# The Impact of COVID-19 on Disability Research: New Challenges and Widening Disparities



## Executive Summary

The COVID-19 pandemic resulted in widespread shutdowns in March 2020 across virtually every sector at the local, state, and federal levels in order to halt the spread of the virus throughout the United States. These shutdowns caused research and development institutions to suspend their research and attempt to transition as many projects as possible to a virtual format. While most studies resumed in 2020, including some essential in-person research, many projects experienced significant impacts to finances, quality and efficiency, knowledge dissemination, disparities for researchers, and topics of research. COVID-19 has significantly affected research productivity, with an estimated loss in federal research output between 20 to 40 percent (Council on Governmental Relations, 2020).

To address these far-reaching impacts of COVID-19, federal legislation has allocated funding to COVID-19 research and development as well as economic relief. Funding specifically related to COVID-19 and disability has been provided to the Administration for Community Living to assist with programs serving people with disabilities in a variety of areas. Additionally, the Centers for Disease Control and Prevention (CDC) has contributed funding to ensure COVID-19 educational resources are available for people with disabilities who have low literacy.

Despite increased funding for disability-related programing, no specific funding was allocated for research on COVID-19 and disability although this population faces a higher risk of developing the virus and experiencing adverse outcomes. While a few studies on disability and COVID-19 exist across federal research institutions, people with disabilities have largely been left out of the major COVID-19 studies, with no information being collected on disability as a main demographic category. People with disabilities must be included in future research on COVID-19. Efforts to collect disability statistics must improve in order to address the virus’s disproportionate impact for people with disabilities.

COVID-19 has led to an increased reliance on technology across disability research, creating significant benefits and challenges to both disability researchers and people with disabilities. To adapt to the changing research climate, disability researchers have adjusted their projects in innovative ways, shifting their interventions and assessments to virtual formats. Increased collaboration is a positive result of this virtual shift, as many researchers have connected virtually who might not have otherwise. However, it is important to note that while virtual interventions might increase access for some people with disabilities, this format has the potential to leave out a significant portion of this population due to disparities in ownership and use of technological devices for people with disabilities.

New topics and concerns have emerged in the disability research sphere as a result of COVID-19. Some of the emerging topics include: the direct service professional workforce, health care rationing, effect of COVID-19 on preexisting health disparities, increased susceptibility of people with disabilities to COVID-19, unemployment, pandemic-related stress and trauma, and the shift to virtual services and supports. Several important findings have emerged from studies in these areas, yet additional research is imperative to fully understand the impact of COVID-19 on the lives of people with disabilities.

Disability research has expanded its scope in creative ways to examine COVID-19 and disability, yet several areas still remain largely unaddressed. Areas that warrant future research on disability and COVID-19 are: accessible technology, economic impacts, emergency planning, and social isolation. While these topics have been examined as they relate to the general population, they have yet to be addressed in the context of the unique challenges that people with disabilities face during the pandemic. The field of disability research should continue to examine the impact COVID-19 is having on people with disabilities and develop unique solutions to the increasing challenges and widening disparities.

## Introduction

The field of disability research has worked extensively to bridge disparities between people with and without disabilities. However, the COVID-19 pandemic has highlighted and accentuated existing disparities for people with disabilities. Furthermore, the pandemic has vast implications for federal research, creating new challenges for the safe and efficient continuation of research with human subjects throughout the pandemic. Disability research has turned to technology to provide virtual options for conducting research, yet technology access is an area of inequality between people with and without disabilities. This paper discusses COVID-19’s impact on federal research, as well as the impact on the disability research community specifically. Challenges to the continuation of disability research during the pandemic are discussed in addition to innovations and emerging topic areas. Finally, this paper highlights areas of disability research related to COVID-19 that warrant further exploration.

## The Impact of COVID-19 on Federal Research and Development

The effects of COVID-19 on federal research and development (R&D) have been significant, impacting research projects in wide-ranging and long-lasting ways. R&D institutions have had to make tough decisions about what projects should continue in person, be suspended temporarily, or shift to being conducted remotely. Some of the major areas COVID-19 has impacted in federal R&D are costs, quality and efficiency, knowledge sharing, and research focus (Morgan & Sargent, 2020).

### Financial Impacts

COVID-19 has impacted finances for R&D institutions in a variety of ways. Starting and stopping research efforts has led to increased costs for materials and resources (Morgan & Sargent, 2020). In addition, planned research conferences have been cancelled or transitioned remotely, often leading to substantial cancellation costs or added costs for virtual platforms and planning. Obtaining the necessary computing and networking equipment to accommodate working remotely is another significant added expense for research institutions. Furthermore, while grant and funding amounts remain the same, increased costs for transitions to remote research are typically not added to the total funding amount. This leads to reduced quality of research, as there are fewer resources to draw from for the research process itself.

Increased health care costs at university hospitals is another major financial impact for large research universities. Universities that do not have their medical schools or hospitals housed in a separate not-for-profit organization face significant liability for the increased costs of treating COVID-19 patients. In spring 2020, some university hospitals faced losses of more than $100 million (Radecki & Schonfeld, 2020). Government assistance is designed to alleviate some of this financial burden; however, this will likely still have an impact on the budgets of large universities with hospitals.

COVID-19 has redirected federal resources toward the national pandemic response, reducing the overall amount of funding available for R&D efforts in other fields (Morgan & Sargent, 2020). Due to the economic impacts of COVID-19, federal revenue has also decreased, leading to potential decreases in federal research funding. However, different research fields will be impacted disproportionally from this, as health-related fields may see an increase in federal funding resulting from increased funding toward the COVID-19 response.

