# The Impact of COVID-19 on Disability Research: A 2022 Update

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## Executive Summary

 During the two years since the pandemic began, COVID-19 has had vast local, nationwide, and global impacts across all fields of federal research. These new implications for federal research include impacts to research institution finances, quality and efficiency, knowledge dissemination, preexisting disparities for researchers, research focus, and productivity. An updated estimate of the impact of the pandemic on federal research from March 2020 through February 2021 calculated a financial loss of $218 million and research output losses between 20 to 40 percent (Council on Government Relations, 2021). This paper provides an update to the first Interagency Committee on Disability Research (ICDR) [COVID-19 white paper](https://icdr.acl.gov/resources/reports/impact-covid-19-disability-research-new-challenges-and-widening-disparities) and presents recent information on how the field of disability research has changed and adapted throughout the pandemic, highlighting important areas of new research and how the shift to virtual research methods has modified the research landscape.

 To address the continuing negative effects of COVID-19, the American Rescue Plan Act was signed into law in March 2021, providing a third stimulus check and a variety of other relief funding to help the economy, public health agencies, state and local governments, and businesses. While this law directed additional funding to institutions of higher education, the amount allocated was not enough to fully address the enormous impact of the pandemic to universities’ finances and research productivity. In March 2022, the Consolidated Appropriations Act was signed into law, providing significant budget increases across almost all federal agencies. These increases were significant and larger than previous years. Despite the large amount of targeted funding for COVID-19-specific research during the pandemic, people with disabilities are a population that continues to be neglected from being specifically addressed in major COVID-19 relief efforts.

 The disability research community has experienced additional impacts from the COVID-19 pandemic on top of those felt by the general research community. Disability researchers have experienced several unique challenges with shifts in research design, a lack of data collection on COVID-19 for people with disabilities, and a lack of inclusion of the disability community in COVID-19 research studies and public health guidance. New studies continue to show a higher risk of developing COVID-19 for people with disabilities and a variety of other disparities in outcomes due to the pandemic. Considering both preexisting disparities and those resulting from the pandemic, inclusion of people with disabilities is essential across COVID-19 surveillance, research, and public health messaging.

 Since the previous iteration of the ICDR COVID-19 white paper, additional disability research has emerged in the previously identified focus areas, including the direct support professional workforce, health care rationing, effects 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. Many important findings continue to emerge in these areas, yet additional research is imperative to fully understand the impact of COVID-19 on the lives of people with disabilities.

 The field of disability research continues to adapt to new challenges the COVID-19 pandemic has presented over the past two years. The first ICDR COVID-19 paper recommended addressing the areas of accessible technology, economic impact, emergency planning, and social isolation. Significant strides have been made in these areas, particularly in accessible technology. However, these continue to be areas that warrant further exploration on the impact of COVID-19 for people with disabilities. Additionally, for the field to adequately address the needs of people with disabilities, targeted funding is needed to address the following areas of research: community living, long COVID-19, the impact of COVID-19 on children with disabilities, and the impact of COVID-19 on people with mental health disabilities. The field of disability research should continue to adapt in creative ways to explore the impact of COVID-19 on the lives of people with disabilities while advocating for full inclusion of this population across all COVID-19 efforts.

### Introduction

The COVID-19 pandemic continues to profoundly impact the federal disability research landscape. Challenges with conducting disability research persist, and people with disabilities continue to be left out of large-scale, ongoing COVID-19 research studies. In January 2021, the Interagency Committee on Disability Research (ICDR) released a white paper, [*The Impact of COVID-19 on Disability Research: New Challenges and Widening Disparities*](https://icdr.acl.gov/resources/reports/impact-covid-19-disability-research-new-challenges-and-widening-disparities), detailing these challenges and the overall impact of the COVID-19 pandemic on disability research. This paper examined how the pandemic perpetuated disparities between people with and without disabilities as well as the vast implications for federal disability research. As the pandemic continues, the landscape of disability research continues to shift. This paper provides an update to the ICDR white paper and examines additional impacts of the COVID-19 pandemic on the disability community and disability research in the previously identified areas. Recommendations are also provided on emerging topic areas future disability research should explore.

### An Update on the Impact of COVID-19 on Federal Research and Development

At the beginning of the COVID-19 pandemic, the National Institutes of Health (NIH) deputy director reported that around 80 percent of non-COVID-19 trials around the country had been stopped or interrupted (as cited in Van Dorn, 2020). However, farther into the pandemic, research is still being impacted when compared to pre-pandemic levels. A study of scientists across the United States and Europe found that total work hours, while still slightly lower than pre-pandemic levels, have increased from -14 percent in April 2020 to -4 percent in January 2021 (Gao et al., 2021). However, despite this increase in total work hours, scientists reported initiating fewer research projects than previously. The number of scientists that reported initiating zero new research projects that year increased from 9 percent in 2019 to 27 percent in 2020 (Gao et al., 2021). Furthermore, scientists who were not working on COVID-19-related research reported larger decreases in work time, new publications, new submissions, and new projects (Gao et al., 2021).

These significant impacts to federal research have implications for non-COVID-19-related federal disability research projects. Many disability research areas that previously saw momentum may be experiencing fewer new projects than pre-pandemic levels. Furthermore, for projects related to COVID-19, disability researchers and advocates are still working to ensure that people with disabilities are considered in large-scale COVID-19 research, a group that has been overlooked across the majority of COVID-19 research studies.

