (please specify).

**During COVID-19**

In this section, representatives of disability organizations were asked to consider the organization during COVID-19. The same services were listed, however, in addition to in person, remote and not applicable, respondents could also select with additional precautions/new guidelines and no longer offered. If respondents selected with additional precautions/new guidelines for any service, then an additional question appeared asking which precautions were implemented. The precautions included social distancing, use of masks, use of other PPE (face shields, gowns, gloves), reduced hours, reduced staff density, reduced group sizes, increased sanitizing of space/equipment, temperature screenings, other (please specify).

Qualitative questions included describing creative solutions found to continue providing services, describing which of the changes during COVID-19 has had the greatest impact on clients, and an opportunity for open-ended comments (data not reported here).
Some additional questions were included in the During COVID-19 section to assess information and other changes during COVID-19. Questions about information in this section included sources for reliable information about COVID-19 and people with disability, COVID-19 topics where information was limited, and how organizations had sent health and wellness resources related to COVID-19 to consumers and/or stakeholders. Respondents were also asked if staff or clients at their organization had been directly impacted by COVID-19 positive cases.

**Survey Operationalization**

At the time of survey development, survey items specific to organizational concerns during COVID-19 had not previously been published. Thus, survey items were developed based on the authors’ experience. Questions asking respondent to rank organizational priorities were included in the Prior to and During COVID-19 sections (data are not reported here). In addition, the original list of services also included housing and group home or other residential provisions (data not reported here).

Each respondent from a disability organization is represented by a single survey response. For brevity, the term “organization” is used throughout the manuscript to indicate “a respondent from a disability organization.”

For the purpose of clear data reporting, health information questions from the Prior to COVID-19 section and sources of information about COVID-19 and people with disability were reported using the original categories - National Center on Health, Physical Activity and Disability (NCHPAD), New York State Department of Health (NYSDOH), and Centers for Disease Control and Prevention (CDC) – as well as a combined “other” category. The other category included DRDC (Disability Research and Dissemination Center), Research publication database (PubMed, Google Scholar, etc.), Search Engine (i.e., Google, Bing, Yahoo), Email listserv, and other for general access to information. Meanwhile, included in the combined other for the sources for reliable information about COVID-19 and people with disability question, in the During COVID-19 section were Association for Community Living (ACL), Office for People with Developmental Disabilities (OPWDD), ADA National Network, Association of University Centers of Disability (AUCD), and other were included in this combined other for the sources for reliable information about COVID-19 and people with disability question.

**Data Analysis**

Frequencies and other descriptive analyses were completed using Microsoft Excel, and location data visualization was completed using ArcGIS ArcMap version 10.7.1. Paired samples t-tests were completed using JASP version 0.11.1 2019; a significance level of α=0.05 was used.

**Results**

Fifty-three responses were complete and are included in the study (N=42 for all questions, N=11 from the initial sample without all of the health information questions). The completion rate was 29% (53 complete responses, out of 181 opened surveys), while the response rate was 17% (53 complete responses out of 309 emails sent). Respondents were from thirty-eight (38) zip codes in twenty-two (22) counties in New York State, none of which were in New York City (Figure 1). The most common county was Onondaga County in Central New York, with forty percent of responses (N=21).
Sixty-two percent of respondents indicated that the staff at their organization had been directly impacted by COVID-19 positive cases (62%, N= 33), while seventy-two percent indicated that clients had been directly impacted by COVID-19 positive cases (72%, N= 38). Age ranges served, disability types served, and other organizational information is described in Table 1.

Overall, there were fewer services offered during COVID-19 compared to prior to COVID-19 (Figure 2; t = 3.323, p=.006). This overall decrease was also observed in nine of the service categories. The other four included advocacy, which increased by one report, and assistive equipment, financial/legal planning, and nursing, all three of which were the same prior to and during COVID-19 (Figure 2). In addition, services overall shifted to remote (t =-3.213, p = .007) rather than in person (Figure 3; t =4.532, p <.001).

Notably, many organizations stopped offering previously available services during COVID-19. The services that were most frequently no longer offered were health promotion (13%, N=7), emergency/crisis services (11%, N=6), and recreational services (9%, N=5). At the same time, some services were initiated by organizations during COVID-19, which had not offered them prior to COVID-19. Thirty (57%, N=30) organizations initiated advocacy during COVID-19, while twenty-four (45%, N=24) organizations began caregiver related services and education during COVID-19.