### Impacts to Quality and Efficiency

Agencies that have suspended some elements of their research or shifted to remote technology will likely experience an impact on the quality and efficiency of their studies. Starting and stopping research or transitioning research to being conducted remotely takes up significant time and resources. For institutions able to continue their R&D projects uninterrupted, they may have faced other impacts to their quality or efficiency, such as closures of service providers involved in the research (Morgan & Sargent, 2020). In addition, many federally funded research studies are conducted at universities, which have relied on a variety of conditions to make decisions about the safety of continuing research during the COVID-19 pandemic. Some of these conditions include: federal agency directives, ethical considerations about the safety of the individuals being studied, and the university’s risk management decision-making process (Morgan & Sargent, 2020). Grantees at universities that chose to suspend in-person activities in response to the pandemic likely will see a decrease in the quality and efficiency of their studies. This is due to having to pause the study in the spring when universities shut down and having to reformat studies for remote technology.

### Impacts to Knowledge Dissemination

Knowledge dissemination is another area impacted by COVID-19. Cancelling or postponing research conferences greatly impacts efforts toward knowledge sharing and translation, with certain fields impacted more significantly than others (Morgan & Sargent, 2020). For example, conference proceedings may be more impactful than published papers for particular research fields. Travel restrictions imposed due to COVID-19 can also impact knowledge dissemination at conferences or other research-related in-person events. While knowledge dissemination can occur virtually, there appears to be a learning curve as research institutions are gathering the necessary hardware, software, and user skills to achieve comparable results to in-person events. While virtual dissemination events will likely improve as researchers familiarize themselves with virtual conferencing platforms, the learning curve to improve at virtual conferencing will take time and likely result in less cumulative knowledge dissemination occurring than prior to the pandemic.

However, a positive innovation resulting from COVID-19 is increased collaboration and cooperation among researchers. Working together to share research related to COVID-19 has brought together a variety of researchers who might not have otherwise worked together. Innovative methods of sharing information have emerged, allowing researchers to share their research methods, data, and findings. As researchers improve at using videoconferencing platforms, this type of virtual collaboration could increase access to research and collaboration partners in the future.

### Increasing Disparities Among Researchers

Not only has COVID-19 exacerbated disparities in the general population, it has also widened disparities among researchers. One major area of impact for researchers is gender equality. A study found the pandemic has accentuated gender disparities within the field of research that existed beforehand. Female researchers are publishing less and starting fewer research projects during the pandemic than their male peers (Harper et al., 2020). A potential explanation for this difference is that women are navigating caregiving roles for their family and children despite working from home. Further indicating increased gender inequality, a survey found female scientists, especially ones with young children, report a substantial decline in time devoted to research during the COVID-19 pandemic (Myers et al., 2020). The work-life balance for researchers, and disproportionately for women, has significantly impacted federal research.

Immigration status is another area in which COVID-19 has widened disparities for federal researchers. Prior to COVID-19, many international students had challenges in their educational and career development due to difficulty obtaining visas. However, COVID-19 has heightened these issues, with significant delays in the immigration system and the tightening of immigration policies (Loweree et al., 2020). For noncitizen researchers, this has often resulted in a lapse in their research in addition to the added stress and pressure this creates.

### Shift in Research Focus

Research institutions have also had to make decisions about which projects are essential, such as COVID-19 research, and which should be put on hold or transitioned to being conducted remotely (Morgan & Sargent, 2020). Projects that are suspended and cannot be adapted remotely risk being lost in their entirety (Council on Governmental Relations, 2020). Additionally, many institutions have transitioned their resources to COVID-19-related research, diverting resources from other major research topics. Many research specialties will see less progress in other topic areas as they devote much of their new funding to COVID-19 R&D.

### Estimated Impact of COVID-19 on Federal Research Productivity

The Council on Governmental Relations developed a new model, known as the Research Impact Metric model, which estimates the research output loss and financial impact resulting from the COVID-19 pandemic and economic downturn (Council on Governmental Relations, 2020). This model estimates the losses in federal research output resulting from COVID-19 are between 20 and 40 percent. Additionally, they estimate financial disinvestment has impacted hundreds of millions of dollars at individual institutions and in the tens of billions of dollars across the entire federal government research sphere.

## Federal Legislation and Funding for COVID-19 Research

### Coronavirus Preparedness and Response Supplemental Appropriations Act

The Coronavirus Preparedness and Response Supplemental Appropriations Act passed on March 6, 2020. It allocates a total of $6.2 billion to the U.S. Department of Health and Human Services (HHS), which includes $3.4 billion to the Public Health and Social Services Emergency Fund, $1.9 billion to the CDC, $836 million to the National Institute of Allergy and Infectious Disease at the National Institutes of Health (NIH), and $61 million to the Food and Drug Administration (Oum et al., 2020). This funding covers a wide range of activities within these programs, to include: research and development of vaccines, therapeutics and diagnostics, grants for the Health Center Program, local response efforts, and addressing supply chain interruptions. In addition to the funding to HHS, this supplemental funding also offers $20 million in administrative funds to the Disaster Loans Program Account for the Small Business Administration and $1.3 billion to fund foreign operations activities, to include U.S. Department of State operations, global health efforts, and international disaster assistance, support, and oversight (Sekar et al., 2020). Funding from this Act did not specifically address the disability community or disability research related to COVID-19.

### Families First Coronavirus Response Act

The Families First Coronavirus Response Act passed on March 19, 2020. This law mandated certain employers to offer paid sick leave or expand paid family and medical leave to cover circumstances related to COVID-19 (U.S. Department of Labor, 2020). The expanded leave applied through December 31, 2020. Additionally, this law increases Medicaid federal matching funds by 6.2 percent for the duration of the pandemic as well as funding for food assistance and free COVID-19 testing. Disability advocates identify that while this law represents progress in the right direction, additional Medicaid funding will be needed to handle the increased enrollment in Medicaid due to the pandemic (Center for Public Representation, 2021).