#### Financial Impacts

As the COVID-19 pandemic continues, research institutions are still experiencing the financial effects of the research shutdowns during the beginning of the pandemic in early 2020. A study found that 41 percent of researchers reported that their institutions’ ability to maintain research functions may be impacted by the financial repercussions of the COVID-19 pandemic (NIH, 2021). Other potential factors negatively affecting institutions’ finances include a loss of revenue from charitable organizations, diversion of funds to COVID-19 research, and difficulty borrowing from affiliated academic medical centers (McNally et al., 2021). Estimated losses from the three months of full laboratory closure range between $2,000 to $100,000 in financial losses per research program (Carr et al., 2021). This can threaten the survival of smaller research programs that are still struggling to recoup these losses. Researchers report that the pandemic intensified concerns around job security for those in non-tenure-track or temporary positions due to budget cuts, reduced enrollment, and elimination of programs that have occurred during the pandemic (Levine et al., 2021). Impacted finances also affect an institution’s ability to send researchers to conferences. A return to travel for scientific conferences will be contingent on addressing these financial issues (Kalia et al., 2020).

#### Impacts to Quality and Efficiency

The pandemic impacted the quality and efficiency of research, and many of these impacts have continued to present. In an NIH study conducted in October 2020, 83 percent of those surveyed reported that COVID-19 had a moderate or major impact on the overall research productivity at their institution (NIH, 2021). Some of the most frequently reported factors impacting research productivity are: virtual instead of in-person interactions with trainees, mentors, or supervisors; cancellation of in-person, regional, national, and/or international conferences; and changes in laboratory and/or animal facility access (NIH, 2021). Reduced productivity has also affected researchers’ publication rates and number of new projects launched. A survey of research scientists found that those with work unrelated to COVID-19 reported that their rate of new publications dropped by 9 percent and new submissions dropped by 15 percent during 2020 (Lewis, 2021). Furthermore, scientists reported launching fewer research projects during 2020, with an average drop of 26 percent compared to 2019 (Lewis, 2021).

While researchers have adapted to many of these negative impacts to research, there are still lingering effects of COVID-19 on research quality and efficiency. A study in the United Kingdom during February and March 2021 found that the impacts of the pandemic on researchers were still high. The majority of researchers surveyed (61 percent) reported that lockdown or prevention strategies had negatively impacted their time for research (UK Research and Innovation, 2021). In the same survey, 58 percent of researchers reported that COVID-19 made it difficult to engage in their other typical work activities, such as teaching or administrative work, leaving less time for research. Across the globe, impacts from the COVID-19 pandemic to research quality and efficiency are still being felt and must be addressed.

#### Impacts to Knowledge Dissemination

Methods of knowledge dissemination have shifted virtually as the pandemic continues. However, this has opened up unique opportunities for global collaboration. With the common goal of understanding more about COVID-19, international research efforts have experienced increased collaboration in the past two years, leading to the increased speed of knowledge translation in this area (Sohrabi et al., 2021). Illustrating this shift in methods of collaboration, 94 percent of life scientists reported “ample use of [videoconferencing] to collaborate, discuss, and develop science” (Korbel & Stegle, 2020). However, non-COVID-19 research areas may be experiencing greater impediments to knowledge dissemination, as research institutions are operating with impacted finances.

Research conferences have remained mostly in virtual formats from the onset of the pandemic until present, with a handful of research conferences planned in-person for 2022. Prior to 2020, the majority of conferences were held in-person; however, this presented limitations for some researchers, particularly early career researchers (Sarabipour et al., 2021). Virtual conference formats continue to offer flexibility for researchers and allow greater access to knowledge dissemination activities. In a survey from March 2020 to March 2021, the journal *Nature* conducted a poll that found 74 percent of respondents “think that scientific meetings should continue to be virtual, or have a virtual component, after the pandemic ends” (Remmel, 2021). Participants stressed that this would help conferences to be more accessible, lower costs, and have a smaller carbon footprint. A survey conducted by NIH in 2020 also found that respondents thought that a hybrid format could combine the benefits of both virtual and in-person formats (Kalia et al., 2020). The field of disability research should consider hybrid options moving forward for knowledge dissemination events to ensure broad access to participation.

Another way knowledge translation has shifted during the pandemic is the streamlining of the peer review process. The pandemic has allowed for biomedical scientists to upload preliminary versions of their papers to freely accessible websites, which allows others to build upon their work (Yong, 2021). While this practice existed prior to 2020, it has gained popularity during the pandemic and can accelerate knowledge dissemination and research collaboration (Yong, 2021). As increased collaboration and open knowledge sharing across the research community continues into the pandemic, it is hopeful that these practices can continue to be applied post-pandemic to further all areas of the research community (Sohrabi et al., 2021).

#### Increasing Disparities Among Researchers

##### Disparities Between Early Career and Senior Researchers

The pandemic has caused several disparities among researchers to worsen. Early career researchers have experienced a disproportionate number of negative impacts to their research during the pandemic than senior researchers. During the pandemic, early career researchers have had their attention directed toward other work away from their research, such as providing support with planning for distance learning in local school districts (Levine et al., 2021). Additionally, early career investigators report experiencing more negative impacts to their mental health than senior investigators (NIH, 2021). Early career investigators are also more likely to be from diverse and underrepresented backgrounds, and disruption to their research can limit future career opportunities, promotion/tenure, and grant competitiveness (McNally et al., 2021). A survey found that over 80 percent of graduate student respondents reported that the pandemic had highly or somewhat negative impacts to their research (Sutherland et al., 2021). Common issues that graduate students mentioned were lack of access to needed resources (i.e., lab equipment and libraries), lack of funds to create a suitable work environment at home, unreasonable work expectations, and research tasks they could not perform due to pandemic restrictions. These disparities should be addressed to ensure that early career investigators have equal opportunities to succeed in their careers.

