



The Impact of COVID-19 on People with Disabilities



National Council on Disability

October 29, 2021

National Council on Disability (NCD)
1331 F Street NW, Suite 850
Washington, DC 20004

The Impact of COVID-19 on People with Disabilities

National Council on Disability, October 29, 2021
Celebrating 36 years as an independent federal agency

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

October 29, 2021

President Joseph R. Biden Jr.
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear Mr. President,

On behalf of the National Council on Disability (NCD), I hereby transmit our statutorily mandated annual Progress Report for 2021. The report is also available on NCD's website at www.ncd.gov. The report, *The Impact of COVID-19 on People with Disabilities*, examines COVID-19's disproportionate negative impact upon people with disabilities in (1) accessing healthcare; (2) accessing direct care workers; (3) congregate care settings and transition; (4) education; (5) employment; (6) effective communication; (7) mental health and suicide prevention services; and the congressional, federal, and state response.

To develop this report, NCD monitored pandemic-related developments, examined emerging research, and relied on stakeholder involvement. NCD began with two virtual convenings: the first with healthcare experts, bioethicists, direct care workers and advocates, independent living leaders, people with disabilities, and family members of people with disabilities to discuss the experiences of people with disabilities in healthcare, congregate care facilities (CCFs), direct care workers, and barriers to effective communication. The second convening was with educators, school administrators, employment attorneys, mental health and suicide prevention policy experts, people with disabilities, and parents of students with disabilities, to discuss education, employment, and mental health. This mixed participant engagement provided us with insights from individuals with expertise and personal experience on more than one topic area and from those who live at the intersection of multiple personal characteristics, such as age, race and ethnicity, income level, sexual orientation, gender identity, and religion.

NCD found that COVID-19 exacted a steep toll on certain populations of people with disabilities, and the events that unfolded during the pandemic, including measures to mitigate the spread, posed unique problems and barriers to people with disabilities in each of our seven focus areas. The pandemic also exposed extreme disability bias, failures in modifying policies to accommodate the needs of people with disabilities, and gaps in disability data collection and antidiscrimination laws that need to be rectified before the next pandemic or public health emergency.

NCD's key findings include:

- People with intellectual or developmental disabilities, and medically fragile and technology dependent individuals, faced a high risk of being triaged out of COVID-19 treatment when

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hospital beds, supplies, and personnel were scarce; were denied the use of their personal ventilator devices after admission to a hospital; and at times, were denied the assistance of critical support persons during hospital stays. Informal and formal Crisis Standards of Care (CSC), pronouncements that guided the provision of scarce healthcare resources in surge situations, targeted people with certain disabilities for denial of care.

- Residents of CCFs such as nursing homes, assisted living homes, psychiatric facilities, and board and care homes, where bedrooms, direct care workers, and amenities are shared, and infection control is highly challenging, caught the virus and died in large numbers, largely due to lack of personal protective equipment (PPE), close contact with others in confined settings, and the higher susceptibility to the virus due to other health conditions. The institutional model was once again shown to be detrimental to vulnerable individuals.
- Limited opportunities to transition out of congregate settings to community-based settings, to mitigate the risk of contracting the virus, revealed continuing weaknesses and lack of sufficient Medicaid Home and Community-Based Services (HCBS).
- The growing shortage of direct care workers in existence prior to the pandemic became worse during the pandemic. Many such workers, who are women of color earning less than a living wage and lacking health benefits, left their positions for fear of contracting and spreading the virus, leaving people with disabilities and their caregivers without aid and some at risk of losing their independence or being institutionalized.
- People with disabilities and chronic conditions who were at particularly high risk of infection with, or severe consequences from the virus, were not recognized as a priority population by many states when vaccines received emergency use authorization.
- Physical, communication, and procedural barriers were common in both testing for COVID-19 and vaccination.
- Students with disabilities were cut off from needed in-person special education services and supports and were given last or no priority when schools attempted to preserve educational opportunity. Some students under the jurisdiction of the Bureau of Indian Education faced an especially challenging combination of Internet barriers on Indian and rural lands.
- People with disabilities have historically been underrepresented in the workforce even in robust economic times and the pandemic exacerbated this long-standing problem.
- Deaf, Hard of Hearing, Deaf-Blind, and Blind persons faced a profound communication gulf as masks became commonplace, making lipreading impossible and sign language harder.
- Both youth and adults who had mental health disabilities that predated the beginning of the pandemic experienced measurable deterioration over its course, made worse by a preexisting shortage of community treatment options, effective peer support, and suicide prevention support.

NCD's key recommendations include:

Healthcare

Congress or the Department of Health and Human Services (HHS) should require all hospitals and managed care plans that receive federal financial assistance to increase public transparency of, and nondiscrimination and due process within, crisis standard of care (CSC) guidelines and medical rationing policies adopted during public health emergencies and emergency surge situations.