For each service provided, at least four organizations (8%, N=4) reported additional precautions used (financial/legal planning and health promotion programming). The average number of organizations reporting additional precautions was seven (13%, N=7) per service. The maximum number of organizations reporting additional precautions was eleven (21%, N=11). Eleven organizations reported additional precautions for education (early childhood, special education, etc.), and employment/job skills. Ten organizations (19%, N=10) reported additional precautions for mental health/counseling services and recreational services (Table 2). The proportion of organizations who used a specific precaution out of the total number of organizations reporting that they implemented additional precautions for that service is also reported. For example, for eight of the thirteen services, one hundred percent of organization that indicated additional precautions indicated social distancing and use of masks. (Table 2).

Of the fifty-three respondents who provided information about accessing information, fifty (94%, N=50) reported the New York State Department of Health (NYSDOH), while forty-four (83%, N=44) reported accessing information from Centers for Disease Control and Prevention (CDC). Of the forty-two respondents who provided information about accessing health information related to COVID-19 and people with disability, thirty-nine (93%, N=39) accessed information from the New York State Department of Health (NYSDOH), while thirty-six (86%, N=36) reported accessing information from Centers for Disease Control and Prevention (CDC). (Figure 4)

Four (10%, N=4) individuals from disability organizations reported that there were topic areas relating to COVID-19 and people with disabilities for which they had not been able to find sufficient information. The topics listed included “socialization; personal care attendant aides”; “How to assist people who cannot tolerate wearing a mask.”; “health and safety protocol for Early Intervention and preschool service providers”; “health and safety recommendations/algorithms for EI [early intervention] and preschool services”.
Forty-two responses related to health information were analyzed. Of those, thirty-nine (93%, N=39) reported that they had sent information related to COVID-19 to their consumers and/or stakeholders. Of those thirty-nine, seventy-four percent (74%, N=31) sent health information related to COVID-19 via email, and fifty-seven percent (57%, N=24) sent information via social media. Notably, in the “other” section, eight (21%, N=8) individuals from organizations reported using traditional mail to send COVID-19 information. Terms in this category included “mail,” “us mail,” “paper mail,” “snail mail,” “mailing,” and “letters” (Figure 5).

Discussion

The findings from this survey support the anecdotal evidence that disability services were greatly impacted by COVID-19. As hypothesized, disability organizations offered significantly fewer services overall. In addition, the number of in-person services was significantly reduced, while the number of remote services increased. These findings may be used by disability organizations to advocate for additional funding or other resources to allow for people with disabilities to continue to have access to needed services.

The results of this survey indicate that there was not only an observable overall decrease and shift to remote services during COVID-19, but a variety of more nuanced changes in service provision by individual organizations. These changes are represented in this data, but certainly warrant further study to understand the details of these changes, their underlying causes, and if the changes have been sustained.

The changes in service provision likely exacerbated existing health disparities. It is apparent that COVID-19 has disproportionally impacted people with disability. People with disability have also had decreased access to healthcare services, which has exacerbated existing health disparities. (Drum et al. 2020) Finally, disparities experienced by people with disability were highlighted when action was needed to reiterate the civil rights of people with disability facing ableist decisions about end-of-life care related to limited resources during COVID-19. (“Health and Human Services: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)” 2020) The effect of the interaction of these many factors influencing health disparities experienced by people with disability is not yet well understood. The results of this study, among others, can be utilized to justify additional research and resources to counteract these factors.

These results give an initial assessment of the changes in service provision for people with disability in New York. Although the changes were statistically significant, they may initially appear minor. However, additional nuance shows reason for concern. For example, although no service was completely unavailable in New York State, several respondents were from organizations in relatively rural areas. Decreases in services in those areas likely had a greater impact on people with disability than decreases in more urban areas, where other organizations may still offer similar services. However, even in urban areas, organizations may not have the resources to provide services to an increased number of clients. Further investigation into service provision would be valuable in order to more fully understand the true impact of changes in service provision. Based on these findings, investigation into rural vs. urban locations, resource allocation, and other nuances of service provision would be warranted.
The pandemic also exacerbated longstanding workforce shortages in community support services, especially those frequently utilized by people with disability. Prior to COVID-19, there were low staffing levels and high use of overtime to meet the needs of people with disability. Direct care professionals in home care, group homes, and other support agencies have been challenged by limited career advancement, low wages, and limited benefits. The pandemic contributed to loss of workers with poor emergency planning including limited personal protection, access to testing, and early access to vaccines. A recent report supported by the Office of Behavioral Health, Disability, and Aging Policy (BHDAP), US Department of Health and Human Services has noted new policies and practices for future planning, in the hopes of maintaining needed supports for people with disability.