##### Gender Disparities

During the pandemic, existing gender disparities for researchers were exacerbated, and new research has been conducted in this area since the previous paper. The NIH completed a study in October 2020 finding that researchers identifying as women or other genders experienced more negative impacts than men to their mental health due to the pandemic (NIH, 2021). Furthermore, this study found that women were more likely than men to report that caregiving made completing their work responsibilities more difficult. A productivity gap has also been noted for female social science researchers during the COVID-19 pandemic. A study of academic social science researchers examined paper submissions across 25 different countries in the 10 weeks after the U.S. lockdown (Cui et al., 2021). While total research productivity increased by 35 percent during this time period, female academics’ productivity was 13.2 percent less than their male peers. Another study found that in the biomedical field, the proportion of female first authors publishing papers dropped by 9.1 percent, and for papers related to COVID-19 the proportion of female authors dropped by 28 percent (Muric et al., 2021). The productivity gender gap is intensified for assistant professors and for academics at top-ranked universities (Cui et al., 2021). An increase in telecommuting can lead to unbalanced domestic responsibilities, impacting female social science academics disproportionately (Cui et al., 2021). Special attention should be paid to addressing these disparities and supporting female researchers.

##### Racial Disparities

The pandemic also highlighted racial disparities among researchers. When examining race, Asian researchers frequently cited visa concerns as contributing to negative effects to their mental health at twice the average rate (NIH, 2021). Additionally, Hispanic researchers were more likely to report concerns about mental health and external stressors than peers of other racial groups (NIH, 2021). These effects were multiplied for early career scholars of color, as they reported being asked to complete additional work related to diversity, equity, and inclusion issues highlighted by national protests and the pandemic (Levine et al., 2021). The form of these extra projects were often professional development and not research scholarship, adding to worries about how this might negatively impact the tenure process (Levine et al., 2021). Other extra projects included mentoring students of color or being the “go-to” person when racism and policy brutality were being examined (Levine et al., 2021). To summarize, early career researchers of color reported “being stressed and stretched thin by multiple demands” (Levine et al., 2021). Additionally, they noted that their higher education research institutions and the research fields were not immune to the effects of systemic bias, racism, or microaggressions (Levine et al., 2021). The field of disability research should work to address the racial disparities researchers face.

#### Shift in Research Focus

The inevitable shift in research focus toward COVID-19-related topics has transformed the research landscape. Around 80 percent of non-COVID-19 trials were stopped or interrupted, and research efforts and funding were directed toward COVID-19 (as cited in Van Dorn, 2020). A survey in the United States, Canada, and Europe found that 32 percent of researchers reported shifting their research focus to COVID-19 (Yong, 2021). Among researchers authoring papers on COVID-19, around 67 percent had no prior relevant research (Hill et al., 2021). As the second year of the pandemic continues, concerns about funding for non-COVID-19 research are being voiced (Sohrabi et al., 2021). While some financial relief is available for researchers affected by the pandemic, funders should ensure adequate support is provided across all research fields once pandemic relief is no longer available (Sohrabi et al., 2021).

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

In January 2021, the Council on Government Relations (COGR) provided an addendum to its paper, *Research Impact Under COVID-19*. The updated projected financial loss to research from the pandemic is estimated to be $218 million from March 2020 through February 2021 (COGR, 2021). The updated information confirms COGR’s initial hypothesis that the pandemic would cause significant research output loss. Some of the major losses COGR cites include interrupted, altered, or cancelled research; permanently lost experiments and specimens; and talent and expertise lost to other countries. COGR concludes the following effects of the pandemic on research productivity: “1) research output losses between 20 and 40 percent; 2) financial disinvestment impact in the hundreds of millions of dollars at individual institutions, and 3) potential impact approaching tens of billions of dollars across the entire U.S. research enterprise.” These impacts may be irreversible without dedicating federal funding to address these issues (COGR, 2021).

### Federal Legislation and Funding for COVID-19 Research

#### American Rescue Plan Act of 2021

The American Rescue Plan Act provided COVID-19 relief funding for the “economy, public health, state and local governments, individuals, and businesses” (American Rescue Plan Act, 2021). The American Rescue Plan Act allocated $22 billion to higher education; however, university administrators calculated they would need $122 billion to address the impact of the pandemic shutdown and that the federal government would need $26 billion more to make up for the lost or delayed research when campuses shut down (Mervis, 2021). Additionally, this law provided budget increases for the following institutions: 3 percent to NIH, 2.5 percent to the National Science Foundation, 2.3 percent to NASA, and 0.4 percent to the Department of Energy’s science office (Mervis, 2021). However, these increases were disappointing to the research community, as they were smaller than increases in previous years (Mervis, 2021).

#### Consolidated Appropriations Act of 2022

In March 2022, the Consolidated Appropriations Act became law, which provided appropriations for federal agencies through the rest of fiscal year (FY) 2022. This law included approximately $171.3 billion specifically for research and development (R&D), an 8.5 percent increase from FY 2021 (Congressional Research Service, 2022). All agencies, except for the Department of Defense, received an increase in funding levels compared to FY 2021. The largest increases in R&D funding include the Department of the Interior (up 30.8 percent), Department of Commerce (up 29 percent), Department of Agriculture (up 21.7 percent), and the Department of Health and Human Services (HHS) (up 18.8 percent). The largest increases were to applied research (14 percent), followed by basic research (10.2 percent), R&D facilities and equipment (9 percent), and development (3.6 percent) (Congressional Research Service, 2022).