HHS' Office for Civil Rights (HHS OCR) should develop a Patient's Bill of Rights for People with Disabilities on: effective communication, policy modifications, treatment without discrimination, access to personal support persons, use of personal medical equipment, advance directives, Physician Orders for Life-Sustaining Treatment (POLST), or Do Not Resuscitate (DNR) orders without undue influence, information on and assistance for returning to the community from hospital or institutional care, and treatment decisions free of bias about one's quality of life and capacity to benefit from treatment due to the presence of a disability.

HHS/Administration for Community Living (ACL), HHS OCR, and the Department of Justice (DOJ) should work together to establish a healthcare technical assistance project to inform a range of healthcare providers on civil rights issues regarding patients with disabilities.

Congregate Care Facilities

Centers for Medicare and Medicaid Services (CMS), ACL, Substance Abuse and Mental Health Services Administration (SAMHSA), Department of Housing and Urban Development (HUD), Federal Emergency Management Agency (FEMA), and DOJ should develop and implement a strategy to mitigate the risks of infectious disease transmission in CCFs and address the civil rights concerns that impact the lives of people with disabilities in CCFs.

Centers for Disease Control and Prevention (CDC) should emphasize CCF census reduction as an infection control strategy by expanding its guidance beyond long-term care facilities (LTCFs) to include all CCFs and emphasize that reducing the census of CCFs through accelerating discharges and diversions is a critical strategy.

CMS should prioritize all CCFs for infection control purposes and ensure that they receive equipment such as test kits and proper PPE necessary to follow CDC guidelines in a similar health emergency. CMS should clarify that community providers conducting in-reach transition support to facility residents are "essential care providers," not "visitors," and should not be restricted from entering facilities during future pandemics or crises.

Direct Care Workforce

Congress should enact federal legislation based on the principle of Universal Family Care, a social insurance program model for early childcare and education, paid family and medical leave, and long-term services and supports as envisioned by the National Academy of Social Insurance.

Congress should ensure that future and proposed legislation, such as the Better Care Better Jobs Act, includes funding to improve direct care workforce wages and benefits and increase recruitment and retention.

Education

Congress should enact measures that include funds dedicated to compensatory education for students with disabilities who could not receive necessary services and supports during the pandemic and who have experienced disruption and regression in their behavioral and educational goals.

The U.S. Department of Education (ED) should direct school districts to provide compensatory education to students with disabilities to allow them to recover and regain skills. The right to and need for compensatory education should be presumed for children with disabilities who did not receive necessary instruction and supports during the COVID-19 pandemic.

ED and DOJ should issue a joint guidance document outlining the elements of accessible remote education for students with disabilities.

Employment

The Equal Employment Opportunities Commission (EEOC) should clarify and enforce legal protections for workers with disabilities who seek telework, leaves of absence, and safety policy modifications as reasonable accommodations. The EEOC should offer guidance to employers in accommodating employees with needs that appear to conflict.

The Office of Personnel Management (OPM) should maintain maximum telework flexibility for all federal agencies on a permanent basis and ensure that federal employees with disabilities receive necessary, reasonable accommodations in their technology while working remotely and retain flexibility to work from their designated federal office as needed or desired.

Effective Communication

HHS OCR and DOJ should direct hospitals and other healthcare entities to include in their nondiscrimination notices and staff training the recognition of policy modifications as part of a patient's right to effective communication, in addition to the provision of auxiliary aids and services when needed by patients with disabilities to receive effective care.

All federal entities involved in public health, emergency management, and the provision of public announcements or briefings of broad public importance should prepare and disseminate information related to any pandemic or public health emergency in accessible formats, including providing sign language interpretation and/or captions during live and prerecorded video briefings; making all written materials available in alternative formats; and making all online materials accessible.

State Hospital Associations should develop guidance and best practices for ensuring effective communication in hospitals and associated urgent care clinics during public emergencies, including the provision of qualified in-person interpretation and fully accessible telemedicine platforms consistent with the Web Content Accessibility Guidelines (WCAG) 2.1 standards.

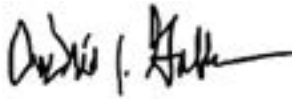
Mental Health and Suicide Prevention

Congress should permanently authorize telehealth flexibilities that enabled tele-mental health services while also ensuring that in-person services and hybrid in-person and virtual services are available options for those who need and want them.

States should expand the mental health workforce and peer support workforce, including through using HCBS dollars and mobile crisis dollars available through the American Rescue Plan and Certified Community Behavioral Health Center (CCBHC) funds.