Since this survey was completed, COVID-19 vaccines have become widely available, though only 62.4% of the population in New York State is fully vaccinated with completed vaccine series (“COVID-19 Vaccine Tracker | COVID-19 Vaccine” n.d.). Barriers in access to vaccination have existed for people with disability early on, and some, such as access to transportation or scheduling, may still impact vaccination access for people with disability.

With the implementation of the COVID-19 vaccine, there was optimism that the changes in access to services, such as those that are supported by this study, may be resolved. However, given low vaccination rates and the increased incidence of the Delta variant, increases in case rates in the United States and in New York State threaten the reopening of previously limited services. Projection models indicate that this trend in COVID-19 cases may continue (“COVID-19” n.d.) This context makes the need for additional research on access to services for people with disability even more pressing.

As with all studies conducted in 2020, this study was designed and executed in a rapidly evolving environment with changing uncertainty, as well as fluctuations in prevalence of COVID-19 cases. These changes may have impacted responses to the survey, and continued changes, especially related to vaccination, is an important area for further study. Although the response rate was acceptable for analysis and interpretation in this study, additional responses could have provided valuable information.

The questions in the survey provided general service categories. Although some definitions were provided, it is likely that organizations used some subjective interpretation when answering these questions. For example, health promotion programming was not clearly defined in the survey. Questions related to housing and group home, or other residential provisions were removed from data analysis after determining that the distinction was not clear enough to draw conclusions based on responses. Future surveys might consider adding questions for respondents to indicate which services they provide specifically, in addition to these more general categories.

There were a number of respondents who indicated that they were in person rather than with additional precautions in the During COVID-19 section. It is possible that the distinction between these two categories was not clear, although this may not be the case (at least one respondent used “with additional precautions” and “in person” for different services). It is also possible that some organizations were already using precautions such as wearing a mask, and therefore these precautions were not new. Organizations may also have continued to provide services without precautions – this might be appropriate despite New York State policy at the time indicating that additional precautions were necessary. For example, in group
living situations where staff live in the same house as people with disability and therefore could be considered a single household. A follow up study could investigate this phenomenon further to better understand if it is an unintended effect of the survey format or a true reflection of service provision.

When considering additional precautions reported (Table 2), it is notable that some precautions were utilized more consistently across organizations than others. For example, for eight of the thirteen services, one hundred percent of organization that indicated additional precautions indicated social use of masks. This demonstrates that social distancing and use of masks were used more consistently across organizations offering services with additional precautions. Although a lower percent of organizations reported reduced hours, reduced staff density, and reduced groups sizes, compared to social distancing, use of masks, and use of other PPE (face shields, gowns, gloves), these were still reported by several organizations.

The importance of the additional precautions implemented is nuanced. Earlier in this discussion, we address the issue of varied access to services. An additional layer to that is the limiting of services due to additional precautions. Several of the categories of additional precaution – specifically reduced hours, reduced staff density, and reduced groups sizes – represent an additional reduction in services. Due to the nature of this survey, we were not able to quantify the magnitude of this reduction. However, given the reduction in services offered, the addition of limited space, group size and hours may have exacerbated the change in the availability of services for people with disability. Future research to assess the impact of both the reduction in availability of services and changes in access to services related to the implementation of necessary precautions would be a valuable follow-up to this survey.

Health information seeking among people with disability is not well understood (French-Lawyer et al. n.d.), and therefore supplementing health information seeking by distributing accurate health information from likely trustworthy sources is an important service provided by disability organizations. More far-reaching distribution of credible information about COVID-19 related to people with disability may also help to address the sense that there is only minimal available information or that it is hard to find (Goss et al. 2019). This sense has likely been exacerbated by the changing information currently available about COVID-19 generally, and that the easily accessed COVID-19 information is more general and not specific to people with disability (“COVID-19: People with Disabilities | CDC” 2020). That being said, it appears that disability organizations report similar sources for information when asked about information in general and when asked about reliable information about COVID-19 and people with disability. Furthermore, sending out this type of information could be a way to counteract the extensive misinformation about COVID-19 that is available on the internet and via social media.