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

The disability research community experienced additional impacts from the COVID-19 pandemic on top of those felt by the general research community. Disability researchers have experienced several unique challenges with shifts in research design, a lack of data collection on COVID-19 for people with disabilities, and a lack of inclusion of the disability community in COVID-19 research studies and public health guidance.

#### Challenges and Changes in Research Design

Disability researchers made major pivots to research design throughout the course of the pandemic, opening up new opportunities and presenting new challenges. In the research field as a whole, major shifts occurred in research design, publishing ethics, and the peer review process over the course of the pandemic (Barroga & Matanguihan, 2020). The expansion to virtual data collection has benefited specific types of research, such as participatory action research (Barroga & Matanguihan, 2020). While even pre-pandemic virtual formats allowed researchers access to larger sample sizes, virtual formats are especially relevant now in light of social distancing requirements (Howlett, 2021). Furthermore, virtual methods can connect researchers across the world, increasing collaboration and coordination (Howlett, 2021). Other important opportunities from this shift in research design include being able to complete timely research relevant to COVID-19, methodological innovation, and improved data quality (Garcia & Barclay, 2020).

Along with the new opportunities remote disability research presents come new challenges that must be addressed. With the increased flexibility that comes with remote data collection, researchers must ensure that ethical standards and research quality are still being met (Barroga & Matanguihan, 2020). Other challenges that exist include building and maintaining relationships remotely, distrust, sampling and recruitment, inclusivity, and steep learning curves (Garcia & Barclay, 2020). Furthermore, while remote methods may be convenient, they may not always be the best methodological fit for a research question (Garcia & Barclay, 2020). These are dilemmas that disability researchers are currently working to address.

Disability research that was conducted in-person pre-pandemic has experienced the greatest impact. Due to people with disabilities being at increased risk of contracting COVID-19 and having worse outcomes, disability researchers have had to be especially cautious to not expose research participants and switch to remote methods (Topping et al., 2021). Due to advancements in technology, virtual interviews, for example in qualitative disability research, are now much more plausible to conduct than previously (Topping et al., 2021). Nevertheless, for quality disability research to continue, it is important that researchers examine how the shift to virtual methods impacts people with disabilities to ensure it is not creating new participation barriers (Topping et al., 2021).

#### Limited Disability-Specific COVID-19 Research

Two years into the COVID-19 pandemic, the disability community is still frequently excluded from the majority of COVID-19 research, surveillance, and public health guidance. COVID-19 impacts people with disabilities disproportionately, and a 2021 study found that participants with disabilities reported a variety of unmet needs during the pandemic (Epstein et al., 2021). To address these, participants stated the necessity of including disability perspectives in the public health COVID-19 response. The field of disability research has been working throughout the pandemic to make the voices of people with disabilities heard despite the lack of inclusion in public health initiatives and research.

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

Similar to the lack of inclusion of people with disabilities in COVID-19 research, there is also an absence of adequate data collection on disability and COVID-19. Despite being two years into the pandemic, COVID-19 data and surveillance on people with disabilities is severely lacking (Swenor & Deal, 2022). While Pfizer-BioNTech and Moderna reported data from COVID-19 vaccine trials by age, race, and ethnic group, they did not include data on people with disabilities (Swenor & Deal, 2022). When considering surveillance data, there are 19 states that do not report on COVID-19 cases and deaths in long-term support settings that serve non-elderly adults with disabilities (Easterseals, 2021). Another survey found similarly that less than half of states collected COVID-19 death data for people with intellectual or developmental disabilities (IDD) (Assistant Secretary for Planning and Evaluation [ASPE], 2021). As states use data to make decisions about where to allocate resources, this severely limits the available resources for this population that is disproportionally impacted by COVID-19 (ASPE, 2021). This lack of surveillance on COVID-19 for people with disabilities makes it difficult to craft a proper public health response to address the needs of this population (Epstein et al., 2021). Data collection on disability is essential for the proper allocation of resources and policy to address the needs of people with disabilities (Swenor & Deal, 2022). This major gap in the data for COVID-19 perpetuates the inequities that people with disabilities face (Swenor & Deal, 2022). Future research should collect and disaggregate data on COVID-19 by disability status to ensure that the COVID-19 response is disability-inclusive (United Nations, 2020).

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

The lack of inclusion of people with disabilities in the COVID-19 public health response is related to the lack of their inclusion in COVID-19 research. This must be addressed to ensure people with disabilities have equal access to participate in society. A main reason that people with disabilities are not included in COVID-19 research is exclusion criteria during the subject selection process for studies. A frequent argument against inclusion of people with disabilities in COVID-19 research is that their disability status would hinder the generalizability of the collected data (Bard, 2021). Using this argument, many trials restrict participation to individuals with only one condition. However, this directly harms the disability community by preventing them from having important information about conditions affecting the general population that may impact people with disabilities differently (Bard, 2021). Secondly, this is a direct violation of human rights, as it is excluding people with disabilities from full participation in society and the right to have access to research (Bard, 2021). Another reason for the lack of inclusion of people with disabilities in research is inaccessible study design. Failing to ensure accessibility can hinder people with disabilities’ participation in the research areas of recruitment, consent, intervention, and measurement (Rios et al., 2016). Studies on COVID-19 should improve study exclusion criteria and accessibility to ensure people with disabilities are not excluded from their right to participate in research.

### New Areas of Focus in Disability Research

Since the previous iteration of the ICDR COVID-19 white paper, additional disability research has emerged in the previously identified focus areas, including the direct support professional (DSP) workforce, health care rationing, effects 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. The following sections provide a brief overview of new disability research in these emerging fields.

