

# Annotated Bibliography: People with Disabilities and COVID-19 Project

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## Introduction

This is a comprehensive annotated bibliography list of peer reviewed journal literature and gray literature/organizational reports that contain evidence-based research and information on the impact of COVID-19 on people with disabilities.

**Objective:** Improve understanding of the overall impact of COVID-19 on people with disabilities, specifically as it relates to healthcare access and utilization and acquired comorbidities. This information will also be used to inform future Medicaid research and analysis.

**Themes:** Access to clinical and social services, social and healthcare inequities, high-risk disability groups, telehealth, health outcomes in people with disabilities, caregiver barriers, COVID-19 response, Medicaid, mental health, and COVID-19 associated conditions

**Methodology:** Literature review and environmental scan conducted through George Mason University Library Catalog, PubMed, Google Scholar, *Disability and Health Journal*, national organization reports from national organizations (e.g., National Academy of State Health Policy, World Health Organization, American Association on Health and Disability, and Kaiser Family Foundation), and relevant news articles

**Key Search Terms:** COVID, COVID-19, SARS-CoV-2, coronavirus, disability, people with disabilities, intellectual and developmental disabilities, mobility disabilities, neurological disabilities, comorbidities, mental health, behavioral health, diabetes, obesity, cardiovascular disease, asthma, Medicaid, children with special healthcare needs, Children’s Health Insurance Program (CHIP), home and community based services, telehealth/telemedicine, access to care, primary care, emergency department, emergency room, outpatient care, caregiver, and public health response.

**Limitations:** No or low publicly availability of data on: Primary/acute care and emergency department utilization rates for people with disabilities during COVID-19, COVID-19 infection and mortality rates in certain groups of people with disabilities, use of Medicaid or CHIP services for people with disabilities during COVID-19, mental health impact on people with disabilities specifically, and COVID-19 observational studies on different groups of people with disabilities.

## People with Disabilities: Health Outcomes and COVID-19

This section includes citations that reference the COVID-19 risk of infection among people with disabilities and data on existing comorbidities for people with disabilities. They also discuss predicted factors that could impact the health of people with disabilities during the COVID-19 pandemic.

1. Landes SD, Turk MA, Formica, MK, et al. “COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State.” *Disabil Health J*. Available at <https://doi.org/10.1016/j.dhjo.2020.100969>. Accessed 1-22-2021.

### Abstract

*Background:* People with intellectual and developmental disabilities (IDD) may be at higher risk of severe outcomes from COVID-19.

*Objective:* To describe COVID-19 outcomes among people with IDD living in residential group homes in the state of New York and the general population of New York state.

*Methods:* Data for people with IDD are from a coalition of organizations providing over half of the residential services for the state of New York, and from the New York State Department of Health. Analysis describes COVID-19 case rates, case-fatality, and mortality among people with IDD living in residential group homes and New York state through May 28, 2020.

*Results:* People with IDD living in residential group homes were at greater risk of severe COVID-19 outcomes: case rates—7,841 per 100,000 for people with IDD compared to 1,910 for New York state; case-fatality—15.0% for people with IDD compared to 7.9% for New York state; and mortality rate—1,175 per 100,000 for people with IDD compared to 151 per 100,000 for New York State. Differences in cases and mortality rate were confirmed across regions of the state, but case-fatality rate was only higher for people with IDD in and around the New York City region.

*Conclusions:* COVID-19 appears to present a greater risk to people with IDD, especially those living in congregate settings. A full understanding of the severity of this risk will not be possible until U.S. states begin publicly sharing all relevant data they have on COVID-19 outcomes among this population.

**Summary:** There is an increased risk of severe COVID-19 outcomes among people with IDD living in residential group homes in New York state compared to the general population.

### Key Takeaways

- There may be an increased risk of COVID-19 infection for people living in congregate care settings due to challenges with physical distancing. For example, 13% of people with IDD reside in congregate care settings with shared essential living spaces.
- COVID-19 case rates and case fatality rates were higher for people with IDD living in residential group homes and settings in New York state than the general population.
- **Recommendations:** Including disability status as a basic demographic characteristic in public health surveillance systems to properly examine outcomes.

2. Turk MA, Landes SD, Formica, MK, et al. "Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis." *Disabil Health J.* 2020. 13(3). Available at <https://doi.org/10.1016/j.dhjo.2020.100942>. Accessed 1-22-2021.

### Abstract

*Background:* Despite possibly higher risk of severe outcomes from COVID-19 among people with intellectual and developmental disabilities (IDD), there has been limited reporting of COVID-19 trends for this population.

*Objective:* To compare COVID-19 trends among people with and without IDD, overall and stratified by age.

**Methods:** Data from the TriNetX COVID-19 Research Network platform was used to identify COVID-19 patients. Analysis focused on trends in comorbidities, number of cases, number of deaths, and case-fatality rate among patients with and without IDD who had a positive diagnosis for COVID-19 through May 14, 2020.

**Results:** People with IDD had higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes. Distinct age-related differences in COVID-19 trends were present among those with IDD, with a higher concentration of COVID-19 cases at younger ages. In addition, while the overall case-fatality rate was similar for those with IDD (5.1%) and without IDD (5.4%), these rates differed by age: ages  $\leq 17$ —IDD 1.6%, without IDD  $< 0.01\%$ ; ages 18–74—IDD 4.5%, without IDD 2.7%; ages  $\geq 75$ —IDD 21.1%, without IDD 20.7%.

**Conclusions:** Though of concern for all individuals, COVID-19 appears to present a greater risk to people with IDD, especially at younger ages. Future research should seek to document COVID-19 trends among people with IDD, with particular attention to age related trends.

**Summary:** People with IDD and COVID-19 had higher rates for all pre-existing conditions associated with COVID-19 disease severity and mortality, and case fatalities were higher in younger age groups.

#### Key Takeaways

- People with IDD and COVID-19 had higher rates for all pre-existing conditions associated with COVID-19 disease severity and mortality. (Note: these conditions are not specified in the source.)
- Case fatalities were higher in younger age groups (e.g., individuals under 75). The study suggests accounting for age-related differences in COVID-19 death rates.

### 3. Ciccarelli O, Cohen J, Thompson A. "Response of the multiple sclerosis community to COVID-19." *Mult Scler*. 2020. 26(10):1134-1136. Available at <https://doi.org/10.1177/1352458520948748>. Accessed 1-22-2021.

#### *No abstract available*

**Summary:** People with multiple sclerosis (MS) on high-efficacy treatments are at an increased risk of COVID-19 infection or mortality. In addition, COVID-19 restrictions and triage have significantly impacted care delivery for these individuals.

#### Key Takeaways

- The COVID-19 pandemic has impacted care delivery for people with MS by increasing staff shortages, reducing the allocation of hospital beds for people with MS, suspending routine tests and scans, discontinuing rehabilitation services, and allowing rapid adoption of telemedicine for healthcare facilities and people with MS.
- Individuals with MS receiving high-efficacy treatments are at increased risk of infection or mortality from COVID-19.
- Anticipated COVID-19-related long-term care changes for people with MS include home-drug delivery programs, an increase in digital tool use to record patient self-assessments, and changes in patient monitoring.

4. Chakraborty J. “Social inequities in the distribution of COVID-19: An intra-categorical analysis of people with disabilities in the U.S.” *Disabil Health J.* 2020. Available at <https://doi.org/10.1016/j.dhjo.2020.101007>. Accessed 1-22-2021.

### Abstract

*Background:* While recent reports suggest that people with disabilities are likely to be adversely impacted by COVID-19 and face multiple challenges, previous research has not examined if COVID-19 burdens are unequally distributed with respect to the disability characteristics of the U.S. population.

*Objective:* This article presents the first national scale study of the relationship between COVID-19 incidence and disability characteristics in the U.S. The objective is to determine whether COVID-19 incidence is significantly greater in counties containing higher percentages of socio-demographically disadvantaged people with disabilities, based on race, ethnicity, poverty status, age, and biological sex.

*Methods:* This study integrates county-level data on confirmed COVID-19 cases from the Johns Hopkins Center for Systems Science and Engineering database with multiple disability variables from the 2018 American Community Survey. Statistical analyses are based on bivariate correlations and multivariate generalized estimating equations that consider spatial clustering in the data.

*Results:* Greater COVID-19 incidence rate is significantly associated with: (1) higher percentages of people with disabilities who are Black, Asian, Hispanic, Native American, below poverty, under 18 years of age, and female; and (2) lower percentages of people with disabilities who are non-Hispanic White, above poverty, aged 65 or more years, and male, after controlling for spatial clustering.

*Conclusions:* Socio-demographically disadvantaged people with disabilities are significantly overrepresented in counties with higher COVID-19 incidence compared to other people with disabilities. These findings represent an important starting point for more detailed investigation of the disproportionate impacts of COVID-19 on people with disabilities and highlight the urgent need for COVID-19 data collection systems to incorporate disability information.

**Summary:** People with disabilities who are young, female, and of a racial/ethnic minority group living in socio-demographically disadvantaged areas are significantly over-represented in counties with higher COVID-19 incidence.

### Key Takeaways

- During a pandemic, notable barriers to health for people with disabilities include the ability to socially distance, the ability to increase handwashing, access to equitable healthcare, and medical resource allocation.
- Socio-demographically disadvantaged people with disabilities are significantly overrepresented in counties with higher COVID-19 incidence.
- People with disabilities who are Black, Asian, Hispanic, Native American, below poverty, aged 5-17, and female are significantly more likely to reside in counties with higher COVID-19 incidence compared to their counterparts. This is concerning because women with disabilities have historically faced more discrimination and difficulties attaining access to education, employment, housing, and healthcare and also experience high rates of gender-based violence and sexual abuse.

5. Papa S, Brundin P, Fung V, et al. "Impact of the COVID-19 Pandemic on Parkinson's Disease and Movement Disorders." *Mov Disord.* 2020. 35(5):711-715. Available at <https://doi.org/10.1002/mds.28067>. Accessed 1-22-2021.