### Coronavirus Aid, Relief, and Economic Security (CARES) Act

The Coronavirus Aid, Relief, and Economic Security (CARES) Act passed on March 27, 2020. The CARES Act allocates around $2 trillion toward economic relief due to the COVID-19 pandemic for individuals, small businesses, state and local governments, big corporations, and the public health system. In April, HHS announced $955 million in grants to be awarded to the Administration for Community Living, and they awarded this money for older adults and people with disabilities as follows: $85 million to the Centers for Independent Living, $200 million for Home and Community-Based Services, $480 million for home-delivered meals for older adults, $20 million for nutrition and other services for Native American Programs, $100 million for the National Caregiver Support Program, $20 million for the State Long-term Care Ombudsman programs, and $50 million for the Aging and Disability Resource Centers (HHS, 2020a).

The CARES Act also authorizes stimulus checks of up to $1,200 per individual and $500 per child. However, adults who are dependents on another adult’s tax returns were excluded from receiving a stimulus check. The stimulus checks do not count against the asset limits that people with disabilities face as long as the money is spent within 12 months (Pauli, 2020). Nevertheless, people on Supplemental Security Income had to file taxes to receive their stimulus check, creating a major burden for many people with disabilities as the forms can be challenging. The CARES Act also formed Pandemic Unemployment Assistance, which expanded unemployment insurance to cover self-employed workers, gig workers, and independent contractors. This is important as many people with disabilities work in the gig economy or own a small business. Another critical area the CARES Act supports is allowing Medicaid programs to pay for direct support professionals (DSPs) to assist people with disabilities who are in the hospital. However, despite this improvement, issues related to the DSP workforce during the pandemic remain largely unaddressed.

One major concern of disability advocates is that the CARES Act included provisions to waive requirements from the Individuals with Disabilities Education Act (Pauli, 2020). In the final version of the law, the Secretary of Education must report to Congress within 30 days about “where, how, and why waivers are being used and students with disabilities are accessing online learning” (Pauli, 2020). It is important during the pandemic for students with disabilities to still receive the same access to a free public education as their peers without disabilities. The CARES Act also fails to address the heightened concerns of people with disabilities regarding medical rationing. Disability advocates believe the CARES Act missed the chance to provide a universal message about treating people with disabilities equally.

### Paycheck Protection Program and Health Care Enhancement Act

The Paycheck Protection Program and Health Care Enhancement Act passed on April 24, 2020. Its primary purpose is to replenish the Paycheck Protection Program, which offers forgivable loans to small businesses and nonprofits and to provide funding for COVID-19 testing R&D. It allocates $11 billion for states, localities, territories, tribes, tribal organizations, urban Indian health organizations, or health service providers to tribes, $1 billion for the CDC, $1.8 billion for the NIH, $1 billion for HHS’s Biomedical Advanced Research and Development Authority, $22 million for the Food and Drug Administration, $600 million for the Health Resources and Services Administration, $225 million for rural health clinics, and $1 billion to cover testing for people who are uninsured (Moss, 2020). This law also includes a fund to reimburse medical providers for any COVID-19-related expenses or lost revenue. While this law addresses COVID-19 testing for rural areas and the uninsured, it does not specifically address the disability community in relation to COVID-19 testing.

### CDC Disability-Related COVID-19 Funding

As part of the funding from the first three COVID-19 relief bills, the CDC awarded $3 million to assist with the development of COVID-19 resources for people with disabilities who have low literacy. The goal of this funding is to ensure emergency response communications are accessible (HHS, 2020b). The CDC also provided $10 million to the Association of State and Territorial Health Officials, the National Association of County and City Health Officials, and the Association of University Centers on Disabilities to assist with the development of COVID-19 preparedness and planning efforts for people with disabilities (HHS, 2020b).

### COVID-19 Relief in the Consolidated Appropriations Act, 2021

The Consolidated Appropriations Act, 2021, became law on December 27, 2020. This law includes several measures for COVID-19 relief as part of the package to fund the federal government through the end of the next fiscal year. This law allocates money to extend unemployment benefits, to include self-employed or gig workers, and to extend rental assistance and the Supplemental Nutrition Assistance Program (Naylor, 2020). This law also allocates stimulus checks of $600 for each adult and child for those earning up to $75,000 per year. While the Consolidated Appropriations Act extends the employer tax credits for offering paid sick leave and expanded family and medical leave for employees through March 31, 2021, this Act does not extend employees’ entitlement to this type of leave past December, 31, 2020 (U.S. Department of Labor, 2021). Therefore, employers are not legally obligated to continue to offer this expanded leave through March 2021.

The Consolidated Appropriations Act also issues $82 billion to the education system and $45 billion to the transportation system. Transportation and education are two important areas in which people with disabilities often face issues with accessibility (Naylor, 2020). This extra funding could potentially benefit people with disabilities, depending on how the funding is used. This Act also allocates $68 billion to the purchase and distribution of the COVID-19 vaccine, with $20 billion of this funding to ensure the vaccine will be cost-free to people who need it (Naylor, 2020). The last major area this law addresses is broadband access, providing $7 billion to increase access to broadband across the country. As people with disabilities experience reduced access to broadband internet, this allocation has the potential to increase broadband access for people with disabilities.

## The Impact of COVID-19 on the Disability Research Community

The COVID-19 pandemic has had additional implications for the disability research community. Not only has the pandemic changed the landscape of how research is conducted, but it has also changed the focus of disability research. Additional developing challenges include COVID-19 data collection efforts on disability and the inclusion of people with disabilities in COVID-19 research. While research has illuminated the disproportionate impact of COVID-19 on people with disabilities, a variety of other areas related to the impact of COVID-19 for this population deserve increased attention from the research community.