There is previous evidence that reliable health information specific to people with disability is not always easy to find (Goss et al. 2019), and anecdotal evidence indicating that information related to COVID-19 and people with disability may not exist, let alone be available. However, in our study only ten percent of individuals from disability organizations reported topic areas relating to COVID-19 and people with disabilities for which they had not been able to find sufficient information. This is a surprising result and may warrant additional study. It may be that the lack of COVID-19 information overall at the time of the survey (August 2020 – December 2020) influenced this response.
Some strengths of this study were the sample size of fifty-three complete responses, and the spread of respondent locations throughout Upstate New York. The survey format allowed for insight into the changes in services offered as a result of COVID-19, including the unexpected initiation of some in person and remote services. At this time, there have been a few COVID-related studies specific to disability service organizations nationally; (Schwartz et al. 2021; Kennedy et al. 2020) however, this survey specific to New York State provides a unique perspective on the provision of services. The extent to which this perspective can be used to infer the impact on or experience of people with disability would be an interesting area for future study.

Despite its strengths, this study also had a number of limitations. Our initial sampling strategy had a strong focus on Onondaga County and Central New York, seemingly resulting in an over-representation in respondents from those areas, where there were generally lower rates of COVID-19 cases than other areas in New York State. (“Workbook: NYS-COVID19-Tracker” n.d.) Also, the original recruitment involved phone contact to the organizations, with few successful responses. The recruitment was changed to direct email without phone contact. There were few additional contacts suggested by those contacted, limiting the potential for snowball sampling. Additionally, though NYC organizations were considered in the sampling strategy, no organizations located in NYC participated in this study. Future research may look to assess differences between service changes in rural and urban locations. Questions about health promotion and additional questions about health information were added after eleven respondents from the initial sampling of Onondaga county completed the survey, resulting in a different total sample size for those questions. All modifications were approved by the SUNY Upstate Medical University IRB. Another limitation relates to email-only contacts. While the intention was that only one individual from an organization should respond, due to the use of anonymous surveys, it is unclear if this was the case. More than one respondent from an organization would primarily impact the response rate calculations and could lead to some duplicate data. Lastly, recall bias may have had an impact on the responses to the survey for the Prior to COVID-19 section.

Conclusion

People with disability experience meaningful disparities in healthcare that have been highlighted and compounded as a result of the SARS-CoV-2 pandemic (COVID-19). This study provides valuable initial data about how disability service provision has changed in New York State as a result of COVID-19. Service provision has decreased overall, with significantly more services are being offered remotely. This change may have meaningful implications for the availability of disability services in New York State, and further exacerbate negative outcomes and experiences of people with disability as a result of the COVID-19 pandemic. Use of COVID-19 related precautions that reduce services may also have impacted service availability. Disability organizations also accessed information from reputable sources, and the vast majority distributed COVID-19 related health information. Additional research would provide important insight into the impact of these changes on people with disability, specifically how health disparities have been exacerbated as a result of COVID-19.
Figure 1 Map of Respondent County and Zip Code
Figure 2 Overall Change in Services
Figure 3 Services Provided Prior vs. During COVID-19
Figure 4 Access Information and Reliable Information about COVID-19 and PWD

Figure 5 Sent health and wellness resources related to COVID-19
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<tr>
<td>31 - 40</td>
<td>10(5)</td>
</tr>
<tr>
<td>41 - 50</td>
<td>8(4)</td>
</tr>
<tr>
<td>50+</td>
<td>40(21)</td>
</tr>
<tr>
<td><strong>Number of clients</strong></td>
<td></td>
</tr>
<tr>
<td>0 - 19</td>
<td>6(3)</td>
</tr>
<tr>
<td>20 - 39</td>
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</tr>
<tr>
<td>40 - 59</td>
<td>0(0)</td>
</tr>
<tr>
<td>60 - 79</td>
<td>6(3)</td>
</tr>
<tr>
<td>80 - 99</td>
<td>9(5)</td>
</tr>
<tr>
<td>100+</td>
<td>74(39)</td>
</tr>
<tr>
<td><strong>Medical staff</strong></td>
<td></td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>47(25)</td>
</tr>
<tr>
<td>Medical Doctor/Doctor of Osteopathic Medicine</td>
<td>17(9)</td>
</tr>
<tr>
<td>Licensed Practical Nurse</td>
<td>21(11)</td>
</tr>
<tr>
<td>Certified Nursing Assistant</td>
<td>2(1)</td>
</tr>
<tr>
<td>Medical Assistant</td>
<td>2(1)</td>
</tr>
<tr>
<td>Mental Health Provider</td>
<td>15(8)</td>
</tr>
<tr>
<td>PT/OT/ST/Recreation</td>
<td>38(20)</td>
</tr>
<tr>
<td>No medical providers on staff</td>
<td>36(19)</td>
</tr>
<tr>
<td>Total N = 53</td>
<td></td>
</tr>
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*Other included: all/any types of disabilities (3), LD, ADHD, ASD, Chronic health conditions, communication, mental health (4)
Table 2 Precautions N (%)