**No abstract available**

**Summary:** People with Parkinson's disease (PD) have an increased risk of experiencing severe forms of COVID-19 due to existing comorbidities and a higher risk of hospitalization complications. Healthcare facilities can use live-video telemedicine to conduct routine maintenance and care delivery for people with PD during the COVID-19 pandemic.

**Key Takeaways**

- There is currently insufficient evidence showing that PD alone increases the risks associated with COVID-19. The existing comorbidities that were found to be associated with PD include coronary artery disease, cerebrovascular disease, and heart failure, all of which may put people with PD at increased risk for more severe forms of COVID-19.
- People with PD are at higher risk of in-hospital complications such as delirium, adverse drug reactions, syncope, aspiration pneumonia, falls, and fractures.
- People with PD need routine hospital visits for physical assessment and medication maintenance. During the COVID-19 pandemic, healthcare facilities can use telemedicine to assess people with PD through live-video physical examinations.

6. Antonini A, Leta V, Teo J, et al. "Outcome of Parkinson's Disease Patients Affected by COVID-19." *Mov Disord.* 2020. 35(6):905-908. Available at <https://doi.org/10.1002/mds.28104>. Accessed 1-22-2021.

**No abstract available**

**Summary:** People with Parkinson's disease (PD) who are older, on advanced therapies, and have longer disease duration are more susceptible to COVID-19 infection and have a higher mortality rate.

**Key Takeaways**

- Anxiety and other nonmotor features such as fatigue, orthostatic hypotension, cognitive impairment, and psychosis worsened during the infection for people with PD. Fatigue was a dominant COVID-19 symptom in all people with PD on advanced therapies.
- Patients with PD who were over 75 and had a longer disease duration are more susceptible to COVID-19 infection and have a 40% mortality rate.
- Patients on advanced therapies, such as deep brain stimulation, are especially vulnerable to COVID-19 complications and have a mortality rate of 50%. Three out of ten patients died from COVID-19-related pneumonia.
- Comorbidities in patients with PD and COVID-19 include dementia, hypertension, chronic kidney disease, asthma, diabetes, and congestive cardiac failure.

7. Mills W, Sender S, Lichtefeld J, et al. “Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA.” *J Intellect Disabil Res.* 2020. 64(7):489–496. Available at <https://doi.org/10.1111/jir.12740>. Accessed 1-22-2021.

## Abstract

*Background:* It is unknown how the novel coronavirus SARS-CoV-2, the cause of the current acute respiratory illness COVID-19 pandemic that has infected millions of people, affects people with intellectual and developmental disability (IDD). The aim of this study is to describe how individuals with IDD have been affected in the first 100 days of the COVID-19 pandemic.

*Methods:* Shortly after the first COVID-19 case was reported in the USA, our organization, which provides continuous support for over 11,000 individuals with IDD, assembled an outbreak committee composed of senior leaders from across the health care organization. The committee led the development and deployment of a comprehensive COVID-19 prevention and suppression strategy, utilizing current evidence-based practice, while surveilling the global and local situation daily. We implemented enhanced infection control procedures across 2,400 homes, which were communicated to our employees using multi-faceted channels including an electronic resource library, mobile and web applications, paper postings in locations, live webinars and direct mail. Using custom-built software applications enabling us to track patient, client and employee cases and exposures, we leveraged current public health recommendations to identify cases and to suppress transmission, which included the use of personal protective equipment. A COVID-19 case was defined as a positive nucleic acid test for SARS-CoV-2 RNA.

*Results:* In the 100-day period between January 20, 2020 and April 30, 2020, we provided continuous support for 11,540 individuals with IDD. Sixty-four percent of the individuals were in residential, community settings, and 36% were in intermediate care facilities. The average age of the cohort was 46 ± 12 years, and 60% were male. One hundred twenty-two individuals with IDD were placed in quarantine for exhibiting symptoms and signs of acute infection such as fever or cough. Sixty-six individuals tested positive for SARS-CoV-2, and their average age was 50. The positive individuals were located in 30 different homes (1.3% of total) across 14 states. Fifteen homes have had single cases, and 15 have had more than one case. Fifteen COVID-19-positive individuals were hospitalized. As of April 30, seven of the individuals hospitalized have been discharged back to home and are recovering. Five remain hospitalized, with three improving and two remaining in intensive care and on mechanical ventilation. There have been three deaths. We found that among COVID-19-positive individuals with IDD, a higher number of chronic medical conditions and male sex were characteristics associated with a greater likelihood of hospitalization.

*Conclusions:* In the first 100 days of the COVID-19 outbreak in the USA, we observed that people with IDD living in congregate care settings can benefit from a coordinated approach to infection control, case identification and cohorting, as evidenced by the low relative case rate reported. Male individuals with higher numbers of chronic medical conditions were more likely to be hospitalized, while most younger, less chronically ill individuals recovered spontaneously at home.

**Summary:** Less than one-quarter of people with IDD required hospitalization during the first 100 days of the COVID-19 pandemic, and older males with IDD with higher numbers of existing chronic conditions were more likely to be hospitalized.

## Key Takeaways

- Less than one quarter of the study population (n = 11,540) required hospitalization.
- In the study, older individuals with IDD (especially males) with higher numbers of chronic medical conditions (e.g., diabetes, hypertension, schizophrenia, or kidney disease) were more likely to be hospitalized. Younger individuals with IDD with fewer chronic conditions were more likely to recover at home.
- **Recommendations:** A highly coordinated and frequently communicated infection control approach, employee screening, and visitor management facilitated the relatively low prevalence of COVID-19 in the congregate setting.

8. Swarnakar R, Santra S. “Personal hygiene care in persons with spinal cord injury during the COVID-19 pandemic and lockdown: an Indian perspective.” *Spinal Cord Ser Cases*. 2020. 6(76). Available at <https://www.nature.com/articles/s41394-020-00328-8>. Accessed 1-22-2021.

## No abstract available

**Summary:** COVID-19 restrictions and isolation have made it more difficult for people with spinal cord injury (SCI) to maintain adequate hygiene. The pandemic has also increased the need for caregiver services and reduced opportunities for mobility exercises for this population.

## Key Takeaways

- Mobility restrictions make it more difficult for people with SCI to follow COVID-19 handwashing hygiene recommendations.
- COVID-19 restrictions have made people with SCI more dependent on care providers due to an increased need for care services like assistance in clean intermittent catheterizations.
- Pandemic isolation has increased the duration of bed time and sitting and decreased the frequency of exercises, outdoor activity, and wheelchair mobilization for people with SCI.

9. Cuypers M, Schalk B, Koks-Leensen M, et al. (2020). “Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic.” *J Intellect Disabil Res*. 2020. 64(7):482-488. Available at <https://doi.org/10.1111/jir.12739>. Accessed 1-22-2021.

## Abstract

**Background:** Data on the development of COVID-19 among people with intellectual disabilities (IDs) are scarce and it is uncertain to what extent general population data applies to people with ID. To give an indication of possible implications, this study investigated excess mortality patterns during a previous influenza epidemic.

**Methods:** Using Dutch population and mortality registers, a historical cohort study was designed to compare mortality during the 2017–2018 influenza epidemic with mortality in the same period in the three previous years. People with ID were identified by entitlements to residential ID-care services as retrieved from a national database.



**Results:** Data covered the entire adult Dutch population (12.6 million people), of which 91,064 individuals were identified with an ID. During the influenza epidemic, mortality among people with ID increased almost three times as much than in the general population (15.2% vs. 5.4%), and more among male individuals with ID (+19.5%) than among female individuals with ID (+10.6%), as compared with baseline. In both cohorts, comparable increases in mortality within older age groups and due to respiratory causes were seen. Particularly in the ID cohort, excess deaths also occurred in younger age groups, due to endocrine diseases and ID-specific causes.

**Conclusions:** During the 2017–2018 influenza epidemic, excess mortality among people with ID was three times higher than in the general Dutch population, appeared more often at young age and with a broader range of underlying causes. These findings suggest that a pandemic may disproportionately affect people with ID while population data may not immediately raise warnings. Early detection of diverging patterns and faster implementation of tailored strategies therefore require collection of good quality data.

**Summary:** During an influenza outbreak, mortality rates were 3 times higher in people with ID than in those without ID, and middle-aged people with ID experienced similar mortality as elderly people with ID. Comorbidities that existed in people with ID and people with influenza included dementia and increased metabolic and endocrine diseases.

#### Key Takeaways

- During an influenza outbreak, mortality rates were 3 times higher among people with ID than in the general population. People with ID of ages 45-64 experienced similar mortality rates to people of ID ages 65 and older.
- Excess mortality in the cohort of people with ID was found to be caused by ID itself, dementia, and increased deaths from metabolic and endocrine diseases like diabetes versus the general population.
- **Recommendations:** Policymakers should rely on quality data that provides more than a national snapshot of public health data for people with ID. This can be done by include ID as a variable in national data sets, establishing prospective registration in dedicated ID-related databases, and accurately reporting causes of death to detect patterns at early stages to better understand underlying causes of death and quickly implement protective measures and tailored strategies.

**10. Nygren MA, Lulinski A. “State of the Science on COVID-19 and People with IDD.”**  
 [Research brief.] American Association on Intellectual and Developmental Disabilities.  
 Available at <https://www.aaid.org/docs/default-source/publication/state-of-the-science-on-covid-19-and-people-with-idd---dec-2020.pdf>. Accessed 1-22-2021.

**No abstract available**

**Summary:** People with intellectual and developmental disabilities (IDD) are more likely to be exposed to COVID-19 and have poorer COVID-19-related health outcomes than the general public but are as likely as the general population to engage in preventive health strategies. In addition, these individuals have experienced massive disruption in health, home, and community services, exacerbating existing inequities in healthcare, and putting additional pressure on already over-taxed formal and informal support networks.