### Challenges and Changes in Research Design

The shift to conducting research remotely due to COVID-19 creates major changes in the field of disability research. In spring 2020, the majority of designated “non-essential” research was put on hold. For disability studies spanning multiple years, this results in holes in the data, especially for studies that relied on in-person evaluations or assessments. Although most research resumed in summer 2020, research projects were significantly modified due to the constraints of social distancing. Researchers have shifted to using online questionnaires or phone interviews, and interventions are being delivered remotely via videoconferencing services. While a handful of disability research projects used remote methods prior to COVID-19, little is known about the effectiveness of virtual interventions. While this remains a huge challenge for the consistency of research studies and the potential effectiveness of interventions, it provides a unique opportunity for innovation. If virtual methods prove effective, adding remote options for participants could increase the diversity of the population studied. However, it is important to note the inequality related to technology access that persists for people with disabilities and, therefore, the equal importance of maintaining in-person options post-pandemic.

While these modifications have impacted the conduct of research, researchers note COVID-19 has provided time for them to focus on activities such as “writing literature reviews, maintaining and updating laboratory notebooks, organizing data and back-burnered data analysis” (Radecki & Schonfeld, 2020). Certain aspects of federally funded disability research have been modified, but the volume of research-related activities appears to be steady if not increasing due to additional COVID-19-related research funding.

### Limited Disability-Specific COVID-19 Research

Many of the major COVID-19 research studies have not specifically involved people with disabilities or collected information about disability. Disability-related organizations have continued to voice concerns about the lack of inclusion of people with disabilities in COVID-19 research. Many of the resources related to COVID-19 and disability are resources educating individuals on safety precautions for the pandemic. Little information is available about the scientific impact of the disease on people with disabilities. To attempt to change this, some federally funded research institutions have started to engage in disability-specific research on COVID-19.

#### Minimal Data Collection on Disability in COVID-19 Research

People with disabilities and advocacy groups have voiced concerns that information related to disability is not being collected in major COVID-19 research studies. A National Institute on Disability, Independent Living, and Rehabilitation Research- and NIH-funded grantee released a research paper in July 2020 discussing the lack of data on COVID-19 and disability, stating, to date, there were only two current reports of COVID-19 trends among people with disabilities (Sabatello, Landes, et al., 2020). This paper emphasizes that disability status should be part of the important demographic information collected from all participants in COVID-19 research studies. Some disability researchers are attempting to address this lack of data collection by conducting disability-specific research on COVID-19. For example, John Hopkins Disability Health Research Center is recruiting people with disabilities for a study to inform COVID-19 policy for the disability community. The study will use focus groups to gather qualitative information about health care, accessibility, and employment-related gaps in the response to COVID-19. Despite more disability-specific COVID-19 studies emerging, it is essential that the large COVID-19 studies consider people with disabilities and collect data on disability status.

#### Lack of Inclusion of People with Disabilities in COVID-19 Research

The Disability and Rehabilitation Research Coalition (DRRC) wrote a letter to the director of the NIH in September 2020 explaining the crucial nature of including people with disabilities in COVID-19 research and examining complications and outcomes for this population. They emphasized that this population already experiences poorer health and health outcomes compared to their peers, so including them in this research is essential (DRRC, 2020). The DRRC recommended four main areas for federal funding of research on COVID-19 and people with disabilities: (1) ensuring inclusion of people with disabilities in existing COVID-19 research, (2) disability-specific COVID-19 research, (3) rehabilitation interventions for COVID-19 and recovery, and (4) immediate impacts of the COVID-19 pandemic on people with disabilities (DRRC, 2020).

An additional area initially lacking inclusion for people with disabilities was the COVID-19 vaccine allocation plans. The National Academies of Sciences, Engineering, and Medicine was commissioned by the NIH and the CDC to develop a vaccine distribution framework in July 2020. The National Academies released their draft distribution plan in early September 2020, which had no specific mention of people with disabilities. The Disability Rights Education and Defense Fund provided a statement on the final vaccine framework, stating the plan does not recognize the disability community broadly as a group who has a higher risk and reduced resilience to COVID-19 (Disability Rights Education and Defense Fund, 2020). In addition, the National Council on Disability recommended that the vaccine allocation framework include a statement about the federally protected right to access to health care for people with disabilities (National Council on Disability, 2020). Furthermore, the draft failed to recognize the people with disabilities under 65 who currently reside in nursing homes (15.5 percent of the nursing home population), stating only “older persons” in nursing homes would be eligible in one of the phases despite these younger residents in the same living conditions (Disability Rights Education and Defense Fund, 2020). In the final draft, people with disabilities living in group homes are mentioned in the second phase, yet disability status is not otherwise accounted for throughout the vaccine allocation framework (Bureau of Internet Accessibility, 2020). A potential reason for this oversight could be the lack of concrete data on COVID-19’s effect for people with disabilities.

### New Areas of Focus in Disability Research

As a result of COVID-19, the landscape and focus of disability research has shifted. New topic areas have emerged due to their importance to the disability community. Some of the new focus areas include the DSP workforce, health care rationing, effect of COVID-19 on preexisting health disparities, increased susceptibility of people with disabilities to COVID-19, job loss, pandemic-related stress and trauma, and the shift to virtual services and supports.

#### Direct Support Professional Workforce

DSPs provide critical supports to people with disabilities and have largely been underfunded and under supported, even prior to COVID-19. There is currently no Bureau of Labor Statistics occupational classification for DSPs; they are typically categorized with home health aides or certified nursing assistants (Hewitt et al., 2020). DSP roles utilize a specialized skillset in providing home and community-based supports for people with intellectual and developmental disabilities, yet they continue to experience low wages and limited benefits due to low Medicaid reimbursement rates. The pandemic has highlighted widespread DSP workforce issues, such as low job retention rates and burnout. In 2018, one-third of DSPs left their position within their first six months of employment (National Core Indicators, 2019, as cited in Hewitt et al., 2020). During the COVID-19 pandemic, 26 percent of DSPs reported their organization being more short-staffed than prior to the pandemic; 34 percent said their organization was equally as short-staffed as prior to the pandemic (Hewitt et al., 2020). Additionally, nearly half (42 percent) of DSPs know another employee who left their position due to COVID-19 (Hewitt et al., 2020). When asked about additional hours they are working due to the pandemic, 34 percent of DSPs reported working more hours per week (Hewitt et al., 2020). A study surveying DSPs in Pennsylvania also found heightened turnover rates and a decrease in individuals able to receive services (Disability Rights Pennsylvania et al., 2020). This study recommends increasing financial supports for DSP and provider organizations during the pandemic, as well as ensuring proper personal protective equipment and training is provided for DSPs to feel safe at their jobs.