#### Direct Support Professional Workforce

The National Council on Disability (NCD) discusses the impact of COVID-19 on the DSP workforce in its 2021 report. It explains that people with disabilities often rely on DSPs for activities of daily living, meaning that neither the workers nor the individuals with disabilities could fully shelter in place during the pandemic (NCD, 2021). A lack of personal protective equipment has been another major issue for DSPs during the pandemic (NCD, 2021). Additionally, the DSP workforce shortage that existed prior to the pandemic was exacerbated during the pandemic and led many workers to leave due to low wages and poor health benefits (NCD, 2021). However, despite these significant issues, few recent research studies or interventions exist that try to identify solutions to strengthen the DSP workforce.

#### Health Care Rationing

Much of the discussion around health care rationing and disability occurred during the height of the pandemic, as people with disabilities are almost three times more likely than people without disabilities to be denied needed health care and four times more likely to be treated badly when seeking health care (World Health Organization, 2011). In light of the pandemic, a recent law paper outlines how to address the health care inequities people with disabilities face both during and after the COVID-19 pandemic (Powell, 2021). This paper recommends that governments and hospitals review their policies and immediately amend resource allocation policies that exclude people with disabilities from receiving care based on their disability status. These entities must increase their compliance with existing federal disability rights laws to address the disparities people with disabilities face in health care. Additionally, engaging people with disabilities in the development and implementation of these laws is essential. Furthermore, due to issues people with disabilities face surrounding their right to health care, Congress should allocate additional funding to the protection and advocacy system that provides free legal resources to people with disabilities. Despite this topic receiving less attention as hospitals are no longer at capacity, it is a topic that is relevant for future research long after the pandemic ends.

#### Health Disparities for People with Disabilities

Health disparities for people with disabilities existed prior to the pandemic, with people with disabilities more likely to report poorer health than their peers (40.9 percent of people with disabilities compared to 9.1 percent of people without disabilities) (NICHM Foundation, 2021). Additionally, significant health care access issues existed prior to the pandemic, including stigma around disability in the medical community. In a survey of U.S. physicians, 82.4 percent reported that having a disability indicated a worse quality of life than that of nondisabled people (NICHM Foundation, 2021). Furthermore, only 56.5 percent strongly agreed that they welcomed people with disabilities into their practices. The COVID-19 pandemic has greatly heightened the impacts of these preexisting health disparities for people with disabilities.

##### Heightened Susceptibility to COVID-19

Two years into the pandemic, there is still a shortage of research on how COVID-19 impacts people with disabilities. However, the clearest, most staggering disparity identified in the research thus far is that people with IDD are six times more likely to die from COVID-19 when compared to the general population (NIHCM Foundation, 2021). A recent cross-sectional study found similar findings, noting that having an intellectual disability was the strongest risk factor for being diagnosed with COVID-19 and the strongest risk factor other than age for COVID-19 mortality (Gleason et al., 2021). While the research is clear on the impact of COVID-19 for people with IDD, more research is needed on the impact of COVID-19 for people with other types of disabilities.

##### Access to Care

Recognizing that access to health care for people with disabilities is not a one-size-fits-all approach is essential for health care providers, especially during the COVID-19 pandemic. A study that interviewed DSPs for people with IDD concluded that there is no single solution to providing health care to people with IDD, as it is important to “maximize the fit between the person’s abilities, the skill set of the direct support professionals and health care providers, and the presenting health care issue” (Lunsky et al., 2021). Several studies have examined access to care for people with disabilities during the pandemic.

The barriers to health care that people with disabilities face during the COVID-19 pandemic are wide-ranging, including inaccessible telehealth platforms, lack of access to COVID-19 testing and test sites, inability to wear a mask due to health risks, and a variety of other challenges. One study found that 34 out of 39 participants reported “obstacles in receiving information about the COVID-19 pandemic, including a lack of captions or alternative text, difficulty in finding information relevant to the disability experience, and overwhelming or confusing information” (Epstein et al., 2021).An NIH review found that common barriers to health care for people with disabilities included cessation of home-based therapies, lack of available ambulances and public transportation resources to transport people to the hospital, difficulties finding medications, and changes in typical care (Lebrasseur et al., 2021). And while people without disabilities have reported satisfaction with telehealth services, a recent study found that 69 percent of people with disabilities who used virtual health services want a return to in-person services (Easterseals, 2021). To ensure equal access to health care even after the pandemic, the field of disability research should focus on identifying ways to combat these barriers to health care access for people with disabilities.

##### Accessibility of Testing and Vaccination

While the initiation of the COVID-19 prevention vaccination on December 14, 2020, represented an important step forward in the efforts to eliminate COVID-19, people with disabilities were not considered in many aspects of the implementation. One study found that only six states specifically mentioned people with disabilities in their vaccination plans (Easterseals, 2021). Additionally, widespread accessibility issues have persisted across COVID-19 testing and vaccination sites and informational websites. One study found that 24 out of 39 participants reported experiencing inaccessible COVID-19 testing sites (Epstein et al., 2021).