### Key Takeaways

- People with IDD who are Black, Asian, Hispanic, and Native American have higher positivity rates of COVID-19 compared to their White, non-Hispanic counterparts.
- Children with and without IDD are likely to receive routine childhood vaccinations, and 74% of adults with IDD who receive services through state agencies reported receiving a flu vaccination in the last 12 months.
- Most people with IDD have experienced substantial changes in the types and duration of services they receive since the COVID-19 pandemic began. One survey reported that 74% of people with IDD had lost one or more services entirely.
- Mental health services for people with IDD have been disrupted during the pandemic.
- Caregivers for people with IDD are experiencing increased stressors during the COVID-19 pandemic due to disruption and loss of services. Many caregivers are experiencing fears of COVID-19 infection, increased life stressors, and isolation.

## COVID-19, Behavioral Health, and People with Disabilities

This section includes citations that reference the prevalence of new and worsening behavioral health conditions in people with disabilities and people without disabilities during the COVID-19 pandemic. This section also discusses the impact of the pandemic on the behavioral health of people with disabilities and their caregivers, and provides strategies to address these conditions.

- 11. Capuzzi E, Di Brita C, Caldiroli A, et al. "Psychiatric emergency care during coronavirus 2019 (COVID 19) pandemic lockdown: Results from a department of mental health and addiction of northern Italy." *Psychiatry Res.* 2020. 293:113463-113463. Available at <https://doi.org/10.1016/j.psychres.2020.113463>. Accessed 1-22-2021.**

### Abstract

*Background:* The current COVID-19 pandemic and the consequent containment measures are leading to increasing mental health issues, both in psychiatric patients and general population.

*Objective:* We aimed to compare the number and characteristics of emergency psychiatric consultations during phase 1 of lockdown with respect to the same period in 2019 in a department of mental health and addiction (DMHA) located in the Lombardy region.

*Methods:* We conducted a cross-sectional study including subjects consecutively admitted to two psychiatric emergency rooms of DMHA in Monza, Lombardy, Italy. Sociodemographic data, clinical characteristics, referred symptoms, diagnosis and information on patients' illness course following the emergency consultations were collected. No subjects were excluded for the purposes of the study.

*Results:* Between February 21 and May 3, 2020, there was a marked reduction in the number of psychiatric emergency consultations, if compared to the same period of 2019. Subjects who were living in psychiatric residential treatment facilities, had cannabis addiction, and [had] a diagnosis of obsessive-compulsive disorder were significantly more likely to present to emergency psychiatric consultations during lockdown.

*Conclusions:* COVID-19 epidemic may have a negative impact on more vulnerable individuals. Strategies to enhance relapse prevention and the use of alternative approaches as e-health technologies should be promoted.

**Summary:** Longer periods of pandemic-related lockdowns may lead to higher rates of self-harm, obsessive compulsive disorder, addiction, and psychiatric hospitalizations.

#### Key Takeaways

- There was a decrease in psychiatric emergency consultations in the study location during COVID-19 lockdown period.
- Individuals with cannabis misuse were more likely to be present in emergency departments than individuals without cannabis misuse. The COVID-19 lockdown and related isolation may have fostered addiction-related habits (e.g., internet overuse, substance misuse, and increased caloric intake).
- Higher rates of obsessive-compulsive disorder were reported in psychiatric emergency visits during COVID-19 lockdown in the study area compared to the previous year.
- Rates of self-harm and hospitalizations were higher in the study area during the second phase of lockdown than the first phase.

**12. Willner P, Rose J, Stenfert Kroese B, et al. “Effect of the covid-19 pandemic on the mental health of carers of people with intellectual disabilities.” *J Appl Res Intellect Disabil.* 2020. Available at <https://doi.org/10.1111/jar.12811>. Accessed 1-22-2021.**

#### Abstract

*Introduction:* The measures implemented to manage the COVID-19 pandemic have been shown to impair mental health. This problem is likely to be exacerbated for carers.

*Method:* Informal carers (mainly parents) of children and adults with intellectual disabilities, and a comparison group of parents of children without disabilities, completed an online questionnaire. Almost all the data were collected while strict lockdown conditions were in place.

*Results:* Relative to carers of children without intellectual disability, carers of both children and adults with intellectual disability had significantly greater levels of a wish fulfilment coping style, defeat/entrapment, anxiety, and depression. Differences were 2–3 times greater than reported in earlier pre-pandemic studies. Positive correlations were found between objective stress scores and all mental health outcomes. Despite their greater mental health needs, carers of those with intellectual disability received less social support from a variety of sources.

*Conclusions:* The greater mental health needs of carers in the context of lesser social support raises serious concerns. We consider the policy implications of these findings.

**Summary:** Caretakers of people with disabilities experience higher levels of mental health conditions than parents of children without disabilities. A decline in social support is associated with higher stress levels for caretakers.

#### Key Takeaways

- During the COVID-19 pandemic, caretakers of adults and children with intellectual disabilities (ID) reported high levels of negative mental health symptoms compared to parents of children without ID, including a fivefold increase in severe anxiety and fourfold increase in major depression. Negative mental health symptoms were also higher in caretakers during the pandemic than before the pandemic.
- Stress, problems with finances, and challenging behaviors of people with ID were associated with the decline in mental health for caretakers of people with ID. Lower social support is associated with higher stress levels for caretakers of people with ID.
- Most caregiver respondents were females. During the COVID-19 pandemic, caregivers of adults with ID received less support from day services, parents, and professional helpers than caregivers of children with ID.
- Social support was found to be less readily available for caretakers of people with disabilities with more challenging behaviors and for those with fewer financial resources. Caretakers received social support mostly by remote communications (e.g., phone, email, videoconferencing).
- Of the study participants, 90% reported using remote communication with professional helpers versus in-person services.
- **Telehealth:** Telehealth barriers for people with ID include the feasibility and acceptability of remote contact, difficulties accessing remote technologies and equipment, reduced patient confidentiality due to caretakers needing to help manage telehealth calls, and difficulty contacting services.
- **Recommendations:** Provide remote services that offer more flexible social support options for families of people with disabilities, via phone or electronic media. Offer more mental health services and peer support groups for caretakers of people with disabilities.

**13. Kim H, Park K, Shin Y, et al. “Psychological Impact of Quarantine on Caregivers at a Children’s Hospital for Contact with Case of COVID-19.” *J Korean Med Sci*. 2020. 35(28):e255–e255. Available at <https://doi.org/10.3346/jkms.2020.35.e255>. Accessed 1-22-2021.**

#### **Abstract**

Quarantine often provokes negative psychological consequences. Thus, we aimed to identify the psychological and behavioral responses and stressors of caregivers quarantined with young patients after a close contact to a coronavirus disease 2019 case at a children's hospital. More than 90% of the caregivers reported feelings of worry and nervousness, while some of them reported suicidal ideations (4.2%), and/or homicidal ideations (1.4%). Fear of infection of the patient (91.7%) and/or oneself (86.1%) were the most frequently reported stressors. A multidisciplinary team including the infection control team, pediatrician, psychiatrist, nursing staff, and legal department provided supplies and services to reduce caregivers’ psychological distress. Psychotropic medication was needed in five caregivers (6.9%), one of whom was admitted to the psychiatry department due to suicidality. Quarantine at a children's hospital makes notable psychological impacts on the caregivers, and a multidisciplinary approach is required.

**Summary:** Caregivers who work in hospitals and are at risk for COVID-19 may experience high levels of stress-related symptoms and psychological manifestations due to worry and nervousness associated

with COVID-19 exposure. Inaccessibility to comprehensive resources and information could exacerbate these symptoms.

### Key Takeaways

- Worrying (94.4%) and nervousness (90.3%) were observed in almost all of the caregivers of children who were quarantined after close contact with someone who contracted COVID-19. Three caregivers manifested suicidal ideation (4.2%), and one reported homicidal ideation (1.4%). Fear that the patient was infected (91.7%) and fear of infection of oneself (86.1%) were highly prevalent among the caregivers.
- Inadequacies in supplies, medication, and information were indicated as major stressors for caregivers.

**14. Van Hees S, Siewe-Fodjo JN, Wijtvlit V, et al. "Access to healthcare and prevalence of anxiety and depression in persons with epilepsy during COVID-19 pandemic: A multicountry online survey." *Epilepsy Behav.* 2020. 112. Available at <https://doi.org/10.1016/j.yebeh.2020.107350>. Accessed 1-22-2021.**

### Abstract

*Objective:* The objective of this study was to assess access to healthcare and to estimate the prevalence of depression and anxiety among persons with epilepsy (PWE) during the ongoing coronavirus disease 2019 (COVID-19) pandemic.

*Methods:* We conducted a multi-country online survey among PWE. Persons with epilepsy were invited to participate through various social media channels. The Hospital Anxiety and Depression Scale (HADS) and nine-item Patient Health Questionnaire (PHQ-9) scale were used to score anxiety and depression. Logistic regression modeling was used to investigate factors associated with anxiety and depression.

*Results:* Three hundred ninety-nine PWE were included (mean age: 38.22 ± 12.09 years), the majority were female (80.2%) and living in high-income countries (83.2%). Two hundred three PWE reported symptoms of a cold since January 2020. Nine (25%) of the 36 PWE tested for COVID were positive. A total of 72 PWE (19.6%) reported problems to obtain antiseizure medication (ASM), which in 25% of cases was directly COVID-related. Of the 399 PWE, 201 (50.4%) screened positive for anxiety according to the HADS; 159 (39.8%) and 187 (46.9%) PWE screened positive for depression based on the HADS and PHQ-9 scale, respectively. Female gender and financial problems were associated with both depression and anxiety. A planned follow-up consultation with the treating physician was associated with a lower risk of depression, whereas difficulties to access ASM treatment increased the odds of depression. In 65 of 137 (47.4%) PWE with a planned follow-up visit with the treating physician, this consultation was canceled.

*Conclusions:* Innovative approaches are needed to ensure continuity in access to ASM treatment. Healthcare workers should ensure continued follow-up, either through in person or telehealth appointments, to timely identify symptoms of anxiety and depression and act accordingly.

**Summary:** The prevalence of anxiety and depression in people with epilepsy may be higher than noted in the general population. This population can experience pandemic-related challenges with obtaining medications and maintaining healthcare visits.