NCD appreciates your focus on equitable treatment for every American and believes that this report provides information to support needed changes to ensure equity for people with disabilities in a future pandemic or public health emergency. We stand ready to help you to achieve your equity goals and fortify existing protections and programs for people with disabilities.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Andrés J. Gallegos". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Andrés J. Gallegos
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Executive Summary

This report examines over a year of life in a public health emergency as it occurred in real time for people with disabilities in the United States. Its prime focus points are healthcare, the direct care workforce, congregate care facilities (CCFs), education, employment, effective communication, and mental health and suicide prevention policy. The COVID-19 pandemic was marked by multiple crisis points that hit various communities unequally, depending on such factors as one's age (older persons had far higher death rates upon infection), one's job (e.g., healthcare worker, essential worker), where one lived (e.g., urban zip codes high on the social vulnerability index, rural locations), and the color of one's skin (Black and Latino persons had disproportionately high death rates). The number of young children contracting the virus is rising. When the novel coronavirus first started claiming lives in the United States in early 2020, it did so in a country with entrenched economic, social, racial, and health disparities. By September 15, 2021, the nation had seen more than 41 million cases and more than 660,000 deaths attributable to COVID-19, according to the Centers for Disease Control and Prevention (CDC).

Disability is not always singled out as a characteristic that is particularly relevant to COVID-19's complex, tragic history. Even with nursing home deaths comprising approximately 22 percent of U.S. deaths from COVID-19, that disproportionate number tends to be attributed to age and the circumstances of congregate living rather than disability and the way that long-term services and supports have been provided to people with disabilities for more than half a century. Anyone could become infected with the coronavirus, anyone could need hospitalization and treatment for COVID-19, everyone had to practice social distance and wear masks, and anyone could die from the disease, but these

This report stands as witness to the difference that disability made when the pandemic brought the United States to a halt.

few universal facts did not result in the uniform impact of COVID-19 on people with disabilities. This report stands as witness to the difference that disability

made when the pandemic brought the United States to a halt.

NCD found that the coronavirus exacted a steep toll on certain populations of people with disabilities, and the events that unfolded during the pandemic, including measures to mitigate the spread, posed unique problems and barriers to people with disabilities in each of our seven focus

areas. The pandemic also exposed disability bias, failures in modifying policies to accommodate the needs of people with disabilities, and gaps in disability data collection and antidiscrimination law that need to be rectified before the next pandemic or public health emergency.

Key Findings

- Residents of congregate care facilities such as nursing homes, assisted living homes, psychiatric facilities, and board and care homes, where bedrooms, direct care workers, and amenities are shared, and infection control is highly challenging, caught the virus and died in large numbers, largely due to lack of personal protective equipment (PPE), close contact with others in confined settings, and the higher susceptibility to the virus due to other health conditions. The institutional model was once again shown to be detrimental to vulnerable individuals.
- People with disabilities of varying ages relied on direct care workers to aid with daily activities needed to remain functional in their communities, and neither they nor their workers could fully shelter in place or obtain needed personal protective equipment (PPE).
- The growing shortage of direct care workers that existed prior to the pandemic got worse during the pandemic. Many such workers, who are women of color earning less than a living wage and lacking health benefits, left their positions for fear of catching or spreading the virus, leaving people with disabilities and their caregivers without aid, and placing people with disabilities at risk of losing their independence or being institutionalized
- Researchers have increasingly documented how physicians and other healthcare providers hold implicit biases concerning disability that lead to a primary focus on the functional limitations of people with significant disabilities and an assumption that they have a low quality of life as a result. Those assumptions have guided treatment decisions, with deadly consequences.
- People with intellectual and developmental disabilities, and those who were medically fragile and technology dependent, disabilities faced a uniquely high and explicit risk of being triaged out of COVID-19 treatment when hospital beds, supplies, and personnel were scarce, denied the use of their personal ventilator devices after admission to a hospital, and at times, denied the assistance of critical support persons during hospital stays. Informal and formal Crisis Standards of Care (CSC), documents that guided the provision of scarce healthcare in surge situations, targeted people with certain disabilities for denial of care.
- People with disabilities and chronic conditions who were at particularly high risk of infection with, or severe consequences from, COVID-19 were not recognized as a priority population by many states when vaccines were given emergency use authorization and had to advocate from a position of weakness because of a longstanding failure to collect detailed functional disability data in healthcare.

- Physical, online, communication, and procedural barriers remained common in multiple key activities that were commonly needed during the pandemic, such as the administration of testing for COVID-19 and, later on, vaccination.
- Students with disabilities did not receive needed in-person special education services and supports that made learning possible and were given last or no priority when districts attempted to preserve educational opportunity. Some students with special education needs, who were under the jurisdiction of the Bureau of Indian Education, experienced an especially challenging combination of internet barriers on Indian and rural lands.
- People with disabilities have historically been underrepresented in the workforce even in robust economic times and the pandemic exacerbated this long-standing problem.
- Employed people with disabilities and the family members of people with disabilities encountered the difficult choice between the income needed from work and the social distance and isolation needed to keep people with high-risk disabilities safe from the coronavirus, especially in the face of gaps in disability employment protections such as the absence of the ability to seek leave as a care provider for a family member with disabilities.
- Deaf, Hard of Hearing, Deaf-Blind, and Blind persons experienced a profound communication gulf as masks became commonplace, making lipreading impossible and sign language harder, while the virus

made touch dangerous for blind persons and people with visual impairments who typically experience the world through touch.