Vaccination websites provide essential information about eligibility, vaccination sites, and scheduling appointments. Inability to access these websites presents a huge barrier for people with disabilities obtaining information about and getting vaccinated. For unvaccinated adults, people with disabilities are more likely than those without disabilities to experience issues such as difficulty obtaining an appointment online, not knowing where to get vaccinations, transportation to the vaccination site, and vaccination sites not being open at convenient times (Ryerson et al., 2021). A study examining the accessibility of 54 U.S. state and territory vaccine registration websites found that only two fully met the World Wide Web Consortium’s Web Content Accessibility Guidelines 2.1 standards (Alismail & Chipidza, 2021). To address accessibility issues surrounding COVID-19 vaccination information, the CDC recently provided funding to the Administration for Community Living to develop a national Disability Information and Access Line to help people with disabilities receive COVID-19 vaccinations (Ryerson et al., 2021). Similar innovations should be considered to address the many barriers that exist for people with disabilities when accessing COVID-19 testing and vaccination.

##### COVID-19 Disparities for Specific Disability Groups

While studies have determined that COVID-19 disproportionately impacts people with disabilities, there are also varying impacts to specific disability subgroups. People with disabilities residing in residential or long-term care facilities are more likely to have increased COVID-19 infection rates (Kamalakannan et al., 2021). People with IDD are more likely to contract COVID-19 when compared to those without IDD (Gleason et al., 2021). Also, if diagnosed with COVID-19, people with IDD are more likely to be admitted to the hospital and more likely to experience mortality due to COVID-19 after an admission (Gleason et al., 2021). Several factors may contribute to increased risk of COVID-19 for this population, including daily care requiring contact with home-care staff, shared transportation, sensory issues that may impact mask-wearing, and residing in high-contact housing facilities (Gleason et al., 2021). However, the impact of COVID-19 for many other disability subgroups has yet to be investigated.

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

Effects of the COVID-19 pandemic are compounded for people of color with disabilities; however, there is a gap in the data on the disproportionate impact for this specific population. Resulting from the overall lack of data collection on disability, few studies have formally conducted research in this area (Easterseals, 2021). However, people of color have experienced a variety of employment, health care, built environment, education, and social disparities during the pandemic that likely are exacerbated for those with disabilities. People of color have experienced higher rates of unemployment during the COVID-19 pandemic (Easterseals, 2021). In a 2021 survey, 34 percent of respondents of color reported decreased financial health during COVID-19 compared to 25 percent of White respondents (Easterseals, 2021). Prior to the pandemic, people of color faced limited access to quality health care and experienced higher rates of preexisting conditions (Eastereals, 2021). This led to greater COVID-19 health impacts for people of color, and Black Americans are three times more likely to experience mortality from COVID-19 (Easterseals, 2021). The digital divide is another major disparity that existed prior to the pandemic for people of color, with Black and Hispanic Americans owning devices, accessing the Internet, and using the Internet at lower rates than their White peers (Easterseals, 2021). With the reliance placed on technology during social distancing measures, people of color experienced a disadvantage in this area (Easterseals, 2021). The Black community also experienced a “collective loss of safety, belonging, and wellbeing” due to violent events that increased as social justice movements intensified during the beginning of the pandemic (Easterseals, 2021). The field of disability research should investigate the specific impacts of COVID-19 to people of color with disabilities.

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

During the past two years, further research has been conducted on job loss for people with disabilities during the pandemic. A study from October 2020 to March 2021 found that almost half of people with disabilities in the study reported pay decreases or serious financial problems, needing to work remotely or from home more than usual, and being furloughed, on medical leave, or working reduced hours (Wong et al., 2022). Additionally, over one-fifth of people with disabilities had a harder time getting their work done or reported an increase in their workload during the pandemic (Wong et al., 2022). Furthermore, during the pandemic employed people with disabilities and their families faced the dilemma of choosing between continuing to work and social distancing to keep themselves or their high-risk family member safe (NCD, 2021).

Despite these struggles, the U.S. economy significantly recovered in 2021, and unemployment rates for people with disabilities also declined from 2020 (U.S. Bureau of Labor Statistics, 2021). Nevertheless, the unemployment rate for people with disabilities was still over two times that of people without disabilities during the third quarter of 2021 (10.6 percent vs. 4.9 percent) (U.S. Bureau of Labor Statistics, 2021). While the percentage of the population that is employed increased for both people with and without disabilities from 2020 to 2021, the increase was smaller for people with disabilities (an increase of 1.2 percent) versus people without disabilities (1.9 percent) (U.S. Bureau of Labor Statistics, 2022). Additionally, the rate of inability to work due to employer cutbacks is 3.5 percent higher for people with disabilities when compared to people without disabilities (Kruse et al., 2022). As employment issues for the general population start to improve, disparities in employment that existed prior to the pandemic for people with disabilities persist.

Increasingly flexible work schedules and remote work resulting from the pandemic have the potential to address employment access for people with disabilities, especially as the pandemic presents additional challenges regarding social distancing for people with certain disabilities. While remote work opportunities can be helpful for many people with disabilities, it also can present barriers; for example, people with disabilities are more likely to be in low-wage remote jobs than their peers without disabilities (National Governors Association, 2021). If the wage gap is addressed, remote work offers a unique solution for both the needs of people with disabilities and employers looking for a new labor pool (National Governors Association, 2021).

#### Stress and Trauma in the Disability Community

The COVID-19 pandemic has led to a variety of new stressors that are often felt disproportionately by the disability community. Individuals with multiple marginalized identities, such as race/ethnicity, LGBTQ+ status, or disability, may face even greater challenges (Lund, 2020). For example, people with multiple marginalized identities may worry about health care rationing due to discrimination based both on their disability and their race (Lund, 2020). A recent study confirmed that individuals with disabilities experienced stressors related to the COVID-19 pandemic at higher rates than that of people without disabilities (Ciciurkaite et al., 2021). Additionally, experiencing these stressors was associated with elevated negative impacts to their mental health and well-being. Another recent study found that people who have a disability that impairs activities of daily living (ADLs) experienced increased mental distress and perceived adversities, such as COVID risk or loneliness, when compared to people without ADL disability (Na & Yang, 2022). Additionally, people with ADL disabilities reported lower resilience, and resilience was found to buffer the impact of mental distress from perceived adversities. This is an important area for research to continue, as effects from the stress and trauma of the last two years will likely last long after the COVID-19 pandemic ends.