## Key Takeaways

- Of the people with epilepsy (PWE) enrolled in the study, 19.6% had difficulties obtaining antiseizure drugs during the pandemic.
- Of the 399 study participants, 39.8% screened positive for depression and 50.4% screened positive for anxiety.
- Follow-up consultations with the treating physician were canceled among 47.4% of the 137 PWE due to COVID-19 restrictions, and 32.8% of the 137 PWE changed visits to telephone or online consult.
- Minimal seizure frequencies were reported by study participants during COVID-19 pandemic.
- One-quarter of PWE with difficulties obtaining ASM reported COVID-19 related causes such as financial challenges (12.5%) and mobility challenges (12.5%).

**15. Embregts PJCM, Tournier T, Frielink N. “Experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic: A thematic analysis.” *J Appl Res Intellect Disabil*. 2020. Available at <https://doi.org/10.1111/jar.12812>. Accessed 1-22-2021.**

## Abstract

*Background:* The present study aimed to explore the experiences and needs of direct support staff during the initial stage of the COVID-19 lockdown in the Netherlands.

*Method:* Overall, 11 direct support staff were recruited from five intellectual disability services to participate in this descriptive qualitative study. They recorded 34 audio messages during the considered period. Thematic analysis was used to analyze these audio recordings.

*Results:* Four themes emerged: (1) Emotional impact, which pertained to various emotions they experienced in their work; (2) Cognitive impact, which referred to challenges and changes they had undergone in their work; (3) Practical impact, which centered on the practical impact of the pandemic on their work; and (4) Professional impact, which concerned their experiences with other professionals.

*Conclusions:* This study provides valuable insights into the experiences and needs of direct support staff during the COVID-19 pandemic, which, in turn, can help inform practice in preparation for a second wave of COVID-19 or another future pandemic.

**Summary:** Direct support staff reported higher levels of fear when caring for people with IDD, with fears of contracting the virus or spreading the virus to family members and loved ones.

## Key Takeaways

- Direct support staff from multiple intellectual disability services reported fears of contracting the COVID-19 virus, and these fears were described as manifestations of anger and frustration, that impacted mental health.
- Staff reported that signs of appreciation and good communication from management may improve their experiences.

16. Embregts PJCM, Van Den Bogaard KJHM, Frielink N, et al. “A thematic analysis into the experiences of people with a mild intellectual disability during the COVID-19 lockdown period.” *Int J Dev Disabil*. 2020. Available at <https://doi.org/10.1080/20473869.2020.1827214>. Accessed 1-22-2021.

### Abstract

*Background:* The COVID-19 pandemic is expected to have a substantial impact on people with an intellectual disability. The goal of the current study was to explore the experiences and needs of people with a mild intellectual disability during the COVID-19 lockdown period in the Netherlands.

*Method:* A descriptive qualitative methodology was conducted, using semi-structured individual interviews with six people with a mild intellectual disability. Data were analyzed thematically.

*Results:* Three overarching themes were found: (i) Missing social contact and having people close; (ii) Being housebound has changed my daily life; and (iii) Hard to understand the preventive measures.

*Conclusions:* Important insights into the experiences and needs of people with a mild intellectual disability during the COVID-19 lockdown period were gained. These insights are valuable with respect to a potential second COVID-19 wave or a future infection-outbreak.

**Summary:** Many people with intellectual disability reported feelings of isolation and changes in daily routine as challenges experienced during the COVID-19 lockdown period.

### Key Takeaways

- Participants used videoconferencing technologies as alternative ways of maintaining contact during the pandemic. However, while some participants found this beneficial, others found it to be unpleasant.
- Participants reported difficulties in following and comprehending COVID-19 preventive measures (e.g., when managing daily food shopping or picking up medications).

## Gray Literature/Organizational Reports

### 17. Urban Institute: “[Families of Children with Disabilities Will Need Support beyond the Pandemic](#)”

- This data reports the increased levels of anxiety, stress, and depression that families of children with disabilities are experiencing during the pandemic and discusses potential policies to alleviate these stressors and support families.

### 18. Blue Cross Blue Shield: “[Blue Cross Blue Shield: The Impact of Caregiving on Mental and Physical Health](#)”

- This document explains that health differences associated with caregiving are more pronounced for millennials and larger for caregivers who live in majority Black or Hispanic communities.
- COVID-19 has increased the demand for caregivers, and it has also increased self-reported stress, isolation, and loneliness among caregivers.

- Caregivers also suffer from more stress-related behavioral and physical conditions like depression, obesity, and hypertension compared to the general population.

## COVID-19 Impact on People with Disabilities and Access to Services

This section includes citations that reference the impact of the COVID-19 pandemic on people with disabilities' access to healthcare, social, and educational services.

- 19. Neece C, McIntyre L, Fenning R. "Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities." *J Intellect Disabil Res.* 2020. 64(10):739-749. Available at <https://doi.org/10.1111/jir.12769>. Accessed 1-22-2021.**

### Abstract

*Background:* The COVID-19 pandemic introduced challenges to families with young children with developmental delays. Beyond the widespread concerns surrounding illness, loss of employment and social isolation, caregivers are responsible for overseeing their children's educational and therapeutic programs at home, often without the much needed support of professionals.

*Method:* The present study sought to examine the impact of COVID-19 in 77 ethnically, linguistically, and socioeconomically diverse families with young children with intellectual and developmental disabilities (IDDs) in California and Oregon, who were participating in larger intervention studies. Parents responded to five interview questions about the impact of the pandemic, services for their child, silver linings or positive aspects, coping, and their concerns about the long-term impact of the pandemic.

*Results:* Parents reported that their biggest challenge was being at home caring for their children with the loss of many essential services. Parents reported some positive aspects of the pandemic, especially being together as a family. Although there were positive aspects of the situation, many parents expressed concern about long-term impacts of the pandemic on their children's development, given the loss of services, education, and social engagement opportunities.

*Conclusion:* Results suggest that parents of young children with IDD report significant challenges at home during the pandemic. Professional support, especially during the reopening phases, will be critical to support family well-being and child developmental outcomes.

**Summary:** Parents and other caregivers caring for children with intellectual and developmental disabilities (IDD) are impacted by COVID-19 more than the general population and experience less social support and higher levels of burnout and stress. The majority of families in the study reported decreased IDD services due to the pandemic.

### Key Takeaways

- The pandemic has impacted families caring for children with IDD even more than the pandemic has impacted the general population. Parents and caregivers of children with IDD are experiencing higher levels of parental burnout, less social support, and a higher amount of stress.



- Quarantining required parents and caregivers of children with IDD to take on additional responsibilities like serving as a child’s special educator, social skills coach, or behavioral therapist. Ethnically diverse families encountered additional challenges such as reduced access to care, resources, and professional support for children with IDDs.
- Parents of children with IDD reported challenges with isolation at home, balancing work and childcare, changes in routine, and financial concerns.
- The majority (77.9%) of the parents in the study reported that their children’s IDD services had decreased due to the pandemic. Eighteen percent reported that their services were being delivered online and that the service intensity remained the same.
- Families in the study indicated concern about the long-term impact of the pandemic on employment, finances, and children’s emotional health and educational and developmental progress.

**20. Jeste S, Hyde C, Distefano C, et al. “Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions.” *J Intellect Disabil Res*. Available at <https://doi.org/10.1111/jir.12776>. Accessed 1-22-2021.**

#### **Abstract**

*Background:* COVID-19 restrictions have significantly limited access to in-person educational and healthcare services for all, including individuals with intellectual and developmental disabilities (IDDs). The objectives of this online survey that included both national and international families were to capture changes in access to healthcare and educational services for individuals with IDDs that occurred shortly after restrictions were initiated and to survey families on resources that could improve services for these individuals.

*Methods:* This was an online survey for caregivers of individuals with (1) a genetic diagnosis and (2) a neurodevelopmental diagnosis, including developmental delay, intellectual disability, autism spectrum disorder, or epilepsy. The survey assessed (1) demographics, (2) changes in access to educational and healthcare services and (3) available and preferred resources to help families navigate the changes in service allocation.

*Results:* Of the 818 responses (669 within the USA and 149 outside of the USA), most families reported a loss of at least some educational or healthcare services. Seventy-four percent of parents reported that their child lost access to at least one therapy or education service, and 36% of respondents lost access to a healthcare provider. Only 56% reported that their child received at least some continued services through tele-education. Those that needed to access healthcare providers did so primarily through telemedicine. Telehealth (both tele-education and telemedicine) was reported to be helpful when available, and caregivers most often endorsed a need for an augmentation of these remote delivery services, such as 1:1 videoconference sessions, as well as increased access to 1:1 aides in the home.

*Conclusions:* COVID-19 restrictions have greatly affected access to services for individuals with syndromic IDDs. Telehealth may provide opportunities for delivery of care and education in a sustainable way, not only as restrictions endure, but also after they have been lifted.

**Summary:** Families of children with intellectual and developmental disabilities (IDDs) have lost a substantial number of educational and medical support services due to the COVID-19 pandemic. General

healthcare services are the most accessible service, although families are still having challenges in obtaining medical supplies, medications, and respite care for children with IDD.

### Key Takeaways

- Of the U.S. study participants, 74% indicated their child was no longer receiving at least one therapy or educational service, 30% percent reported losing all therapy and educational services, and 56% reported changes in service modality.
- Of the U.S. respondents, 70% indicated a need to visit a healthcare provider during the pandemic. Half of these respondents were able to meet with at least one provider through telemedicine, while 51% reported not being able to see at least one healthcare provider during this time. More respondents had access to general healthcare than to behavioral health services.
- Many families preferred to receive education services online instead of in person. However, many from this study cohort reported that their children’s needs were not being considered with tele-education services.
- Caregivers identified barriers to obtaining medical supplies, medications, and respite care for children with IDDs.
- **Telehealth:** Families were often able to connect with neurologist and primary care providers through telemedicine, but providers from other specialties were less available via telemedicine.
- **Telehealth:** Surveys from child neurology telemedicine clinics showed a high satisfaction rate among both patients and caregivers. This effectiveness may be an outcome of proper telemedicine resource allocation and dissemination to families.
- **Telehealth:** The study identified several racial disparities in remote healthcare delivery. Non-White respondents were more likely to use telephone services than video services.
- **Recommendations:** Develop partnerships between service providers and families to enhance the effectiveness of telehealth delivery for children with IDDs.