- The financial, social, and familial adjustments that had to be made over the course of the pandemic, in addition to the constant threat of contracting COVID-19 itself, had a negative impact on everyone's mental health, and mental health symptoms were experienced by some who acquired the virus. But both youth and adults who had mental health disabilities that predated the beginning of the pandemic experienced measurable deterioration over its course, made worse by a preexisting shortage of community treatment options, effective peer support, and suicide prevention support.

In addition to these findings, we highlight that disability is not a characteristic that stands alone but one that intersects with all other aspects of a person's identity such as age, race and ethnicity, income level, sexual orientation, gender identity, and religion. As a result, any one person with a disability can experience multiple barriers and discrimination related to any of the major topics covered in this report.

While people with disabilities have undoubtedly come a long way, in visibility, opportunity, and community integration since the first federal disability rights laws were passed in the 1970s and later, the pandemic has reemphasized that there still is considerable work to be done to achieve fully the objectives of those disability rights laws. The recommendations made in this report are meant to lead the way toward achieving a different status quo, one that



values equal treatment and accommodation in the event of another pandemic or any other public health emergency.

Finally, the reality of the coronavirus as an evolving phenomenon, and the national and international real-time responses to it, mean that this report does not include findings or recommendations on some issues that remain unresolved, e.g., many U.S. states are working on issues concerning “vaccine passports” and how to establish vaccination status and for what purposes. Similarly, how to achieve the equitable vaccination of children, as well as equitable vaccination internationally, remains an open issue. Another example of an unresolved issue

as of the conclusion of writing on this report is ongoing discussions among federal lawmakers on funding and infrastructure for home- and community-based services (HCBS), as well as the long-term federal or state commitment to community integration and accelerating deinstitutionalization in light of the risks to nursing home residents posed by any infectious emergency.

Key Recommendations

To ensure the United States is prepared for a future pandemic or similar national health crisis, NCD’s key recommendations include:

Healthcare

- ***The Department of Health and Human Services (HHS)*** should require all hospitals, hospital systems, and managed care plans that receive federal financial assistance to increase public transparency of, and nondiscrimination and due process within, crisis standard of care (CSC) guidelines and medical rationing policies adopted during public health emergencies and emergency surge situations. These guidelines and policies should be clearly posted on all the entity's websites and hospital and appropriate provider network websites.
- ***HHS' Office for Civil Rights (HHS OCR)*** should develop a Patient's Bill of Rights for People with Disabilities, written in plain language and including information on the following rights that pertain to healthcare: effective communication, policy modifications, treatment without discrimination, access to personal support persons, use of personal medical equipment, physical accessibility, choice of less invasive reasonable treatment or health maintenance alternatives; having an Advance Directive, Physician Orders for Life-Sustaining Treatment (POLST), or Do Not Resuscitate (DNR) orders without undue influence, information on and assistance for returning to the community from hospital or institutional care, and freedom from assumptions about one's quality of life and capacity to benefit from treatment or survive treatment because of the presence of a disability or particular condition.
- ***The National Center for Health Statistics (NCHS)*** should work with state vital statistics offices to initiate revisions in the U.S. Standard Certificate of Death to include functional disability and HCBS consumer information in the demographic section of death certificates and obtain the approval of completed revisions from the HHS Secretary.
- ***HHS/Administration for Community Living (ACL), HHS OCR, and Department of Justice (DOJ)*** should work together to establish a national healthcare technical assistance project to inform a range of professionals on civil rights issues regarding patients with disabilities. This would include providing healthcare providers, medical educators, professional associations, and public health authorities with information and training on implicit disability bias, the importance of policy modifications and reasonable accommodations as needed for effective healthcare, and the critical role that direct care workers and personal support persons play in maintaining the health and functional capacity of certain people with disabilities. ACL could play a central coordinating role over the Center, either as an independent entity or as an adjunct component of existing entities that provide disability expertise such as the regional Americans with Disabilities Act (ADA) Centers, while both HHS OCR and DOJ can provide technical and legal expertise.

