# Rapid Research Report: Barriers the COVID-19 Pandemic Created for People with Disabilities

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## Background Information

This report summarizes current barriers the COVID-19 pandemic created for people with disabilities in addition to what they are already experiencing.

On March 11, 2020, the World Health Organization (WHO) declared the novel coronavirus (COVID-19) outbreak a global pandemic[3]. The WHO's Director General stated: "We cannot say this loudly enough, or clearly enough, or often enough: all countries can still change the course of this pandemic. If countries detect, test, treat, isolate, trace, and mobilize their people in the response, those with a handful of cases can prevent those cases becoming clusters, and those clusters becoming community transmission"[3]. At the time COVID-19 was declared a pandemic, 118,000 cases were reported globally in 114 countries with more than 90% of cases in just four countries[3]. Presently, there are close to 4.5 million confirmed cases of COVID-19 deaths reported to WHO, with a total of 4.95 billion vaccine doses administered[4]. The global impact of the COVID-19 pandemic has been catastrophic. Millions of lives have been lost, economies have suffered greatly, and day to day living has changed drastically. One population that has been significantly impacted due to potential increased risk of contracting COVID-19, higher risk for serious illness from COVID-19, and/or increased difficulty accessing health care are individuals with disabilities.

According to the Centers for Disease Control and Prevention (CDC), 61 million adults in the United States live with a disability[5]. More specifically, twenty-six percent (1 in 4) adults in the U.S. have some type of disability[3]. For individuals with disabilities, the novel coronavirus that caused the COVID-19 pandemic has significantly impacted their health and well-being, profoundly impacting barriers already faced while creating new ones as well. In addition to some individuals with disabilities being at higher risk to become infected (e.g., people with disabilities living in institutional settings such as group homes and assisted living facilities) or to experience

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[3] https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020
[4] https://covid19.who.int/
[5] https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html

complications from COVID-19, many people with disabilities struggle to find access to an aide (e.g., personal care worker), lack access to medical supplies or medical equipment, have increased telehealth barriers, issues accessing transportation, and are at an increased risk of poverty, to name a few. There are several reasons why people with disabilities are more vulnerable during the COVID-19 pandemic. Some of these reasons are directly related to their disability, and other reasons are related to COVID-19 protocol and procedures that impact access to care.

## Research Question

What extra barriers (environmental, societal, attitudinal, etc.) did the COVID-19 pandemic create for people with disabilities, in addition to what they are already experiencing?

### Environmental

The COVID-19 pandemic has had significant economic impact on many families, with a potentially higher impact on families of individuals with disabilities. As seen in the past 18 months, the labor market has significantly changed, with household incomes being drastically reduced. In general, households with members with disabilities tend to have fewer working members to offset loss of income if someone loses work, mainly due to individuals with disabilities either being underemployed or unemployed and other household members choosing to forgo work to provide caregiving to their family member[6]. In addition, many people with disabilities tend to choose more informal settings for employment, which lack job security and financial protection (e.g., unemployment insurance, paid sick leave)[7]. It also may take individuals with disabilities longer to re-enter the workforce after restrictions to the COVID-19 pandemic ease, due to long standing issues of stigma of disability, inaccessible environments, and poor access to education and training that limit job opportunities[6].

Another barrier that the pandemic created for individuals with disabilities is that many of the essential health and social services have been disrupted due to lockdown. Rehabilitation services, assistive devices, care for chronic conditions, psychiatric appointments, medications, personal assistance, and many other services that were in place prior to the pandemic were significantly impacted when restrictions were put in place and people with disabilities no longer had access to their routine. Disruption to crucial services can lead to deteriorating health, both physical and mental, which can also lead to higher future healthcare spending as well as a loss to both immediate and future functioning and productivity[8]. For example, if an individual with a mental health condition is not able to schedule an appointment to see their psychiatrist due to lack of transportation and access to telehealth, they could run out of medication and potentially exacerbate their mental health symptoms. This could have a significant negative impact on their life and, depending on the severity of their illness, take months to recover. For many individuals

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[6] WHO & World Bank (2011). World report on disability. World Health Organization.
[7] Mizunoya, S., & Mitra, S. (2013). Is there a disability gap in employment rates in developing countries: *World Development, 42*, 28-43.
[8] Shakespeare, T., Bright, T., & Kuper, H. (2018). *Access to health for persons with disabilities*. Geneva: United Nations High Commissioner for Human Rights.

with disabilities, this created significant setbacks to personal goals such as independent living or employment that could take years to turn around.