**21. Stillman MD, Capron M, Alexander M, et al. “COVID-19 and spinal cord injury and disease: results of an international survey.” *Spinal Cord Ser Cases*. 2020. 6(21). Available at <https://doi.org/10.1038/s41394-020-0275-8>. Accessed 1-22-2021.**

### Abstract

*Study Design:* Online Survey

*Objectives:* To query the international spinal cord medicine community’s engagement with and response to the novel coronavirus (COVID-19) pandemic and to assess pandemic-specific information needs and patient concerns.

*Setting:* An international collaboration of authors and participants.

*Methods:* Two near-identical surveys (one English and one Spanish language) were distributed via the internet. Responses from those questions shared between the surveys were pooled then analyzed; four questions’ responses (those not shared) were analyzed separately.

*Results:* A total of 783 responses were submitted from six continents. Few participants (5.8%) had tested their outpatients with spinal cord injury/disease (SCI/D) for COVID-19; only 4.4% reported having a patient with SCI/D with the virus. Of respondents who worked at an inpatient facility, 53.3% reported

that only individuals with symptoms were being screened and 29.9% said that no screening was occurring. Participants relayed several concerns offered by their patients with SCI/D, including vulnerability to infection (76.9%) and fragility of caretaker supply (42%), and those living in countries with guaranteed health care were more likely to report widespread availability of COVID-19 testing than were those living in countries without universal care,  $\chi^2 (3, N = 625) = 46.259, p < 0.001$ .

**Conclusion:** There is substantial variability in the rehabilitation medicine community in COVID-19 screening practices and availability of screening kits. People living with SCI/D are expressing legitimate and real concerns about their vulnerability to COVID-19. More and rapid work is needed to address these concerns and to standardize best-practice protocols throughout the rehabilitation community.

**Summary:** Healthcare professionals are more likely to screen for COVID-19 in patients with spinal cord injury and disease (SCI/D) if patients are exhibiting symptoms. Patients with SCI/D are likely to experience challenges accessing treatment, supplies, and caretaker assistance.

### Key Takeaways

- In the study, individuals with COVID-19 and SCI/D were reported to have increased spasticity. Treatments included isolation or quarantine (82.8%), emergency department-level care or hospitalization (20.7%), over the counter medications, and hydroxychloroquine.
- About half (53.3%) of healthcare professionals in the study reported COVID-19 screening in individuals with SCI/D who exhibit symptoms, and 25.9% reported that patients in their facility were not being screened.
- The surveyed health professionals made several changes to their medical practice due to COVID-19, including employing telemedicine (47%), limiting therapies (49%), and promoting the use of home care (50.4%).
- Individuals with SCI/D reported concerns regarding their vulnerability to infection (76.9%), their inability to obtain necessary routine supplies (40.2%), be appropriately tested for COVID-19 (28.5%), obtain transportation to healthcare treatments (28.5%), and self-quarantine (20.7%), along with their concerns about inconsistent caretaker availability (42%).

## Gray Literature/Organizational Reports

### 22. National Core Indicators: [“COVID19 Bulletin #5: Data from Adult Family Survey—Using NCI data to understand the challenges that families of people with IDD may be facing during the pandemic”](#)

- According to this report, adults with intellectual and developmental disabilities (IDD) are more likely to live at home with their families (38%) than in any other residential arrangement, which improves their likelihood of adhering to social distancing guidelines.
- Caregivers of people with IDD are likely to be older adults with increased health challenges.
- Problems with access to IDD support services existed prior to the pandemic and included access to respite care, support workers, and assistance with technology.
- Some states that previously did not allow payments to family caregivers sought and received approval from the Centers for Medicare and Medicaid Services to pay family members to provide care and support to a family member with IDD. Prior to the pandemic, 36% of families reported that a family member was paid to provide support to a family member with IDD.

**23. Avalere Health: “[Avalere Health: Impact of COVID-19 on Organizations Serving Individuals with Intellectual and Developmental Disabilities](#)”**

- The document reports that 68% of all IDD support organizations surveyed had to close one or more service lines due to the pandemic, resulting in an average loss of revenue of 32%.
- Of the surveyed organizations, 52% reported having increased staff overtime expenses.

**24. American Association on Health & Disability: “[COVID-19 & Adults with Disabilities: Health and Health Care Access](#)”**

- Of the adults with disabilities who were surveyed for this document, 44% reported having medical insurance through Medicaid or the Children’s Health Insurance Program. In addition, 77% of respondents received direct care worker services (e.g., from caregivers or home-health aides) during the pandemic, while 23% lost critical care services.
- More than half (54%) of respondents reported that they were unable to safely distance from their provider/care team worker, and 44% of the sample reported experiencing new challenges obtaining healthcare treatment, healthcare access, or prescriptions.
- Television and internet were reported to be important information sources for people with disabilities, even more so than healthcare providers.
- Two-thirds of respondents reported experiencing anxiety or depression during the pandemic and 24% of this study group were not receiving emotional or support services.

**25. United Nations Office for Disaster Risk Reduction Brief: “[People with disabilities in the face of COVID-19 in the Americas and the Caribbean](#)”**

- Most (70.5%) of the people with disabilities who participated in this survey reported requiring the support of another person to carry out their daily activities. In many cases (80%), this was a family member.
- Almost two-thirds (59%) of respondents said that they do not have another person who could provide them with necessary care if their main care provider were to become infected with COVID-19, underlining these individuals’ vulnerability.
- Many (68%) respondents stated that they can access to information related to the pandemic.
- **Recommendations:** Provide communications that can be understood and made available for a variety of people with disabilities, improve information platforms for people with disabilities and improve disaggregated and georeferenced data. Also, develop relevant and accessible state resources, information technologies, partnerships, and support networks.

## Impact of Telehealth on People with Disabilities During COVID-19

This section includes citations that reference data on how telehealth has impacted people with disabilities during the COVID-19 pandemic and discusses how telehealth can be utilized for disease prevention, to triage care, and to treat conditions that affect people with disabilities.

26. Annaswamy TM, Verduzco-Gutierrez M, Frieden L. “Telemedicine barriers and challenges for persons with disabilities: COVID-19 and beyond.” *Disabil Health J*. 2020. Available at <https://dx.doi.org/10.1016%2Fj.dhjo.2020.100973>. Accessed 1-22-2021.

### Abstract

The COVID-19 pandemic has forced a rapid adoption of telemedicine over traditional in-person visits due to social restrictions. While telemedicine improves access and reduces barriers to healthcare access for many, several barriers and challenges remain for persons with disabilities, and novel challenges have been exposed, many of which may persist long-term.

The challenges and barriers that need to be systematically addressed include: Infrastructure and access barriers, operational challenges, regulatory barriers, communication barriers and legislative barriers.

Persons with disabilities are a vulnerable population and little attention has been placed on their healthcare access during the pandemic. Access and communication during a healthcare encounter are important mediators of outcomes for persons with disabilities. Significant, long-term changes in technological, regulatory, and legislative infrastructure and custom solutions to unique patient and health system needs are required to address these barriers going forward in order to improve healthcare access and outcomes for persons with disabilities.

**Summary:** Although telemedicine reduces care costs and disease exposure, people with disabilities experience unique access and communication challenges and need tailored telemedicine efforts. This may require changes to technological, regulatory, and legislative infrastructure and custom solutions that improve the devices and services used for telemedicine programs.

### Key Takeaways

- According to this study, the reported benefits of telemedicine for people with disabilities include lower cost of care, lower transportation costs, improved medication reconciliation communication, less need for paid assistance services, and less exposure to diseases.
- People with disabilities are more likely to live in rural or low-income communities where broadband or fast internet could be a barrier to accessing telemedicine. Technology user interface features like a screen reader, sign language, captions, magnification, and color and contrast could also present issues for people with disabilities, who may need customized devices and services.
- Temporary telehealth policy flexibilities that have improved access could be revoked after the pandemic ends and hinder access for people with disabilities. The lack of regulations that address web accessibility and implementation under the American Disability Act also creates barriers for how companies provide care to people with disabilities.

27. Goodman-Casanova JM, Dura-Perez E, Guzman-Parra J, et al. “Telehealth Home Support During COVID-19 Confinement for Community-Dwelling Older Adults with Mild Cognitive Impairment or Mild Dementia: Survey Study.” *J Med Internet Res*. 2020. 22(5). Available at <https://www.jmir.org/2020/5/e19434/>. Accessed 1-22-2021.

### Abstract

**Background:** The public health emergency of coronavirus disease (COVID-19) is rapidly evolving worldwide; some countries, including Spain, have implemented restrictive measures. Populations that are vulnerable to this outbreak and its physical and mental health effects include community-dwelling older adults with mild cognitive impairment or mild dementia. Telehealth is a potential tool to deliver health care and decrease exposure risk.

**Objective:** The aims of this study were to explore the impact of confinement on the health and well-being of community-dwelling older adults with mild cognitive impairment or mild dementia, to provide television-based and telephone-based health and social support, and to study the effects of a television-based assistive integrated technology, TV-AssistDem (Tele**V**ision-based **A**SSistive Integrated **S**ervice to support **T** European adults living with mild **D**ementia or mild cognitive impairment).

**Methods:** A telephone-based survey was administered in Spain to 93 participants in the TV-AssistDem clinical trial from March 25 to April 6, 2020.

**Results:** Of the respondents, 60/93 (65%) were women. The mean age was 73.34 (SD 6.07), and 69/93 (74%) lived accompanied. Lockdown measures forced 17/93 respondents (18%) to change their living arrangements. Health status was found to be optimal in 89/93 respondents (96%), with no COVID-19 symptoms. Grocery and pharmacy outings were performed by family members of 68/93 participants (73%); 57 (61%) reported overall well-being, and 65 (70%) maintained their sleep quality. However, participants living alone reported greater negative feelings and more sleeping problems. Regarding leisure activities, 53/93 respondents (57%) took walks, 32 (35%) played memory games, 55 (60%) watched television, and 91 (98%) telephoned relatives. 58/93 (64%) respondents reported accessing moderate or too much COVID-19 information, 89 (97%) received it from television, and 56 (62%) stated that their understanding of the information was extreme. 39/93 (39%) respondents had contacted health and social services, while 29 (31%) requested information regarding these services during the telephone call. There were no significant differences in health and well-being between the intervention and control groups. Respondents with TV-AssistDem performed more memory exercises (24/93, 52% vs 8/93, 17.4%;  $P < .001$ ) than control respondents.