#### Health Care Rationing and Disability

Another important emerging disability research topic area is health care rationing and how this relates to disability. At the outset of the pandemic, the disability community sounded the alarm regarding triage plans that allow for medical treatment to be withheld from individuals based solely on disability status. In April 2020, a complaint was filed with the Office of Civil Rights in HHS regarding ventilator rationing guidelines that categorically excluded individuals with profound intellectual disabilities in Alabama (HHS, 2020c). These guidelines have since been rescinded by Alabama, and a statement was released saying future guidelines will not include any similar categorical exclusions.

Disability researchers, as well as law and ethics experts, have produced numerous recent publications regarding medical rationing during the COVID-19 pandemic. One such publication from the psychology field recommends triage decisions be made by interdisciplinary teams, ensuring that they include representation from the disability community (Andrews et al., 2020). Furthermore, more representation of people with disabilities at all levels of the health care decision-making system would improve the development of triage plans. In addition, they recommend avoiding categorical exclusions for care since more individualized assessments of health and assessing likelihood to respond to the treatment are better approaches. Another important way to improve triage planning in relation to disability is to provide medical professionals with education about disability, to include social and political contexts in addition to the medical perspective. People with disabilities should be included more frequently in surveys on public health and health reports so that health disparities are acknowledged. Another recent article argues that quality-adjusted or disability-adjusted life years are not ethical to use, as this calculation values the life of able-bodied people more than a person living with a disability (Solomon et al., 2020). Instead, the authors advocate for using “near-term survivability” and ensuring the health system works with disability rights advocates when developing triage plans. Ultimately, these categorical exclusions based on disability status violate the Americans with Disabilities Act, the Rehabilitation Act, and the Affordable Care Act (Bagenstos, 2020).

#### Health Disparities for People with Disabilities

The COVID-19 pandemic has called increased attention to the health disparities for people with disabilities that existed prior to the pandemic. Access to health care poses additional challenges for people living with disabilities due to barriers such as transportation, lack of disability-sensitive providers, and inaccessible physical environments. In September 2019, the Administration for Community Living launched the Center for Human Dignity in Healthcare for Individuals with Disabilities. Its goal is to “reduce life-limiting healthcare inequities faced by people with disabilities” (HHS, 2020c). In response to COVID-19, this Center has developed educational fact sheets on medical discrimination.

##### Access to Care

The pandemic has created further barriers to access to care for people with disabilities. The American Association on Health and Disability conducted a recent survey on COVID-19 and access to health services for people with disabilities (Drum et al., 2020). For participants with disabilities who receive regular health care treatment, 56 percent experienced a disruption in their health services due to the coronavirus pandemic. Additionally, 46 percent of participants reported experiencing new health challenges related to receiving treatment or prescriptions.

##### Accessibility of COVID-19 Testing

Another major barrier that emerged for people with disabilities during the COVID-19 pandemic has been the accessibility of COVID-19 testing. Reliance on primarily drive-through testing sites makes it difficult for people with disabilities to seek care, especially with public transportation being restricted (Sabatello, Burke, et al., 2020). Many medical offices still have major accessibility issues, compounding the challenges people with disabilities face when accessing COVID-19 testing.

##### Research on COVID-19 and Specific Disability Groups

Studies have also examined the impact of COVID-19 on specific disability groups, including intellectual and developmental disabilities (IDD) and spinal cord injury (SCI). A study examining the first 100 days of the COVID-19 pandemic in the United States found that a coordinated infection control approach benefited people with IDD who reside in congregate settings (Mills et al., 2020). While congregate settings are high risk, this study showed that following vigilant infection control procedures, monitoring and documenting cases, and quickly analyzing data collected can lead to an effective response. Another study on COVID-19 and people with IDD living in residential group homes found that the case fatality rate for people with IDD was 15% compared to 7.9% for those in the general population of New York (Landes et al., 2020). Case rates and mortality rates in this study were higher for people with IDD living in group homes when compared to the general population as well. Initial research on COVID-19 and people with SCI has shown that risk of morbidity from COVID-19 may be higher for this population (Korupolu et al., 2020). In addition, symptoms of COVID-19 for people with SCI may present differently and potentially be masked by the physiological changes from SCI. Medical providers should recognize that people with SCI may not present with a cough, as this ability may be impaired. Ultimately, this warrants a heightened suspicion index for COVID-19 and quick assessment by an SCI-trained physician when symptoms arise or worsen.

##### Disproportionate Impact of COVID-19 for People of Color

Many studies have also found that the COVID-19 pandemic is disproportionately impacting people of color. A study by the CDC found that out of 580 patients hospitalized with COVID-19, 33 percent were African American, who only make up 18 percent of the population, while 45 percent were White, who make up 55 percent of the population (Garg et al., 2020, as cited in Moore et al., 2020). A weekly report from the CDC shows that Native Americans, African Americans, and Latinx people have an age-adjusted hospitalization rate of 5.6 times, 4.6 times, and 4.6 times that of people who are White, respectively (CDC, 2020, as cited in Moore et al., 2020). In addition to further research on COVID-19’s impact on people with disabilities, more research needs to be done on COVID-19’s impact on people of color with disabilities due to the higher rates of transmission and hospitalization.