In the past, telemedicine served as an alternative to traditional medicine for many patients, being utilized when needed and available due to access issues for in-person care. During the pandemic, many healthcare appointments were transitioned to telemedicine (if not cancelled altogether), creating an additional barrier to individuals who did not have access to the appropriate equipment or knowledge to utilize this type of resource. One of the biggest obstacles for utilizing telemedicine is that broadband (i.e., fast internet) is not accessible for many people with disabilities. For example, broadband is inaccessible in rural and low-income communities where many individuals with disabilities live[9]. Unfortunately, there is no financial benefit nor a legal requirement for proper internet access to be granted to everyone, thus private providers and network companies lack incentive to provide equal access[9].

The need for appropriate accommodations when utilizing telehealth services and the lack of access to these accommodations is also a barrier for individuals with disabilities. Accommodations such as screen readers, sign language, captions, magnification, color optimization, and/or contrasting are also possible needs that may not be readily available or accessible during a pandemic[9]. Additionally, many in-person healthcare appointments coincide with ancillary healthcare services such as laboratory testing or diagnostic studies, procedures that cannot be completed properly via telehealth. Communication via telemedicine can also be difficult for some individuals with disabilities such as persons with an intellectual disability, neurological or speech disorders, or an individual with autism spectrum disorder[9].

Circumstances associated with disability, such as older age, underlying health conditions, and experiencing poverty, can also make individuals with disabilities more vulnerable to negative outcomes from the COVID-19 pandemic. Some individuals may be at greater risk due to the nature of their disability. For example, individuals with an intellectual disability may have difficulty understanding and performing routine measures to ensure safety from the coronavirus, thus increasing their risk of becoming infected as well as infecting individuals around them[10]. Other people may not be able to physically distance due to their personal needs,[11] and others may be difficult to diagnose due to screening and triage challenges (i.e., spinal cord injuries)[12]. These additional challenges not only put individuals with disabilities at risk for serious illness due to the coronavirus but also potential increased spread due to lack of access to proper healthcare, safety, and procedures.

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[9] Annaswamy, T. M., Verduzco-Gutierrez, M., & Frieden, L. (2020). Telemedicine barriers and challenges for persons with disabilities: COVID-19 and beyond. *Disability and Health Journal*, *13*(4), 100973.
[10] Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: Impacts of a pandemic. *Irish Journal of Psychological Medicine*, *37*(3), 231-236.
[11] Boyle, C.A., Fox, M.H., Havercamp, S.M., Zubler, J., 2020. The public health response to the COVID-19 pandemic for people with disabilities. *Disability Health Journal, 13* (3), 100943.
[12] Korupolu, R., Stampas, A., Gibbons, C., Hernandez Jimenez, I., Skelton, F., Verduzco-Gutierrez, M., 2020. COVID-19: Screening and triage challenges in people with disability due to Spinal Cord Injury. *Spinal Cord Series and Cases 6*, 1–4.

Transportation barriers for individuals with disabilities have magnified during the COVID-19 pandemic. For many people who rely on others for transportation (i.e., family, friends, public transportation), asking for a ride during the pandemic can be extremely risky for both them and the individual providing transportation[13]. In addition to transportation itself, many individuals, such as individuals who are blind or have low vision, may feel an increased fear or worry about the cleanliness of public transportation due to their heavy reliance on touch for navigation and fear of the coronavirus being transmitted via surfaces[12]. Additional protocols that have been put into place during the pandemic may have lacked attention to accessibility. For example, transit companies moved to rear-door boarding to help people stay distanced and separated, but for individuals using a wheelchair or using paratransit, it is not an option for them to be distanced from the driver[12]. The need to access transit via the front (i.e., door with ramp) and require assistance to secure the wheelchair while on transit poses an increased risk for individuals that require such accommodations.

Not only has the pandemic impacted individuals with disabilities access to rides to and from places but also their ability to perform general, essential tasks that many people take for granted, such as grocery shopping. Some people need assistance with grocery shopping (i.e., cannot reach certain products or cannot read labels), other individuals may need assistance with daily living tasks such as bathing or cooking. Many of these tasks are typically performed by family or friends. During the COVID-19 pandemic, these tasks have become extremely limited, and individuals are unable to maintain their daily routines due to the dangers of exposure to the coronavirus.