**Conclusions:** Our findings suggest that during COVID-19 confinement, the physical and mental health and well-being was optimal for the majority of our vulnerable population. However, those living alone reported greater negative psychological effects and sleeping problems. Measures adopted to address the negative experiences of confinement included keeping informed about the situation, accessing health and social services, having a support network that prevents risk of exposure to COVID-19 and guarantees food and medical supplies, a daily routine with maintained sleeping habits and leisure activities, staying physically and mentally active with cognitive stimulation exercises, and ensuring social connectedness using technology. Television sets were preferred technological devices to access COVID-19 information, watch television as a recreational activity, and perform memory exercises as an intellectual activity. Television-based telehealth support using TV-AssistDem demonstrated potential for cognitive stimulation.

**Summary:** Televisions were preferred technological devices for older adults with mild cognitive impairment or mild dementia to receive COVID-19 information, recreational activity, and perform memory exercises as an intellectual activity. Television-based telehealth services demonstrated potential for improving cognitive stimulation.

### Key Takeaways

- For almost all (96%) respondents, health status was found to be optimal, with no COVID-19 symptoms.

- Respondents living alone reported greater negative feelings and sleep problems than those who lived with others.
- Most respondents (97%) received their COVID-19 information from television, while others received information through phone calls and by contacting health and social services.
- **Recommendations:** For older adults with mild cognitive impairment or mild dementia, providing accessible COVID-19 information, support network services and cognitive stimulation exercises (using telehealth and virtual social activities) and improving access to health and social services can address negative experiences associated with COVID-19 confinement.

**28. Miele G, Straccia G, Moccia M, et al. “Telemedicine in Parkinson’s Disease: How to Ensure Patient Needs and Continuity of Care at the Time of COVID-19 Pandemic.” *Telemed J E Health*. Available at <https://doi.org/10.1089/tmj.2020.0184>. Accessed 1-22-2021.**

### Abstract

*Introduction:* With the spread of the SARS-CoV2 pandemic, telemedicine has become the safest way to guarantee care continuity, especially for chronic disabling diseases requiring frequent medical consultations and therapeutic adjustments, such as Parkinson’s disease (PD). The age-related prevalence of PD, combined with increased vulnerability due to age-related comorbidities, makes PD patient protection a priority.

*Methodology:* We reviewed potentials and limitations of teleneurology in PD and suggested a specific battery of tests, including patient-reported outcomes, smartphone applications, and neurological examination through telemedicine.

*Conclusions:* These tools can provide full neurological consultations, with the engagement of both patients and caregivers, and can support clinicians in defining whether patients need to access diagnostic and therapeutic procedures. Telemedicine will also carry a value in the future, within conventional healthcare, to support clinicians in decision-making, enabling more efficacious follow-up, reducing burden for caregivers, and delivering neurological expertise to local realities. These advantages are very important when there is physical distance between patients and neurologists, and when patients are not recommended to attend in-person consultations.

**Summary:** Teleneurology tools can provide full neurological consultations and support clinicians in deciding if individuals with Parkinson’s disease need to access diagnostic or therapeutic procedures.

### Key Takeaways

- The study reported that possible telemedicine limitations include device-related challenges like lack of access to technology, low webcam quality, and insufficient internet connection and access. In addition, neurological examinations over telemedicine are by nature limited, and data protection regulation for HIPAA and personal privacy is a challenge.
- Telemedicine can decrease the number of patients who must attend appointments in person and can help doctors streamline services.

29. Govindarajan R, Berry JD, Paganoni S, et al. “Optimizing telemedicine to facilitate amyotrophic lateral sclerosis clinical trials.” *Muscle Nerve*. 2020. 62(3):321-326. Available at <https://doi.org/10.1002/mus.26921>. Accessed 1-22-2021.

### Abstract

Amyotrophic lateral sclerosis (ALS) has the largest drug pipeline among neuromuscular diseases, with over 160 companies actively involved in ALS research. There is a growing need to recruit trial participants, but ALS patients often have limited mobility and most ALS trials are conducted in a small number of major centers. These factors effectively limit patient participation, particularly for those in rural areas. The current coronavirus disease 2019 (COVID-19) pandemic has necessitated the more widespread use of telemedicine technology for clinical care, and has prompted consideration of its increased use for clinical trials. In this opinion piece, we describe the current state of telemedicine for recruitment, consenting, and screening of participants for clinical trials. We also summarize the available data on remote administration of outcome measures. Current challenges include validation of outcome measures for remote assessment, as well as technological, regulatory, and licensure barriers.

**Summary:** Telemedicine devices such as digital phenotyping and respiratory function tools are being used to assess clinical trial patients with ALS in the home, but barriers exist with navigation challenges, licensure, and patient access to broadband internet.

### Key Takeaways

- Since many people with ALS live far from ALS treatment centers, telemedicine can increase participation from people with ALS in clinical trials.
- The recruitment was facilitated by the use of social media, search engines, and online advocacy organizations to promote the clinical trial studies to people with ALS. Those interested contacted study teams by phone or email to discuss participation and completed other online processes to ensure participation.
- Tele-consent using video or phone was used to engage participants who lived far away from treatment centers and electronic consent forms were used for documentation management and to maintain privacy and security.
- Remote assessments for people with ALS included physical exams and measuring respiratory function. Trained tele-presenters can be leveraged to perform neurological examinations while being observed by study investigators.
- In-home breathing function measurements for people with ALS, using remote coaching, may offer an alternative to in-office measurements to reduce travel burden and mitigate the spread of COVID-19. Digital phenotyping measures and technology measures of motor function are also being explored.
- Potential barriers to telehealth utilization for people with ALS include patient distrust, licensure barriers, challenges navigating technology, access to broadband internet, and the fact that videoconferencing could be challenging for people with advanced ALS, who may need support from a caregiver during a telehealth visit.



**30. Bonavita S, Tedeschi G, Atreja A, et al. "Digital triage for people with multiple sclerosis in the age of COVID-19 pandemic." *Neurol Sci.* 2020. 41(5):1007-1009. Available at <https://doi.org/10.1007/s10072-020-04391-9>. Accessed 1-22-2021.**

#### Abstract

We propose a possible approach for the remote monitoring of infection risk in people with multiple sclerosis, especially those on immunosuppressant drugs, during the COVID-19 pandemic. We developed a digital triage tool to be sent to patients to quickly identify people with high risk of COVID-19 infection. This tool will also limit unnecessary accesses to the MS centers, reducing the risk of spreading the infection.

**Summary:** A digital triage tool may reduce the spread of COVID-19 in people with multiple sclerosis (MS) by reducing attendance at MS centers and reducing disparities for patients living far away from clinics.

#### Key Takeaways

- Many individuals with MS are on immunotherapies, have mobility disabilities, and are immunocompromised, and therefore may be more vulnerable to COVID-19 infection. These individuals should be kept out of hospital or outpatient clinics when possible to reduce the risk of contracting COVID-19.
- Researchers sent a digital triage tool set up through Google Forms to individuals with MS to identify individuals at risk for COVID-19 so that these patients didn't have to report to a hospital or clinic for surveillance.
- **Recommendations:** The use of a digital tool for surveillance and triage may help mitigate the spread of COVID-19 for immunocompromised MS patients and may improve the management of similar conditions.

**31. Fazzi E, Galli J. "New clinical needs and strategies for care in children with neurodisability during COVID-19." *Dev Med Child Neurol.* 2020. 62(7):879-880. Available at <https://doi.org/10.1111/dmcn.14557>. Accessed 1-22-2021.**

#### *No abstract available*

**Summary:** Disruptions in neurological services during the COVID-19 pandemic have increased mental health conditions in children with neurodisabilities. Telehealth and other virtual services can be used as a care delivery strategy to continue rehabilitative care and offer psychological support for these children.

#### Key Takeaways

- The article notes that social distancing presents a challenge for people who care for children with neurodisabilities and psychiatric disorders due to the need for daily assistance and therapy services. In addition, disruptions in clinical, social, and educational activities due to the COVID-19 pandemic have increased mental health conditions in children with disabilities.
- Call centers that offer behavioral health services can be maximized by children and their families to address high levels of stress, anxiety, and depression that have been exacerbated by the COVID-19 pandemic, and it presents a low-cost infrastructure alternative for psychological and psychiatric support, especially for people without internet service.

- Telehealth has been utilized children with disabilities and their families for rehabilitation purposes and patients have reported high levels of satisfaction.
- Telehealth was found to be an effective, flexible, cost-saving approach to provide care to patients with neurological disorders.

**32. Zaagsma M, Volkens KM, Swart EAK, et al. “The use of online support by people with intellectual disabilities living independently during COVID-19.” *J Intellect Disabil Res.* 2020. 64(10). Available at <https://doi.org/10.1111/jir.12770>. Accessed 1-22-2021.**

### Abstract

*Background:* During the COVID-19 outbreak, service providers in the Netherlands had to switch toward providing remote support for people with intellectual disabilities living independently. This study aims to provide insight into the use of online support during the outbreak.

*Methods:* We analyzed quantitative data on planned and unplanned contacts between the online support service DigiContact and its service users.

*Results:* The results indicate that the COVID-19 outbreak and the related containment measures had a strong impact on online support use, specifically on the unplanned use of online support.

*Conclusion:* Offering online support as a standard component of services for independently living people with intellectual disability enables service providers to be flexible and responsive toward fluctuations in both support needs and onsite support availability during a social crisis such as COVID-19.

**Summary:** People living independently with intellectual disabilities (ID) were found to use online support services more during the COVID-19 pandemic than prior to the pandemic.