<table>
<thead>
<tr>
<th>Service</th>
<th>Total N reporting precautions</th>
<th>Social distancing</th>
<th>Use of masks</th>
<th>Use of other PPE (face shields, gowns, gloves)</th>
<th>Increased sanitizing of space/equipment</th>
<th>Temperature screenings</th>
<th>Reduced hours</th>
<th>Reduced staff density</th>
<th>Reduced group sizes</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recreational</td>
<td>10</td>
<td>10(100)</td>
<td>10(100)</td>
<td>5(50)</td>
<td>8(80)</td>
<td>9(90)</td>
<td>5(50)</td>
<td>6(60)</td>
<td>8(80)</td>
<td>3(30)</td>
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<tr>
<td>Nursing (home nursing, center based)</td>
<td>5</td>
<td>3(60)</td>
<td>5(100)</td>
<td>5(100)</td>
<td>5(100)</td>
<td>1(20)</td>
<td>2(40)</td>
<td>3(60)</td>
<td>1(20)</td>
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</tr>
<tr>
<td>Mental health/counseling services</td>
<td>10</td>
<td>9(90)</td>
<td>9(90)</td>
<td>6(60)</td>
<td>7(70)</td>
<td>7(70)</td>
<td>1(10)</td>
<td>6(60)</td>
<td>4(40)</td>
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<tr>
<td>Housing</td>
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<td>4(80)</td>
<td>5(100)</td>
<td>2(40)</td>
<td>0(0)</td>
<td>4(80)</td>
<td>2(40)</td>
<td>0(0)</td>
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<tr>
<td>Health promotion programming</td>
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<td>4(100)</td>
<td>2(50)</td>
<td>2(50)</td>
<td>3(75)</td>
<td>1(25)</td>
<td>2(50)</td>
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<tr>
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<td>4(80)</td>
<td>2(40)</td>
<td>3(60)</td>
<td>3(60)</td>
<td>1(20)</td>
<td>2(40)</td>
<td>2(40)</td>
<td>1(20)</td>
</tr>
<tr>
<td>Financial/legal planning</td>
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<td>4(100)</td>
<td>4(100)</td>
<td>4(100)</td>
<td>4(100)</td>
<td>3(75)</td>
<td>2(50)</td>
<td>2(50)</td>
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<td>0(0)</td>
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<tr>
<td>Employment/job skills</td>
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<td>10(91)</td>
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<td>8(73)</td>
<td>5(45)</td>
<td>9(82)</td>
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<td>1(9)</td>
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<td>7(100)</td>
<td>5(71)</td>
<td>7(100)</td>
<td>5(71)</td>
<td>1(14)</td>
<td>4(57)</td>
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<tr>
<td>Education (early childhood, special education, etc.)</td>
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<td>11(100)</td>
<td>11(100)</td>
<td>8(73)</td>
<td>11(100)</td>
<td>7(64)</td>
<td>3(27)</td>
<td>8(73)</td>
<td>10(91)</td>
<td>2(18)</td>
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<tr>
<td>Caregiver (education/training, respite)</td>
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<td>5(100)</td>
<td>5(100)</td>
<td>5(100)</td>
<td>0(0)</td>
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<td>4(80)</td>
<td>0(0)</td>
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<td>Assistive equipment/technology/devices</td>
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<td>7(78)</td>
<td>3(33)</td>
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<td>3(43)</td>
<td>6(86)</td>
<td>5(71)</td>
<td>2(29)</td>
<td>3(43)</td>
<td>5(71)</td>
<td>1(14)</td>
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References


Acknowledgements
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