Congregate Care Facilities

- **Congress** should enact the Better Care Better Jobs Act, which would expand access to HCBS and strengthen the HCBS workforce.
- **Centers for Medicare and Medicaid Services (CMS), Administration for Community Living (ACL), Substance Abuse and Mental Health Services Administration (SAMHSA), Department of Housing and Urban Development (HUD), Federal Emergency Management Agency (FEMA), and Department of Justice (DOJ)** should launch a multiagency national strategy to mitigate the risks of infectious disease transmission in CCFs and address the civil rights concerns that continue to impact the lives of people with disabilities in CCFs. That strategy should involve a coordinated effort among key federal agencies including, at a minimum, CMS, ACL, SAMHSA, HUD, FEMA, and DOJ. The agencies should clarify how community services can be paired with housing resources to ensure that people with disabilities have the opportunity to receive services in the most integrated setting and avoid needless risk of infection and death. They should issue guidance identifying strategies and resources available to state and local governments to facilitate transitions and diversions from CCFs, flexibilities that may be used, and how these resources factor into public entities' *Olmstead* obligations.
- **Centers for Disease Control and Prevention (CDC)** should emphasize CCF census reduction as an infection control strategy by expanding its guidance beyond long-term care facilities (LTCFs) to include all CCFs and emphasize that reducing the census of CCFs through accelerating discharges and diversions is a critical strategy to ensure that the physical distancing required for infection control can be effectively done in CCFs.
- **CMS** should prioritize all CCFs for infection control purposes and ensure that they receive equipment such as test kits and proper PPE from federal, state, and local governments that is necessary to follow CDC guidelines in any similar health emergency. CMS should recognize and clarify that community providers conducting in-reach transition support to facility residents are "essential care providers," not "visitors," and should not be restricted from entering facilities during future pandemics or crises. All CCFs should receive priority designation for vaccine allocation.
- **State Medicaid Agencies** should expand Medicaid HCBS services, including through taking advantage of new HCBS funding made available through the American Rescue Plan Act.

Direct Care Workforce

- **Congress** should enact the Better Care Better Jobs Act, the American Families Plan, the U.S. Citizenship Act of 2021, and the HCBS Access Act.
- **Congress** should enact federal legislation based on the principle of Universal Family Care, a social insurance program model for early childcare and education, paid family and medical leave, and long-term services and supports as envisioned by the National Academy of Social Insurance. Built on the models of Social Security and Medicare, Universal Family Care is an integrated approach to care policy that recognizes long-standing social inequities based on race, ethnicity, and disability.
- **Congress** should ensure that future and proposed legislation, such as the Better Care Better Jobs Act, which builds on the American Rescue Plan Act's expanded funding for Medicaid HCBS, includes funding to improve direct care workforce wages and benefits and increase recruitment and retention. This funding should include a mechanism to ensure that workers' wages and benefits are adequate for the present and adjusted as necessary in the future to ensure a stable workforce that is paid a living wage. It should also require as a condition of receiving such funding that states either provide directly or require that home healthcare agencies, CCFs, and other service providers provide paid family and medical leave for their direct care workers. States should also be required to ensure that direct care workers have access to adequate, affordable healthcare insurance either as an employer or union-sponsored benefit, through the Health Insurance Marketplace, or by other means.

Education

- **Congress** should enact measures that include funds dedicated to compensatory education for students with disabilities who did not have necessary educational services and supports during the pandemic and who experienced disruption and regression in their behavioral and educational goals. Priority should be given to compensatory education for children with disabilities living in low-income families, children with disabilities who needed—but did not receive—in-person instruction and supports, and Native American children with disabilities.

(continued)

Education: *continued*

- **Congress** should enact measures to better prepare and plan for the education of children, including children with disabilities, during a future public health crisis or other national emergency by including funds dedicated to making high-speed broadband internet available to and affordable for everyone, and particularly for low-income families, homeless families, and families in rural and other areas where high-speed internet access is not consistently available. Federal recovery efforts must continue to expand connectivity in Native American communities, with a focus on Bureau of Indian Education (BIE) school communities and American Indian reservations. Funds should be allocated soon to ensure that every student has an appropriate laptop or tablet for remote education so that education is not interrupted by another emergency.
- **The U.S. Department of Education (ED)** should direct school districts to provide compensatory education to students with disabilities to allow them to recover and regain skills. The right to and need for compensatory education should be presumed for children with disabilities who did not receive necessary instruction and supports during the COVID-19 pandemic. Given the extended crisis and national emergency caused by the pandemic, the extent and duration of gaps in educational services, and the known impacts on children with disabilities, families should have a right to “opt in” to compensatory education without any requirement of an extensive individualized factual showing. Sustained access to compensatory education will be critical for many students with disabilities, as they were virtually excluded from all education for more than one year.
- **ED and DOJ** should issue a joint guidance document outlining the elements of accessible remote education for students with disabilities. The guidance should review accessibility requirements for digital platforms and digital documents and should emphasize the necessity of designing remote education to be fully accessible to students who are Deaf, Hard of Hearing, and/or blind, or who have other disabilities. The guidance should review necessary auxiliary aids and services such as real-time captioning, accessible transcripts, sign language interpreting, and alternative formats. The guidance should specify the educational contexts in which automatic captioning is not appropriate and should detail the features necessary to properly integrate sign language interpreters into a video platform.