### Key Takeaways

- This article noted that the use of the online support service DigiContact by independently living people with ID increased during the first weeks of the COVID-19 pandemic.
- The substantial increase in online support use could be linked to the higher levels of anxiety in people with ID during the pandemic.
- The findings suggest that, by providing online support in addition to regular onsite support for people with ID living independently, service provider organizations can increase their responsiveness.

## Neurological Disorders Associated with COVID-19

This section includes citations that reference data on COVID-19-prompted neurological disorders and other observed factors of COVID-19 associated neurological disorders related to individual characteristics, treatment, and care delivery.

33. Koralnik I, Tyler K. “COVID-19: A Global Threat to the Nervous System.” *Ann Neurol.* 2020. 88(1):1-11.” Available at <https://doi.org/10.1002/ana.25807>. Accessed 1-22-2021.

#### Abstract

In less than six months, the severe acute respiratory syndrome-coronavirus type 2 (SARS-CoV-2) has spread worldwide, infecting nearly 6 million people and killing over 350,000. Initially thought to be restricted to the respiratory system, we now understand that coronavirus disease 2019 (COVID-19) also involves multiple other organs, including the central and peripheral nervous system. The number of recognized neurologic manifestations of SARS-CoV-2 infection is rapidly accumulating. These may result from a variety of mechanisms, including virus-induced hyperinflammatory and hypercoagulable states, direct virus infection of the central nervous system (CNS), and postinfectious immune mediated processes. Example of COVID-19 CNS disease include encephalopathy, encephalitis, acute disseminated encephalomyelitis, meningitis, ischemic and hemorrhagic stroke, venous sinus thrombosis, and endothelialitis. In the peripheral nervous system, COVID-19 is associated with dysfunction of smell and taste, muscle injury, the Guillain-Barre syndrome, and its variants. Due to its worldwide distribution and multifactorial pathogenic mechanisms, COVID-19 poses a global threat to the entire nervous system. Although our understanding of SARS-CoV-2 neuropathogenesis is still incomplete and our knowledge is evolving rapidly, we hope that this review will provide a useful framework and help neurologists in understanding the many neurologic facets of COVID-19.

**Summary:** Both younger and older patients with severe cases of COVID-19 and associated comorbidities have been found to have several neurological manifestations that have resulted in central nervous system dysfunction, strokes, and skeletal muscle injury.

#### Key Takeaways

- The article notes that 36% of people with COVID-19 had neurologic complications, which were divided into several categories: central nervous system, peripheral nervous system, and skeletal muscle injury.
- One-quarter of patients in this study had central nervous system dysfunction (e.g., dizziness, headaches, impaired consciousness, and low cases of seizures).
- People with severe cases of COVID-19 had more frequent central nervous system symptoms. People with severe cases were also more likely to be older and have more comorbidities (e.g., diabetes, hypertension and other cardiac disease, and kidney disease).
- Acute cerebrovascular disease occurred in 3% of hospitalized people, most of whom had severe cases of COVID-19. Previous studies of individuals with COVID-19 have reported strokes in both older and younger individuals with associated comorbidities like diabetes and hypertension.

34. Luigetti M, Iorio R, Bentivoglio A, et al. “Assessment of neurological manifestations in hospitalized patients with COVID-19.” *Eur J Neurol.* 2020. Available at <https://doi.org/10.1111/ene.14444>. Accessed 1-22-2021.

#### Abstract

*Background and Purpose:* The objective of this study was to assess the neurological manifestations in a series of consecutive severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)-positive patients,

comparing their frequency with a population hospitalized in the same period for flu/respiratory symptoms, finally not related to SARS-CoV-2.

*Methods:* Patients with flu/respiratory symptoms admitted to Fondazione Policlinico Gemelli hospital from March 14, 2020 to April 20, 2020 were retrospectively enrolled. The frequency of neurological manifestations of patients with SARS-CoV-2 infection was compared with a control group.

*Results:* In all, 213 patients were found to be positive for SARS-CoV-2, after reverse transcriptase polymerase chain reaction on nasal or throat swabs, whilst 218 patients were found to be negative and were used as a control group. Regarding central nervous system manifestations, in SARS-CoV-2-positive patients a higher frequency of headache, hyposmia and encephalopathy always related to systemic conditions (fever or hypoxia) was observed. Furthermore, muscular involvement was more frequent in SARS-CoV-2 infection.

*Conclusions:* Patients with COVID-19 commonly have neurological manifestations, but only hyposmia and muscle involvement seem more frequent compared with other flu diseases.

**Summary:** Hospitalized individuals with COVID-19 experience higher levels of respiratory and neurological manifestations than hospitalized individuals without COVID-19, and patients with COVID-19 tended to be younger and were more likely to be male.

#### Key Takeaways

- Hospitalized individuals who were diagnosed with COVID-19 were younger and slightly more likely to be male than other hospitalized individuals.
- Respiratory symptoms (e.g., fever, dyspnea, and cough) were more common in people with COVID-19.
- Rates of diabetes and hypertension were similar among people with and without COVID-19. However, rates of cancer and chronic renal failure were higher in people without COVID-19.
- Neurological manifestations were found in 30% of people with COVID-19. There were higher rates of neurological manifestations (e.g., headaches, encephalopathy related to fever seizures, muscle weakness, and injury) in people with COVID-19.

**35. Perrin P, Collongues N, Baloglu S, et al. "Cytokine release syndrome-associated encephalopathy in patients with COVID-19." *Eur J Neurol.* 2020. Available at <https://doi.org/10.1111/ene.14491>. Accessed 1-22-2021.**

#### Abstract

*Background and purpose:* Neurological manifestations in coronavirus disease (COVID)-2019 may adversely affect clinical outcomes. Severe COVID-19 and uremia are risk factors for neurological complications. However, the lack of insight into their pathogenesis, particularly with respect to the role of the cytokine release syndrome (CRS), is currently hampering effective therapeutic interventions. The aims of this study were to describe the neurological manifestations of patients with COVID-19 and to gain pathophysiological insights with respect to CRS.

*Methods:* In this longitudinal study, we performed extensive clinical, laboratory and imaging phenotyping in five patients admitted to our renal unit.

*Results:* Neurological presentation included confusion, tremor, cerebellar ataxia, behavioral alterations, aphasia, pyramidal syndrome, coma, cranial nerve palsy, dysautonomia, and central hypothyroidism. Notably, neurological disturbances were accompanied by laboratory evidence of CRS. Severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) was undetectable in the cerebrospinal fluid (CSF). Hyperalbuminorrachia and increased levels of the astroglial protein S100B were suggestive of blood-brain barrier (BBB) dysfunction. Brain magnetic resonance imaging findings comprised evidence of acute leukoencephalitis (n=3, one of whom had a hemorrhagic form), cytotoxic edema mimicking ischaemic stroke (n=1), or normal results (n=2). Treatment with corticosteroids and/or intravenous immunoglobulins was attempted, resulting in rapid recovery from neurological disturbances in two cases. SARS-CoV2 was undetectable in 88 of the 90 patients with COVID-19 who underwent reverse transcription-PCR testing of CSF.

*Conclusions:* Patients with COVID-19 can develop neurological manifestations that share clinical, laboratory, and imaging similarities with those of chimeric antigen receptor T-cell-related encephalopathy. The pathophysiological underpinnings appear to involve CRS, endothelial activation, BBB dysfunction, and immune-mediated mechanisms.

**Summary:** People with COVID-19 may present with neurological disturbances in the second week of COVID-19 infection, and these manifestations could be associated with cytokine release syndrome.

#### **Key Takeaways**

- According to the study, 12.7% of people with COVID-19 from this study developed neurological manifestations. Five of these patients who participated in the study did not have previous neurological diseases or manifestations.
- Individuals' neurological disturbances were associated with evidence of cytokine release syndrome.
- Central nervous system-related symptoms included confusion, agitation, tremor, impaired consciousness, dysexecutive syndrome, pyramidal syndrome, cerebellar ataxia, cranial nerve palsy, dysautonomia, and central hormonal dysfunction (mainly in the form of hypothyroidism).
- Neurological manifestations occurred in the second week after COVID-19 symptoms onset.
- Two of the five individuals in the study who received corticosteroids and intravenous immunoglobulins showed some neurological improvement.

## Medicaid Access During the COVID-19 Pandemic

This section includes citations that reference Medicaid-related strategies to increase access to care for people with disabilities and related information on Medicaid enrollment during the COVID-19 pandemic.

### Gray Literature/Organizational Reports

#### **36. Health Management Association: [“Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences”](#)**

- This document provides comprehensive information about people with ID/IDD and the Medicaid program policies and services that support their needs.

**37. National Academy of State Health Policy: “[State Medicaid Strategies to Maintain Access to Care for Children with Special Health Care Needs During the Pandemic](#)”**

- This document notes that, to address the health needs of children and adults with chronic and special healthcare conditions, states are modifying Medicaid policies and programs to increase access to critical services during the COVID-19 pandemic. Some of these changes include relaxing prior authorization requirements, closing home health services gaps, extending timelines for Medicaid fair hearings and appeals, and increasing opportunities for telehealth service delivery.

**38. National Academy of State Health Policy: “[National Academy of State Health Policy: Early Evidence Suggests Increased Medicaid Enrollment Due to COVID-19](#)”**

- This document notes that close to 27 million people could lose their employer-sponsored health insurance (ESI) due to the economic fallout from the COVID-19 pandemic, and approximately 12.7 million will be newly eligible for Medicaid coverage.
- According to this report, 47% of individuals who lose ESI would enroll in Medicaid, increasing national enrollment in the program by approximately 11.8 million people. Together, these findings show that Medicaid will become the primary source of coverage for individuals who have lost ESI coverage during the pandemic.
- There could also be an uptick in enrollment in the Children’s Health Insurance Program (CHIP) during the pandemic as families lose ESI and seek coverage options for their children. Some states have indicated that CHIP enrollment is staying stable or slightly rising because states are opting not to process terminations during the emergency period, while other states have reported significant spikes in CHIP enrollment.