## Societal

During the COVID-19 pandemic, mandates throughout the United States have required people to wear masks in public. Although the use of masks can help reduce the spread of the coronavirus, it also significantly impacts the ability to communicate for many individuals who are Deaf or hard of hearing[14]. Communication accessibility is extremely difficult when many individuals wear non-transparent masks, thus creating additional barriers for individuals who rely on speechreaders (i.e., lipreaders), those who rely on residual hearing and have difficulties hearing muffled speech behind masks, and for individuals who may not speechread but are able to utilize mouth movements and facial expressions to determine some communication[14]. Clear masks and clear face shields are one option to reduce this barrier although oftentimes they are not clear enough to provide adequate communication. Additional resources that can help individuals who are Deaf or have hearing disabilities when they are communicating with someone wearing a mask is to utilize professional sign language interpreters, electronic writing tablets, speech to text apps, apps for writing notes, professionally rendered captioning services, and/or assistive listening devices[14,15].

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[13] Cochran, A. L. (2020). Impacts of COVID-19 on access to transportation for people with disabilities. *Transportation research interdisciplinary perspectives, 8*, 100263.
[14] https://www.nad.org/position-statement-on-communicating-with-dhh-while-wearing-masks/
[15] https://mn.gov/deaf-hard-of-hearing/communication-access/emergency/masks.jsp

Many individuals with disabilities have smaller support networks than people without disabilities, thus creating an additional barrier during a time such as this[16]. Smaller support systems can increase risk during the pandemic due to a person's compromised ability to obtain assistance during or after emergencies[17]. In addition, being more socially isolated may increase risk for missing important communications during emergency scenarios; key information that could assist individuals with making informed choices about their own safety and the safety of those they encounter[18]. Communication during emergencies is not the only communication barrier individuals with disabilities have faced during the COVID-19 pandemic. Many individuals encountered additional challenges due to communications being either inaccessible or inaccurate due to mixed messages. Due to companies being closed, access to transportation changing, and a variety of other system changes during lockdown, many individuals with disabilities did not know if they would have access to the services they typically utilized to meet their needs. In addition, some individuals did not utilize technology or have access to technology to acquire the necessary information needed to know what services were available and when. Due to ongoing changes regarding information throughout the pandemic, access to care and daily needs became increasingly difficult, stressful, and time consuming. Increased risk of interpersonal violence toward people with disabilities has been discussed in the literature for years[19].

The ongoing pandemic and the subsequent lockdown as an attempt to minimize the spread of the coronavirus have had significant albeit unintentional consequences on individuals at risk for violence[20]. More specifically, lockdowns, quarantines, or any other type of safer at home measures can place individuals in situations that put them in more frequent contact with their abuser in addition to removing access to resources that could provide safety (e.g., fewer caregivers coming into the home due to increased social distancing protocols)[18]. Making matters more difficult or unique for individuals with disabilities is the reliance of many individuals on the perpetrators of their abuse for assistance with their activities of daily living such as getting dressed, eating, and bathing[21]. Furthermore, reliance on others, in this case the perpetrator of violence, creates a unique form of disability-related abuse based on the tendency of the perpetrator to deny assistance or destroy medical equipment either through malice or neglect[18].

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[16] Lippold, T., Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research, 53*, 463-473.

[17] Stough, L. M., Ducy, E. M., Holt, J. M., (2017). Changes in the social relationships of individuals with disabilities displaced by disaster. *International Journal of Disaster Risk Reduction, 24*, 474-481.

[18] Matherly, D., Mobley, J. (2011). Transportation and Emergency Management Tool Kit for Communications with Vulnerable Populations: Key Research Findings. *Transportation Res. Rec, 2234*, 62-70.

[19] Hughes, R. B., Lund, E. M., Gabrielli, J., Powers, L. E., & Curry, M. A. (2011). Prevalence of interpersonal violence against community-living adults with disabilities: A literature review. *Rehabilitation Psychology, 55*, 263-271.

[20] Lund, E. M. (2020). Interpersonal violence against people with disabilities: Additional concerns and considerations in the COVID-19 pandemic. *Rehabilitation Psychology, 65*(3), 199-205.

[21] https://www.nytimes.com/2020/04/06/world/coronavirus-domestic-violence.html?fbclid=IwAR1qzC4cbziVwoeGXNEYAKyqSkx1jKPqLB1Jh7qsNvKhf1DtSGrst3iPWg8

Increased time at home and lack of access to resources can increase reliance on the perpetrator, thus creating more barriers for individuals with disabilities during the pandemic.