Employment

- **Congress**, in the event of a future national disaster or public health emergency, should pass legislation immediately to provide dedicated unemployment and relief funds to stabilize households, including those of part-time workers, self-employed individuals, and gig workers, who are disproportionately people with disabilities, working families with children with disabilities, individuals with caregiving obligations, and people with disabilities receiving Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) benefits.
- **The Equal Employment Opportunities Commission (EEOC)** should work to clarify and enforce legal protections for workers with disabilities who seek telework, leaves of absence, and safety policy modifications as reasonable accommodations. The EEOC should offer guidance to employers in accommodating employees with needs that appear to conflict.
- **The Office of Personnel Management (OPM)** should maintain maximum telework flexibility for all federal agencies on a permanent basis and ensure that federal employees with disabilities receive necessary, reasonable accommodations in their technology while working remotely and retain flexibility to work from their designated federal office as needed or desired.
- **The Department of Labor (DOL) and OPM** should issue joint guidance on effective telework tools and highlight the benefit of telework for many people with disabilities. The guidance should describe the need for accessibility in remote work platforms and allow agencies to use the platforms that are most accessible based on employee needs.
- **Congress should task the Government Accountability Office (GAO)** with examining the gaps in employment protections that occurred during the COVID-19 pandemic, including for people with disabilities who were vulnerable to severe outcomes from COVID-19, and for people who have COVID-19–vulnerable household members, or who are caregivers to COVID-19–vulnerable individuals.

Effective Communication

- **HHS OCR and DOJ** should direct hospitals and other healthcare entities to include in their nondiscrimination notices and staff training the recognition of policy modifications as part of a patient's right to effective communication, in addition to the provision of auxiliary aids

(continued)

Effective Communication: *continued*

and services when needed by patients with disabilities to receive effective care. Concrete examples should be provided, such as giving exceptions to face mask mandates when an individual cannot wear a mask by reason of their disability and to general “no-visitor” policies when needed for disability-related communication needs.

- **All federal entities involved in public health, emergency management, and the provision of public announcements or briefings of broad public importance** should disseminate information related to any pandemic or public health emergency in accessible formats, including information about the nature of the emergency, mitigating actions that individuals should take, available federal and state assistance and support, and available medical treatments. This includes providing sign language interpretation and/or captions during live and prerecorded video briefings, making all written materials available in alternative formats, and making all online materials accessible.
- **State Hospital Associations** should work with state departments of public health and disability advocacy groups to develop guidance and best practices for ensuring effective communication in hospitals and associated urgent care clinics during public emergencies, including:
 - the provision of clear, adaptable masks to hospital staff, to be used when an N-95 mask is not required;
 - the provision of qualified in-person interpretation when a person with a disability requests it, with PPE made readily available to interpreters;
 - fully accessible telemedicine platforms to ensure effective communication for people with communication disabilities, including ensuring that their interface supports three-way video visits with interpreters and that the platform and its content are screen-reader accessible, consistent with the Web Content Accessibility Guidelines (WCAG) 2.1 standards.

Mental Health and Suicide Prevention Policy

- **Congress** should permanently authorize telehealth flexibilities that enabled tele-mental health services while also ensuring that in-person services and hybrid in-person and virtual services are available options for those who need and want them.

Mental Health and Suicide Prevention Policy: *continued*

- **SAMHSA and state mental health agencies** should robustly promote effective suicide prevention efforts focusing on approaches that address the underlying problems that cause people to consider suicide. These should include helping individuals connect with housing services and referring individuals to vocational rehabilitation or other employment programs for people with disabilities.
- **CMS** should encourage states to expand peer support services and highlight the value of peer support, particularly by individuals with lived experience with mental health disabilities as well as with the racial, ethnic, and cultural backgrounds of the communities they serve.
- **States** should take steps to expand the mental health workforce and particularly the peer support workforce, including through using new HCBS dollars and mobile crisis dollars available through the American Rescue Plan and new block grant and Certified Community Behavioral Health Center (CCBHC) funds. States should ensure that their mental health systems include robust peer support services.
- **Schools and School Districts** should ensure that remote and in-person mental health services are available to students who need them, even in pandemics or health emergencies when students are required to attend school remotely.

Methodology

This report tries to build a picture of what people with disabilities experienced in their lives during the COVID-19 pandemic. It is divided into seven main chapters that examine healthcare discrimination, the direct care workforce, CCFs, education, employment, effective communication, and mental health and suicide prevention policy. Other areas that are important to the seven main topics, such as transportation and food security, are also touched on in the chapters either because the pandemic either changed them or revealed access barriers in their operation for people with disabilities.

This report is based on multiple sources. First, there were two virtual convenings that took place on November 10 and November 12, 2020. The first convening gathered healthcare experts, bioethicists, direct care workers and advocates, independent living leaders, people with disabilities, and family members of people with disabilities to discuss the experiences of people with disabilities during the pandemic with healthcare discrimination, CCFs, the direct care workforce, and barriers to effective communication. The second convening gathered educators, school administrators, employment attorneys, mental health and suicide prevention

policy experts, people with disabilities, and parents of students with disabilities, to discuss the education, employment, and mental health experiences of people with disabilities.