#### Increased Susceptibility of People with Disabilities to COVID-19

A handful of studies have emerged showing that COVID-19 affects people with disabilities at disproportionate rates compared to their peers without disabilities. A study published in July 2020 discussed findings that COVID-19 appears to present a greater risk to people with IDD, especially those who are younger (Turk et al., 2020). In October 2020, another study determined that there is a greater risk of severe COVID-19 outcomes for people with IDD, particularly those who live in congregate settings (Landes et al., 2020). Most recently, a study published in November 2020 examined the privately insured population and found that having a developmental disorder, such as intellectual disability, is a risk factor for COVID-19 (Makary, 2020). Further research is needed to understand why this disparity exists and which interventions are effective for this population.

Recently the NIH released a novel survey instrument, the Coronavirus Disability Survey. This survey is designed to assess the impact of COVID-19 and disease-mitigation measures on people with disabilities, assessing their physical and psychological health, instrumental activities of daily living, social isolation, financial strain, and information and transportation access (Bernard et al., 2020). This survey has been made publicly available in the hopes of increasing research on disability and COVID-19. NIH is currently conducting research with this survey in Michigan, an area severely impacted by COVID-19.

#### Job Loss for People with Disabilities Due to COVID-19

The COVID-19 pandemic has severely impacted the economy, with millions of jobs lost since the spring. Workers with disabilities have lost their jobs at disproportionate rates to those without disabilities. Since March, one in seven people without disabilities have lost their job, while in one in five people with disabilities have lost their job (National Organization on Disability, 2020). In total, workers with disabilities have lost nearly one million jobs. These disproportionate rates of job loss are exacerbated by the fact that pre-COVID-19, the employment rate for people with disabilities was consistently less than half of that for people without disabilities (Livermore & Hyde, 2020). People with disabilities often face issues related to accessible workplaces and transportation, discrimination, health, and accommodations when seeking or maintaining employment. The COVID-19 pandemic has added additional layers of challenges for people with disabilities to seek and maintain employment.

While the number of research studies on job loss for people with disabilities due to COVID-19 is limited, some important disability research efforts are ongoing to closely monitor the employment rates for people with disabilities during the pandemic. The University of New Hampshire Institute on Disability and the Kessler Foundation produce a monthly National Trends in Disability Employment report. The reports show labor force participation rates and employment-population ratios for people with disabilities and people without disabilities (Kessler Foundation, 2020). In addition, the Office of Disability Employment Policy (ODEP) in the U.S. Department of Labor released a report detailing the impact of COVID-19 on employment statistics for people with disabilities compared to people without disabilities during February 2020 to July 2020 (ODEP, 2020). While unemployment significantly increased for both groups, the unemployment rates more than doubled for people with disabilities from 7.8 in January 2020 to 18.9 percent in April 2020 (ODEP, 2020). The unemployment rate for people with disabilities has since decreased to 14.3 percent as of July 2020 (ODEP, 2020).

##### Impact on Employment for People with Disabilities in Rural Areas

Recent research shows the impact of COVID-19 on employment for people with disabilities is affecting people living in rural versus urban areas differently. A study found that about half of rural people with disabilities felt financially secure, while 14 percent reported “living comfortably” and 37 percent reported “doing OK” (Research and Training Center on Disability in Rural Communities, 2020). Additionally, disparities exist in availability of paid leave. While 60 percent of people with disabilities residing in metro areas had paid leave, only 44 percent of people with disabilities in rural areas did (Research and Training Center on Disability in Rural Communities, 2020).

##### Impact on Employer-Sponsored Health Insurance

Another major implication of job loss is that many people lose their employer-sponsored health insurance as well. This has a profound impact on people with disabilities, as they experience secondary health conditions at much higher rates than people without disabilities. While 87 percent of people with disabilities report at least one secondary condition, only 49 percent of people without disabilities reported a secondary condition (Kinne et al., 2004). A recent study by the Commonwealth Fund found that as many as 7.7 million workers who had employer-sponsored health insurance lost jobs during the pandemic (Fronstin & Woodbury, 2020). Knowing that people with disabilities have lost jobs at higher rates, the negative impact of a large number of people with disabilities losing their health insurance will have profound future effects.

#### Stress and Trauma in the Disability Community

Another impact of COVID-19 is increased stress levels for the disability community. A recent literature review on disability and COVID-19 examined the sources of trauma and stress in the context of the pandemic. For people with disabilities, the COVID-19 pandemic has led to increased sources of trauma and stress, especially related to health care rationing, ableism in health care, inaccessibility, isolation, and deaths and illnesses of close friends and family (Lund et al., 2020). Another study found that 57 percent of people with IDD receiving home and community-based supports reported increased mood swings and/or depression, and 48 percent reported experiencing loneliness (Hewitt et al., 2020). Psychological resources should be deployed to this population to address the increased stress that this population uniquely faces. Prior to the pandemic, psychological resources specifically for people with disabilities were limited, so this is an important area for disability and psychological research to continue to build.

#### The Shift to Virtual Employment, Services, and Activities

Employment, services, and activities have largely been transitioned remotely where possible due to the necessary precautions to prevent the spread of COVID-19. While remote options existed prior to COVID-19, they were much less frequent and not typically considered a first choice. The now-widespread availability of remote options offers new opportunities for people with disabilities, yet also creates significant barriers and disadvantages.

##### New Opportunities for People with Disabilities

Prior to COVID-19 few options existed for people with disabilities to access employment, services, or activities remotely, even when requested. Transportation and accessibility of the physical environment are two major barriers to people with disabilities with maintaining employment or accessing in-person activities and services. With the expansion of virtual options, people with disabilities now have the increased flexibility to participate in these events without having the concerns of transportation or inaccessibility. With increasing numbers of employers offering remote employment, people with disabilities may see increased access to employment if this trend persists post-pandemic.