**39. Kaiser Family Foundation: “[State Actions to Facilitate Access to Medicaid and CHIP Coverage in Response to COVID-19](#)”**

- This article notes that, to expand access to coverage, states are eliminating or waiving Medicaid premiums for people with disabilities in response to the COVID-19 pandemic. States are also modifying eligibility criteria for Medicaid enrollment to increase access to care.

## COVID-19 Public Health Response Strategies for People with Disabilities

This section includes citations that reference public health strategies for maintaining access to care and improving quality of life for people with disabilities during the COVID-19 pandemic.

- 40. Sabatello M, Burke T, McDonald K, et al. “Disability, Ethics, and Health Care in the COVID-19 Pandemic.” *Am J Public Health*. 2020. 110(10):1523-1527. Available at <https://doi.org/10.2105/AJPH.2020.305837>. Accessed 1-25-2021.**

## Abstract

This article considers key ethical, legal, and medical dilemmas arising for people with disabilities in the COVID-19 pandemic. We highlight the limited application of existing frameworks of emergency planning with and for people with disabilities in the COVID-19 pandemic, explore key concerns and issues affecting the healthcare of people with disabilities (i.e., access to information and clinician-patient communication, nondiscrimination and reasonable accommodations, and rationing of medical goods), and indicate possible solutions. Finally, we suggest clinical and public health policy measures to ensure that people with disabilities are included in the planning of future pandemic-related efforts.

The devastation evoked by the COVID-19 pandemic raises challenging dilemmas in bioethics. It also speaks to social justice issues that have plagued historically marginalized communities in the United States.

Responses to the pandemic must be bound by legal standards, principles of distributive justice, and societal norms of protecting vulnerable populations—core commitments of public health—to ensure that inequities are not exacerbated, and should provide a pathway for improvements to ensure equitable access and treatment in the future.

**Summary:** Establishing effective communication strategies and robust data collection and improving guidelines in disability care-settings are key strategies to consider when responding to the COVID-19 pandemic.

## Key Takeaways

- **Recommendations:** To develop effective communications for people with disabilities, states should collaborate with disability advocacy organizations to develop disability-accessible information about COVID-19, hospital admission procedures, and treatment options. States should also maximize multimodal communication strategies (e.g., radio, text, email, and television) to accommodate various groups of people with disabilities.
- **Recommendations:** Studies have shown that healthcare professionals have insufficient training on the needs of people with disabilities. States should classify caregivers as essential personnel to provide proper support to people with disabilities, especially in admission and hospitalization. Disability-friendly accessibility measures also need to be implemented in telehealth platforms to accommodate people with disabilities.
- **Recommendations:** The rationing of medical goods should be based on medical evidence for the likelihood of survival from COVID-19. Diverse interdisciplinary triage committees should be formed to consult about rationing decision-making processes to prevent biases and discrimination during rationing.
- **Recommendations:** States should increase their data collection regarding people with disabilities and COVID-19, including rates of mortality, recovery, and comorbidities. States should identify short-term and long-term remedies for people with disabilities and COVID-19, establish a fair allocation of resources, and improve guidelines in disability care settings and group homes regarding visitation, staff screening, and personal protective equipment.

41. Boyle CA, Fox MH, Havercamp SM, et al. “The public health response to the COVID-19 pandemic for people with disabilities.” *Disabil Health J.* 2020. 13(3). Available at <https://doi.org/10.1016/j.dhjo.2020.100943>. Accessed 1-25-2021.

## Abstract

With the rapidly changing landscape of the COVID-19 outbreak, how to best address the needs and continue to protect the health and well-being of people with disabilities is a global public health priority. In this commentary we identify three public health areas of ongoing need and offer possible strategies to address each. These areas include: the types of data that would help clarify risks for people with disabilities and help assure their safety long term; the prevention, treatment and mitigation measures for people with disabilities that are needed through the duration of the outbreak; and the issues of equity in access to and quality of medical care for people with disabilities. Because of the rapid nature of the public health response, it is critical to reassess and readjust our approach to best address the needs of people with disabilities in the months and years to come and to incorporate these new practices into future emergency preparedness responses.

**Summary:** People with intellectual developmental disabilities (IDDs) are at a higher risk for severe COVID-19 infections than people without IDDs, and people with IDDs are twice as likely to die from pneumonia than people without IDDs. Improving access to data on people with disabilities, disseminating comprehensive and accessible communications, and revising disability setting and care guidelines may improve health outcomes for people with disabilities during COVID-19.

## Key Takeaways

- Compared to the general population, people with disabilities are more likely to have an underlying health problem and more likely to live in congregate care settings, which increase their risks for COVID-19 infections. In addition, since people with IDDs are twice as likely to die from pneumonia than people without IDDs, this group is extremely vulnerable to the severe lung-related complications of COVID-19, like pneumonia.
- **Recommendation:** Improve data collection on people with disabilities to increase the amount of information about disability types affected by COVID-19 and potential risks, and to improve monitoring of public health interventions for people with disabilities. Incorporate disability identifiers into new or revised surveillance or other data collection systems for monitoring COVID-19 in people with disabilities. In addition, examining national, state, and local mortality data or secondary data sources such as state Medicaid data could improve prevention efforts and illustrate important healthcare and policy implications.
- **Recommendations:** Health communication materials for people with disabilities should be accessible and easily understood by all audiences to aid prevention efforts. Public health agencies should consult directly with people with disability-related advocacy groups to develop, disseminate, and evaluate these materials.
- **Recommendations:** To reduce the social and emotional needs of people with disabilities during the pandemic, ease restrictions in group home settings, create more interactive virtual spaces, and partner with local businesses operated by people with disabilities to identify easier ways to address the needs of people with disabilities.
- **Recommendations:** To ensure equitable care is provided to people with disabilities, allow interpreter services, ease visitor restrictions for people with disabilities and provide appropriate PPE to support personnel, and prioritize new COVID-19 treatments for people with disabilities.



42. Kuper H, Morgon-Banks L, Bright T, et al. “Disability-inclusive COVID-19 response: What it is, why it is important and what we can learn from the United Kingdom’s response.” *Welcome Open Res.* 2020. 5(79). Available at <https://dx.doi.org/10.12688%2Fwellcomeopenres.15833.1>. Accessed 1-25-2021.

### Abstract

All too often, disabled people are left behind in emergencies, and this is a risk in the ongoing COVID-19 pandemic. This is an important issue, as globally there are approximately one billion people with disabilities. This number includes one in three people aged over 60, who are the group at greatest risk from COVID-19. The COVID-19 pandemic in the UK has highlighted additional difficulties that disabled people may face. Complying with preventative measures, like social distancing, can be challenging, particular for people who rely on carers. Disabled people may also be at greater risk of morbidity and mortality if they contract the virus, yet in danger of being de-prioritized for care. Many people with disabilities have ongoing healthcare needs, and these need to still be supported during the pandemic. Furthermore, people may become newly disabled as a result of the pandemic, and therefore require appropriate care. Good practice examples have emerged for meeting these challenges, such as guidance for healthcare professionals on treating people with dementia, but these need to be scaled up further and adapted for other settings. In conclusion, it is clear that a disability-inclusive COVID-19 response is needed, both in the UK and as the pandemic unfolds globally. This response will require inclusion of disability measures within data collection, consulting with disabled people, and tailoring responses to be appropriate for this group.

**Summary:** As the article notes, “COVID-19 disability efforts must begin from the planning stage. This will require meaningful consultation with disabled people and their supporters, leadership at policy and program level, and dedicated budget lines. Data collection on disability is needed to allow data disaggregation.”

### Key Takeaways

- **Recommendations:** Improve provider disability education and include people with disabilities when designing strategies to respond to the COVID-19 pandemic. Consult with people with disabilities to learn about their experiences, needs, and potential solutions.
- **Recommendations:** Improve continuity of care by providing online medical services and substitute care options for people with disabilities.
- **Recommendations:** Collect data on disability within the COVID-19 response (e.g., [C-19 COVID Symptom Tracker](#)).
- **Recommendations:** Track possible new disability conditions that arise due to COVID-19 infection and design appropriate services and programs for these individuals.

### Gray Literature/Organizational Reports

World Health Organization: “[Disability considerations during the COVID-19 outbreak](#)”

This document recommends that countries:

- Ensure that public health information and communication is accessible for people with disabilities.

- Undertake targeted measures for people with disabilities, their support networks, and disability service providers in the community such as financing caregivers and families, implementing stimulus packages that include people with disabilities, adopting flexible work from home policies, etc.
- Increase attention to people with disability living in potentially higher risk settings of developing disease.
- Ensure that emergency measures include the needs of people with disabilities by working with people with disabilities and their representative organizations, ensuring disability caregivers are considered essential workers, etc.

Johns Hopkins University: [“COVID-19 poses unique challenges for people with disabilities”](#)

- This document notes that the COVID-19 pandemic poses barriers for people with disabilities, including a lack of access to communication for people with disabilities, difficulty adopting public health strategies like social distancing and handwashing, difficulty accessing healthcare (e.g., inability to access drive-through testing for COVID-19), and rationing of medical resources.
- Telehealth that is customized for people with disabilities can improve healthcare accessibility. In addition, increased access to disability data related to people with disabilities and COVID-19 can improve advocacy efforts for people with disabilities.

CDC: [“People with Certain Medical Conditions”](#)

- This document includes recent data on the increased risk of COVID-19 among people with certain medical conditions such as Down syndrome, cancer, diabetes, and heart failure.

## Other Resources

Center for American Progress: [The ACA Marketplaces Are Poised To Weather COVID-19](#)

- This document provides an overview of the ACA marketplace and describes the effects that COVID-19 could have on insurers and enrollment in the nongroup market and provides policy recommendations to strengthen the nongroup market for both consumers and insurers.

Center for American Progress: [Mental Health Care Was Severely Inequitable, Then Came the Coronavirus Crisis](#)

- This document describes the existing barriers to accessing affordable mental health services and considers the impact of COVID-19 on the mental health system.

CNN: [Covid-19 has disproportionately impacted those living with developmental disabilities](#)

- This resource describes the impact of the COVID-19 pandemic on people living with developmental disabilities.