Each convening included topic-specific small group discussions as well as large group sessions where participants had an opportunity to address connections among the topics. Each convening also included two to three people with disabilities or family members of people with disabilities sharing their experiences during the pandemic relating to one or more of the featured seven topic areas. This mixed mode of participant engagement was useful for capturing the insights of individuals who had expertise and/or personal experience on more than one topic area, or who lived at the intersection of multiple personal characteristics. Participants in both the large and the small group forums had an opportunity to raise observations and make recommendations. One-on-one follow-up emails and conversations took place with convening participants and provided additional details and information.

Second, the authors have had an ongoing literature review on the core topic areas and COVID-19 from November 2020 through to May/June 2021. News coverage, policy analysis, and scientific and legal journal articles

were constantly published during this period as the pandemic progressed in real time. As well, preexisting literature and research on existing disparities experienced by people with disabilities in all topic areas before COVID-19 were also examined. A selection of relevant federal, state, and local policies and guidance related to the pandemic was examined, as well as drafts of new bills or new laws drafted or passed in response to COVID-19. Finally, this report is informed by interactions with people with disabilities who sought advocacy and legal assistance while trying to enforce disability civil rights laws in their own lives.

Each chapter of this report has topic-specific findings and recommendations along with an analysis on the topic. While each chapter is written so that it can be sensibly read on its own, the entire report presents a much fuller picture of how people with disabilities and disability communities fared during the pandemic. The most significant findings and highest-priority recommendations are presented collectively in the Executive Summary, organized according to the major topic area meant to be addressed and specifying the entity to which the recommendation is directed. The full group of recommendations for each individual chapter is organized according to the entity to which it is directed.

Acronym Glossary

ACA	Affordable Care Act
ACIP	Advisory Committee on Immunization Practices
ACL	Administration for Community Living
ACS	American Community Survey
ADA	Americans with Disabilities Act of 1990
ADHD	Attention Deficit Hyperactivity Disorder
ADL(s)	Activity(ies) of Daily Living
ARPA	American Rescue Plan Act of 2021
ASL	American Sign Language
BIE	Bureau of Indian Education
BRFSS	Behavioral Risk Factor Surveillance System
CARES	Coronavirus Aid, Relief, and Economic Security Act of 2020
CART	Communication Access Realtime Translation
CAMS	Collaborative Assessment and Management of Suicidality
CBT	Cognitive Behavioral Therapy
CCBHC	Certified Community Behavioral Health Center
CDC	Centers for Disease Control and Prevention
CDPH	California Department of Public Health
CCFs	Congregate Care Facilities
COVID-19	Coronavirus Disease 2019
CSC	Crisis Standards of Care
CVAC	Community Vaccine Advisory Committee (California)
DNR	Do Not Resuscitate
DOJ	U.S. Department of Justice
DOL	U.S. Department of Labor
DREDF	Disability Rights & Education Defense Fund

ECCE	Early Child Care and Education
EEOC	Equal Employment Opportunity Commission
EUA	Emergency Use Authorization
FAPE	Free and Appropriate Public Education
FCC	Federal Communications Commission
FDA	U.S. Food and Drug Administration
FEMA	Federal Emergency Management Agency
FFCRA	Federal Families First Coronavirus Response Act
GAO	Government Accountability Office
HEROES	The Health and Economic Recovery Omnibus Emergency Solutions Act
HCBS	Home- and Community-Based Services
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act of 1996
HOPWA	Housing Opportunities for Persons with AIDS
HRSA	Health Resources and Services Administration
HUD	U.S. Department of Housing and Urban Development
IADLs	Instrumental Activities of Daily Living
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
LTCFs	Long-Term Care Facilities
LTSS	Long-Term Services and Support
NASEM	National Academies of Science, Engineering, and Medicine
NCD	National Council on Disability
NCHS	National Center on Health Statistics
NFCSP	National Family Caregiver Support Program
NSPL	National Suicide Prevention Lifeline
HHS OCR	U.S. Department of Health and Human Services Office for Civil Rights
OPM	Office of Personnel Management
PASRR	preadmission screening
PFML	Paid Family and Medical Leave
POLST	Physician Orders for Life-Sustaining Treatment
PPE	Personal Protective Equipment
Promotoros	“Promotores de salud” (<i>community health worker</i> in Spanish)
REL	Race, Ethnicity, and Language
SAMHSA	Substance Abuse and Mental Health Services Administration
SNAP	Supplemental Nutrition Assistance Program

SSI	Supplemental Security Income
SSDI	Social Security Disability Insurance
TTP	TeleType
UFC	Universal Family Care
USDA	U.S. Department of Agriculture
VRI	Video Remote Interpreting



[W]hen people with disabilities lost their lives because they were unnecessarily housed in CCFs where infectious diseases cannot be controlled, or COVID-19 treatment was denied because of discriminatory medical rationing, or because states failed to recognize that people with significant disability need priority for vaccination because they are subject to higher risks of infection and death, these were not only “pandemic losses.” These lives were lost due to the devaluation of the lives of people with disabilities . . .