## Attitudinal

As mentioned previously, access to medical care has been a barrier for individuals with disabilities throughout the pandemic. Not only have individuals been fearful of going to appointments, lacked transportation to make it to appointments, or been unable to access telehealth appointments, but individuals with disabilities are also fearful of being de-prioritized when it comes to emergency medical interventions and potentially being passed over for testing due to the perception of being "lower priority" than individuals without disabilities[22]. Shortages in medical treatment, medical staff, and medical equipment continue to threaten access to medical care for everyone in the United States, and although rationing strategies using likelihood of survival and life expectancy seem reasonable during desperate times, there are also complex ethical and social justice issues that come to the forefront including how these decisions affect marginalized groups such as individuals with disabilities[23]. Individuals with disabilities may also have difficulty with the accessibility of COVID testing sites or need interpreter services at testing sites. Community based drive-through testing sites are inaccessible in urban areas, where fewer people have access to cars and many individuals with disabilities live[24]. To try to mitigate these issues, a Disability Core Advisory Group in New Jersey initiated a pilot mobile testing service, which allows individuals with disabilities to be tested at home[22]. In addition, the Northwest Americans with Disabilities Act Center developed a toolkit to assist with accessibility at drive-through medical sites. This toolkit provides information such as: training staff on disability etiquette, wheelchair-user access, service animals, effective communication for people who are deaf or hard of hearing or for people who are blind or have low vision[25]. A testing site in Chicago reserves the first hour of testing for older adults and for individuals with disabilities[22]. And in Colorado, a risk analysis was conducted to ensure testing sites were accessible and appropriately located[22]. These best practices should be considered throughout the country to ensure accessibility for everyone.

Several guidelines have been published that have specifically targeted individuals with disabilities as being less likely candidates for proper care and access to medical equipment during a time when rationing is needed. For example, the Alabama triage guidelines published in response to the COVID-19 pandemic stated that individuals with severe or profound intellectual disabilities "are unlikely candidates for ventilator support"[26]. Additionally, Tennessee developed guidelines identifying individuals with spinal muscular atrophy and other individuals who required assistance with activities of daily living as those who are ineligible for critical care

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[22] Lund, E. M., & Ayers, K. B. (2020). Raising awareness of disabled lives and health care rationing during the COVID-19 pandemic. Psychological Trauma: *Theory, Research, Practice, and Policy, 12*, S210-S211.
[23] Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2020). No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *The American Psychologist, 76*(3), 451-461.
[24] https://www.fema.gov/case-study/covid-19-testing-considerations-people-disabilities
[25] https://nwadacenter.org//factsheet/accessibility-drive-thru-medical-sites
[26] https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html

when equipment is limited[18]. Guidelines were also developed by the University of Washington Medical Center that rationed care to "the survival of young otherwise healthy patients more heavily than older, chronically debilitated patients"[27]. The American Association of People with Disabilities sent a letter to Congress about this discrimination, urging Congress to swiftly pass a statutory prohibition on the rationing of scarce medical resources and provide equal access to scarce medical resources to people with disabilities[28]. Although a statutory prohibition has not been signed, the director of the federal health department's civil rights office has opened a series of civil rights investigations to ensure that states do not allow medical providers to determine course of care or discriminate based on disability, race, age, or certain other factors when deciding who would receive lifesaving care during the COVID-19 pandemic[29].

## Conclusion

Prior to the COVID-19 pandemic, individuals with disabilities faced many environmental, societal, and attitudinal barriers. The pandemic has worsened many of these barriers as well as created new ones for people with disabilities to now fight and overcome. Access to healthcare and proper medical equipment, access to transportation, lack of resources to assist with activities of daily living, increased risk due to other underlying conditions, increased risk due to living facilities, inability to properly access telemedicine, and many other barriers mentioned in this report have been identified and discussed as ongoing issues throughout this pandemic. Additional resources, appropriate access, and accurate information are some of the few things that are necessary to aid individuals with disabilities in overcoming some of these barriers, especially during such a difficult time.

[27] https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf
[28] https://www.aapd.com/wp-content/uploads/2020/03/COVID-19-Response-Package.pdf
[29] https://www.nytimes.com/2020/03/28/us/coronavirus-disabilities-rationing-ventilators-triage.html