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

Employment, services, and activities experienced a virtual shift during the pandemic, and as the pandemic continues, a majority are still operating virtually or in a hybrid format. Since more time has passed from the beginning of this virtual shift, more efforts have been made to ensure accessibility for people with disabilities; nevertheless, several barriers persist. Furthermore, it is unclear if the shift to virtual employment, services, and activities will remain an option for people with disabilities post-pandemic.

##### New Opportunities for People with Disabilities

During the pandemic, many people with disabilities have experienced increased opportunities to access employment, services, and activities remotely, an option that was typically unavailable prior to the pandemic, even when requested. However, many workplaces are now shifting back to in-person or hybrid work formats. Despite this, many employers that did not consider remote work previously may now be more willing to consider remote work as an option for employees, especially for those with disabilities. Additionally, some people with disabilities have reported that it is easier to attend virtual medical appointments and that they hope this option will continue post-pandemic (Schwartz et al., 2021). The increase in virtual employment, services, and activities presents a unique opportunity to increase access for people with disabilities.

##### Disadvantages for People with Disabilities

###### Teleworking Disparities

Despite these increased opportunities, people with disabilities still face many barriers that result from the shift to virtual platforms. A recent study found that in May 2020, 35.8 percent of people without a disability teleworked while 25.7 percent of people with a disability teleworked (Kruse et al., 2022). People with disabilities often work lower-wage jobs where teleworking is not available, which may explain this significant gap. As the pandemic continues, the number of people teleworking has declined, yet the decline was more severe for people with disabilities (Kruse et al., 2022). In June 2021, 14.5 percent of people without a disability were teleworking while 12.7 percent of people with a disability were teleworking (Kruse et al., 2022). It is important to keep this gap in mind when considering remote options for increasing access to services for people with disabilities.

###### The Digital Divide

The digital divide between people with and without disabilities is another factor that can make remote options difficult for people with disabilities. A recent study found that only 62 percent of adults with a disability reported owning a desktop or laptop computer compared with 81 percent of adults without a disability (Perrin & Atske, 2021). Furthermore, only 72 percent of adults with a disability reported owning a smartphone, 16 percent less than the percentage of adults without disabilities who owned a smartphone. Similar percentages of people both with and without disabilities have access to broadband and to a tablet device; however, only 26 percent of people with disabilities report having all the elements that allow online access (high-speed internet, smartphone, desktop or laptop, and a tablet) while 44 percent of people without disabilities report access to all these elements. It is essential the field of disability research consider this divide when planning virtual studies and interventions.

###### Service Interruptions

A recent study found that people with chronic health conditions and disabilities experienced significant service disruptions during the pandemic in a sample with greater social, economic, and educational privilege than the general population of people with chronic conditions and disabilities (Schwartz et al., 2021). With the reduction to in-person activities due to the pandemic, many school-based and mental health interventions for people with disabilities were also significantly reduced (NIHCM Foundation, 2021). Another major disruption people with disabilities faced was interruptions in access to their caregivers (NIHCM Foundation, 2021). When examining home and community-based services (HCBS) during the pandemic, these services received less federal pandemic assistance than other types of providers (NIHCM Foundation, 2021). Additionally, at least half of states reported permanent closure of HCBS providers during the pandemic (NIHCM Foundation, 2021). While there are positive aspects of the shift to virtual services, it is important to also consider the major service disruptions that occurred with this shift.

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

The first ICDR COVID-19 white paper had several recommendations to move the disability research community forward during the pandemic. The following section will provide an update on the state of research in each of these recommendation areas. Overall, the areas of accessible technology, economic impact, emergency planning, and social isolation continue to be areas that warrant further exploration on the impact of COVID-19 for people with disabilities.

#### Accessible Technology

In early 2021, the ICDR recommended further research on virtual meeting platforms, telemedicine, and virtual supports and services for people with disabilities. Since then, more research has been initiated in these important areas. Several studies have been conducted in the last year regarding the accessibility of online learning platforms for children participating in online education (Steed et al., 2021; Kim & Fienup, 2022; Li et al., 2021; Russ & Hamidi, 2021). As a result, many recommendations have emerged for improving the accessibility of online education platforms. The shift to virtual meeting platforms has led technology companies to make a variety of improvements to the accessibility of their meeting platforms, although there is still more work to be done in this area. Additionally, more research has been done on telerehabilitation services, including the development of guidelines and standards for these services (Caprì et al., 2021; Anil et al., 2021; Buckingham et al., 2022). Several studies have also been conducted on the accessibility of telemedicine for people with disabilities (Norman et al., 2021; Shaw et al., 2022). Overall, there have been significant strides toward accessibility of virtual platforms, telemedicine, and services accelerated by the pandemic.

#### Economic Impact

Since the last paper, a handful of studies have examined the economic impact of COVID-19 for people with disabilities. Many studies related to the economy and COVID-19 for people with disabilities focus solely on employment. However, one recent study in the UK examined financial stress and working hours for people with disabilities. It found that people with disabilities were more likely than those without disabilities to report higher levels of financial stress and to be working reduced hours (Emerson et al., 2021). Similar studies should be conducted in the U.S. to examine how people with disabilities are experiencing financial stress from the pandemic. Other important economic topics that have yet to be investigated include financial savings or loss of employer-sponsored health insurance due to job loss. Future research should examine these topic areas to determine the full scope of the economic impact of the pandemic for people with disabilities.