The shift to telehealth services instead of in-person medical appointments has benefited rural Americans with disabilities who face major transportation issues and a scarce network of providers (Christensen & Bezyak, 2020). A recent report found that people with disabilities residing in rural areas view telehealth services as an effective way to manage their chronic health conditions and mental health needs, yet a major barrier in implementation was the provider’s comfort with the technology. COVID-19 has rapidly caused providers to familiarize themselves with telehealth options, in addition to insurance providers making significant exceptions to coverage for virtual appointments during the COVID-19 pandemic. Nevertheless, the increased availability of these virtual options does not necessitate their accessibility or usability.

##### Disadvantages for People with Disabilities: The Digital Divide

With the shift to almost solely virtual options for employment, services, and activities, significant downsides exist for people with disabilities. A survey conducted at Centers for Independent Living found that respondents reported a variety of disruptions in the services they were receiving (Kennedy et al., 2020). As Centers for Independent Living switch to virtual communication via telephone, emails, and videoconferencing, many consumers living in low-income or rural areas are unable to reliably access these methods of communication. The survey also noted disruptions in consumers’ medical, rehabilitative, and social supports, including difficulty accessing needed personal protective equipment. In another study, a survey of families with children with IDD found that 74 percent of respondents reported that their child “lost access to at least one therapy or education service” and 35 percent “lost access to a healthcare provider” (Jeste et al., 2020). The digital divide and inaccessible technology and websites create disproportionate impacts on people with disabilities during this virtual shift.

###### Defining the Digital Divide

The digital divide refers to the significant gap in internet and technology use between people with and without disabilities. Despite the development of most adaptive technology prior to the explosion of the internet and electronic devices, the widespread adoption of inaccessible devices has led to a significant digital divide for people with disabilities (Goldstein & Care, n.d.). According to the Pew Research Center, 54 percent of adults with disabilities use the internet, compared to 81 percent of adults without a disability (Fox, 2011). Among internet users, people with disabilities are also less likely to have access to high-speed internet or wireless access. This study also found that 41 percent of adults with disabilities have broadband access at home, compared to 69 percent of adults without disabilities. A similar, larger study by the Federal Communications Commission found that 39 percent of people without broadband access are living with a disability (Horrigan, 2010). Not only is there a divide in internet access, but there is also a divide in technology ownership and use. When looking at laptop or desktop ownership, only 61 percent of people with disabilities own these devices at home, compared to 81 percent of people without disabilities (Anderson & Perrin, 2017). This digital divide pre-COVID-19 means that the shift to virtual and remote options brings significant disadvantages for people with disabilities. These disadvantages related to internet access are even more significant in rural communities. A recent study found that while 25 percent of people with disabilities living in metro areas were able to telework, only 9 percent of people with disabilities in rural areas were able to telework (Research and Training Center on Disability in Rural Communities, 2020).

###### Disparities in Accessibility and Usability of Technology and Websites

Adding to the difficulties people with disabilities face in access to broadband internet, significant, persisting issues exist with the accessibility and usability of technology and websites. As many interventions shift to being delivered with videoconferencing software or web portals, it is important to keep the frequent inaccessibility of many of these delivery methods in mind. Even with online meeting platforms beginning to strengthen their accessibility features as a result of COVID-19, this does not guarantee their usability. Many people with disabilities have had to voice their continuing concerns about the accessibility of these platforms in order for companies to begin to modify them. While some progress has been made, COVID-19 has highlighted and likely widened the disparities in access to the internet and technology due to the increased reliance on this method of communication. In 2019, the U.S. Department of Justice ruled that websites must comply with the Americans with Disabilities Act, yet a recent review of 10 million web pages found that 98 percent did not meet the Web Content Accessibility Guidelines (AccessiBe Research, 2020).

###### The Digital Divide in Rural Areas

The digital divide is even more prominent in rural areas. According to the Federal Communications Commission, around 35 percent of Alabamians lack broadband access, meaning this number is likely even more significant for people with disabilities in Alabama. Research studies on autism spectrum disorder often offers the only therapeutic interventions available for families in Alabama, yet due to COVID-19 many of these studies have switched to virtual interventions (Amaral & de Vries, 2020). With the widespread lack of broadband access, this significantly limits the number of rural families able to receive autism spectrum disorder-related services in Alabama during the pandemic. More research is needed in this area to determine the full effects of COVID-19 for people with disabilities living in rural areas.

## Areas for Future Research on the Impact of COVID-19 for People with Disabilities

While efforts to expand research on COVID-19 and disability are underway, it is important that all aspects of impacts to people with disabilities are considered, not solely health effects. A variety of topics relating to COVID-19 have yet to be investigated but have the potential to significantly benefit the disability community. The following areas are suggested topics for future research: accessible technology, economic impacts, emergency planning, and social isolation. These topic areas have been examined and discussed in relation to the general population, but little has been published on the disability community specifically. It is important that research is expanded to examine the long-term impacts of COVID-19 for people with disabilities. For a population that already experienced health disparities prior to COVID-19, the pandemic is likely to add significant negative implications. It is important that the disability research community collaborate to address these disparities and work toward innovative solutions.

### Accessible Technology

For the general population, adapting to the use of technology for previously face-to-face interactions has presented several challenges. There has been a steep learning curve for adjusting to technology that was often infrequently used prior to COVID-19. However, there is little to no published information on how this transition has impacted people with disabilities. While some discussion has occurred over ensuring the accessibility of virtual platforms, many of these conversations have been happening too late into the switch, leaving people with disabilities at a disadvantage. Further research should investigate the impacts of this for people with disabilities.