#### Emergency Planning

Emergency planning and preparedness for people with disabilities is a research area that has received more attention during the COVID-19 pandemic, yet few studies currently exist on COVID-19 emergency and pandemic preparedness for people with disabilities. However, one recent study found that individuals who were classified as “medically vulnerable” had a 40 percent decreased odds of reporting that they were prepared for emergencies when compared to people without chronic illnesses or disabilities (Barbato et al., 2021). Despite the increasing interest in this area, the actual resources available are limited, as most are targeted toward natural disasters and inapplicable to COVID-19 (Sabatello et al., 2020). Since the first ICDR COVID-19 paper, disability researchers have continued to develop a variety of informational tools to ensure people with disabilities have accurate information they can understand about the pandemic, yet considerations for people with disabilities continue to be left out of emergency planning systems across the country.

#### Social Isolation

Social isolation for people with disabilities is another area that has received increasing attention across the disability research community since the first ICDR paper. One study found that “access to family and friends” was the most impacted area related to community participation during the pandemic (Koon et al., 2022). Additionally, the National Institute on Disability, Independent Living, and Rehabilitation Research held a four-part webinar series on social isolation and loneliness for people with disabilities during COVID-19 throughout 2021 (National Rehabilitation Information Center, 2021). However, research in this area is still limited. Future studies should explore the impact of social isolation during the pandemic for people with disabilities due to social distancing requirements, the digital divide, and inaccessibility of virtual platforms and social media. Studies should also explore the impact of social isolation for specific disability subgroups.

### Areas for Additional Research

As the pandemic continues, several new topic areas have emerged and warrant consideration by the disability research community for future research on the impact of COVID-19 on people with disabilities. While it is important to expand upon the areas mentioned earlier in the paper, the topic areas below have been only minimally explored and warrant consideration as well. The following areas are suggested topics for future research: community living, COVID-19 and children with disabilities, long COVID-19, and COVID-19 and people with mental health disabilities.

#### Community Living

While some research has been conducted on important issues during COVID-19 that impact community living for people with disabilities, such as social isolation, interruptions in services, etc., there are not many studies examining the outcomes of this for people with disabilities. One recent exploratory study examined travel behavior for people with disabilities during COVID-19 (Park et al., 2022). This study found that during the pandemic, people with disabilities experienced a greater reduction in trips to grocery stores and community service providers compared to people without disabilities. Similar exploratory studies are needed in this area to examine the full impact of COVID-19 on the many aspects of community living for people with disabilities.

#### Impact of COVID-19 on Children with Disabilities

One important research area receiving increased attention is the impact of COVID-19 on children with disabilities. There are several studies that examine accessibility of online learning for children with disabilities, but other aspects of the impact of COVID-19 should be examined as well. For example, the 2021 NCD report discusses how children receiving special education under the jurisdiction of the Bureau of Indian Education faced additional barriers to distance learning during COVID-19 due to difficulty accessing the internet in rural areas (NCD, 2021). Additionally, a rapid review found that there were no papers examining the impact of COVID-19 on children with physical disabilities despite their vulnerability to COVID-19 and the interruption to services such as occupational therapy or speech therapy (Lebrasseur et al., 2021). Additional studies are needed to examine the various ways COVID-19 has impacted children with disabilities.

#### Long COVID-19 and Resulting Disability

Another emerging area of disability research is “long COVID,” a condition where individuals experience symptoms months after their first COVID-19 infection or may have new or recurring symptoms later (HHS, 2021). In 2021, the federal government released guidance on long COVID and its classification as a disability under the Americans with Disabilities Act, Section 504, and Section 1557 (HHS, 2021). The guidance provides specific details on the criteria that must be met for long COVID to be considered a disability under these federal laws. Currently, the only published work thus far funded from the federal government has been related to return to work needs for individuals with Long COVID in a single small qualitative study (Wong et al., 2021). There is potential for an emerging evidence base as data are being collected and no findings are yet available, on the impacts of long COVID on an individual’s ability to work, the needs and challenges relating to employment services and supports including disability benefits, and information on potential interventions to maintain employment. In future research, disability researchers should explore both the ways that long COVID can impact people with preexisting disabilities and the ways it can result in new disability.

#### Impact of COVID-19 on People with Mental Health Disabilities

The impact of the pandemic on people with mental health disabilities is another important area for further research. Necessary social distancing and isolation measures have had a negative impact on the entire population’s mental health, but these impacts were felt more profoundly by those with preexisting mental health disabilities. For example, both youth and young adults with mental health disabilities experienced a deterioration of their mental health during the pandemic, compounded by a preexisting lack of treatment options and supports (NCD, 2021). One study found that those with psychiatric disorders reported more frequent mental distress and missed medical visits and medications than those without a psychiatric disorder (Dickerson et al., 2022). However, there is a lack of information on the other impacts of COVID-19 for this specific population, and more research in this area is warranted.

### Conclusion and Next Steps

The field of disability research has continued to expand and adapt throughout the various waves of the COVID-19 pandemic. Disability research continues to innovate and move forward despite limited targeted funding for disability research and lack of inclusion of people with disabilities in major COVID-19 research studies. The field of disability research has initiated important studies in a variety of new areas related to COVID-19 and disability. However, as the pandemic exacerbated existing disparities for people with disabilities, it is important that the field of disability research collaborate to address the identified areas that need further research.

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