##### Virtual Meeting Platforms

In regards to virtual meeting platforms, not all commonly used platforms are both accessible and usable. While some may have accessibility features, they are sometimes not user-friendly, increasing the challenges for people with disabilities to easily use these features. While companies have been making efforts to increase accessibility features of meeting platforms, it is an important area for disability research to pursue as well. Research regarding perspectives and experiences of users could provide insight into whether the recent changes in meeting platforms are truly meeting the accessibility and usability needs of people with disabilities.

##### Telemedicine

Telemedicine is another area that warrants further exploration by disability researchers. The transition to solely telemedicine for many medical providers also leaves people with disabilities at a significant disadvantage, as many of these platforms have yet to ensure web accessibility standards. There is no standardized set of nationwide regulatory standards for telemedicine, but instead a combination of sometimes contradictory state, local, federal, and insurance regulations (Annaswamy et al., 2020). Additionally, medical devices to measure vital signs that medical providers might require for a tele-evaluation may not be suitable for all people with disabilities, especially those with mobility or dexterity limitations. As many regulations regarding telemedicine were suspended due to COVID-19, such as receiving services across states, it is unknown if these rules will be reinstated after the COVID-19 pandemic. Research on telemedicine for people with disabilities is needed, especially to provide insight into the current accessibility and usability of this technology.

##### Virtual Services and Supports

Services and supports for people with disabilities largely shifted to being implemented virtually throughout the pandemic. Studies examining the effectiveness of virtual versus in-person interventions for people with disabilities could prove insightful. It is unclear if the transition to remote services will continue to produce the same effective results as in-person services. Additional research could clarify the effectiveness of this method of service delivery and allow for it to remain a delivery method post-COVID-19.

#### Economic Impact

There is a lack of published studies regarding the overall economic impact of COVID-19 on people with disabilities. As some studies discuss the economic impact on the general population, it is important to delve deeper into how the economic effects have impacted people with disabilities, as this group was already experiencing lower rates of employment and income prior to the pandemic. Examining aspects like financial savings or loss of employer-sponsored health insurance could prove helpful for determining the impact of COVID-19 for people with disabilities. While some disability research is being conducted related to employment, it is important to examine the full range of economic impacts that COVID-19 has had for people with disabilities.

#### Emergency Planning

Inclusion of people with disabilities in emergency planning was a research area that was gaining ground prior to COVID-19. However, despite increased focus on this area, actual resources are limited, with many focused on natural disasters and unapplicable to COVID-19 (Sabatello, Burke, et al., 2020). The Federal Emergency Management Agency has indicated that local governments are responsible for the inclusion of people with disabilities in their emergency planning and programs, yet there is a lack of consolidated and consistent guidelines. Disability researchers have constructed a variety of educational tools to ensure people with disabilities have access to information about the pandemic to make informed choices, yet these considerations are not built directly into the emergency planning systems across the nation.

A current research opportunity from the National Association of County and City Health Officials seeks methods for improving local health department capacity to address the needs of people with disabilities when addressing public health outbreaks, specifically COVID-19 (National Association of County and City Health Officials, 2020). Their efforts seek to encourage these health departments to better address disability issues, develop subject matter experts to advise emergency planning efforts, and update local emergency response plans to consider the needs of their community members with disabilities. The National Association of County and City Health Officials plans to offer 10 of these awards ($83,000 each) to local health departments to make these modifications to emergency management systems.

#### Social Isolation

Research has brought to light the social isolation and mental health impacts of COVID-19 for the general population, yet no current published studies exist on the impact of social isolation for people with disabilities. Residential services for people with disabilities across the country have frequently limited or prohibited visitors during the COVID-19 pandemic, so this vulnerable population was left with even less social support than previously. As services and supports have been transitioned virtually, some people with disabilities have lost this avenue for social connection as well due to the digital divide. Furthermore, as people have been connecting virtually, particularly through social media platforms, social media has major accessibility issues with the majority of content not containing closed captioning or image descriptions. The COVID-19 pandemic’s effect on the social well-being of people with disabilities is an area that warrants further exploration.

## Conclusion and Next Steps

The COVID-19 pandemic has far-reaching impacts on all federal research, with changes affecting funding, quality and efficiency, knowledge dissemination, focus of research, and disparities among researchers. Federal legislation has provided significant amounts of increased funding to a variety of pandemic response and research efforts, with some going directly to Centers for Independent Living and Aging and Disability Resource Centers to respond to the needs of people with disabilities. However, there remain significant areas related to COVID-19 and its impact on people with disabilities that are unaddressed. People with disabilities have been left out of major research studies on COVID-19, and no information is being tracked on disability status in many of the prominent studies.

Despite the major gaps in the federal COVID-19 response for people with disabilities, the disability research community has engaged in transitioning their projects to virtual methods of intervention in novel, creative ways. These efforts are vital to maintaining momentum in working to improve the lives of people with disabilities and their families. Disability researchers have also engaged in a variety of information and education campaigns to ensure accessible materials about COVID-19 are available to people with disabilities.

The disability community has voiced both longstanding and emerging concerns as a result of the pandemic, such as disability discrimination in medical rationing and the inaccessibility of technology. Several recent studies show that people with disabilities are impacted more significantly by COVID-19 than their peers without disabilities. To address this disparity, it is essential that the disability research community conduct research on the effects of COVID-19 for people with disabilities, especially in topic areas that have yet to be explored. Additionally, further medical research that includes people with disabilities is needed, as well as major improvements in collecting disability statistics. Other areas that warrant additional research include: (1) the impact of the transition to reliance on technology and virtual services and supports for people with disabilities, (2) the economic impact of COVID-19 on people with disabilities, (3) inclusion of people with disabilities in current emergency planning systems, and (4) the impact of COVID-19 on social isolation for people with disabilities. The disability research community should continue to investigate the disproportionate impact of COVID-19 for people with disabilities and advocate for inclusion in COVID-19 research and responses.

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