Introduction

When the first case of COVID-19 in the United States was officially confirmed in January 2020, people with disabilities were living their lives: attending schools, working, raising families, enjoying their communities, and planning for the future. The pandemic caused by the novel coronavirus upended the lives of people with disabilities just as it disrupted the lives of nondisabled persons, but this statement does not reveal the full story. By 2020, people with disabilities had spent decades fighting for equal opportunity and their civil rights. Key federal laws such as Section 504 of the Rehabilitation Act of 1973,¹ the Individuals with Disabilities Education Act (IDEA),² and the Americans with Disabilities Act³ had helped people with disabilities integrate into their communities, receive improved educational services, and increase their presence in the workforce, but many barriers remained before the pandemic struck. The impact of the pandemic on people with disabilities cannot be understood without laying the critical groundwork of what living with disabilities looked like immediately before the pandemic. This introduction provides context for the report using brief topical “snapshots” of disability discrimination that were exacerbated by the pandemic.

Prior to the pandemic, health and healthcare disparities already exposed people with

disabilities to heightened risk for poor health outcomes.⁴ Moreover, despite the fact that people with disabilities are a population subject to healthcare disparities, many healthcare professionals continue to see the poor health outcomes of people with disabilities as an inevitable function of disability rather than an avoidable consequence of accessibility barriers, lack of needed modifications in policies and procedures, and explicit and implicit bias among providers.⁵ In 2019, NCD reported that the disability bias of healthcare providers leads many providers to “critically undervalue life with a disability,”⁶ representing a real threat to people with disabilities who may be denied life-saving care due to physicians relying on stereotypes about the lives of people with disabilities, including the common assumption that someone who cannot walk or who cannot talk has no quality of life. In addition to assumptions and attitudinal barriers, the lack of accessible examination and medical equipment in medical care means that people with disabilities, specifically people with mobility disabilities, receive substandard primary care compared to people without disabilities.⁷ When people with disabilities require a period of acute care, they can encounter denials of their personal care attendants or support persons, even though they benefit greatly from having their regular

assistants in the hospital. Prior to the pandemic, hospital policies on support persons were opaque and varied greatly among institutions and among providers, leading to harmful medical results.⁸ As a result of these factors, people with disabilities entered the pandemic in a far worse position than people without disabilities. They found themselves in need of intensive care or life-sustaining services and devices, and being treated by emergency room physicians who typically had little or no extended contact with patients who go through their daily lives with chronic disabilities,⁹ and who were quick to deem them expendable in a situation where medical resources were becoming scarce. Notably, those physicians who acknowledged ableist medical rationing policies that occurred during the pandemic tended to

be specialists who work regularly with people with disabilities.¹⁰

The pandemic brought renewed attention to the medical, social, and economic vulnerability of those living in CCFs or institutions. The history of people with physical, mental, or developmental disabilities is illustrated by involuntary institutionalization in terrible conditions, even where a facility's origins may have been benign.¹¹ CCFs are usually justified on the basis that people with significant disabilities could not otherwise survive or stay well, yet recent research across states has found that those states where residents have higher measures of implicit disability prejudice also institutionalize more people, even controlling for state size, and these same states tend to spend more on institutional funding, controlling for both state size and wealth.¹² These facts

indicate that disability prejudice has more to do with the assumption that people with disabilities need to be cared for in nursing homes than the objective health needs of people with disabilities. The disability community has long fought to avoid the overuse and misuse of institutions, and this battle was brought to a head in the U.S. Supreme Court decision *Olmstead v. L.C.* in 1999.¹³ The Court held that people with disabilities must receive community-based care in the least restrictive environment possible if they are qualified. Unfortunately, many remain confined in institutions because community-based services and supports are lacking. Medicaid, the largest single payer of home- and community-based services (HCBS) has a historic "institutional bias" because federal law requires states to

cover institutional care in nursing homes but makes Medicaid coverage of community living through HCBS optional for Medicaid enrollees,¹⁴

even though services in the community are less expensive than institutional care. The reliance on CCFs for lower-income people with disabilities is worsened when housing expenses rise. For example, the approximately 4.8 million people with disabilities who rely on SSI cannot afford to live in their own home, even where home-based care might be available.¹⁵ When natural disasters and public emergencies occurred prior to the pandemic, people with disabilities were often relegated to institutions in contravention of federal law that prohibits institutionalization.¹⁶ When people without disabilities lose their jobs, their income, their housing, their health coverage, or their personal support network, they are not confronted with the specter of institutionalization

[P]eople with disabilities entered the pandemic in a far worse position than people without disabilities.

as are people with disabilities, and especially people with disabilities who have long-term services and supports (LTSS) needs. People with significant disabilities must have access to equally effective healthcare and needed services and supports in their communities, or they are at risk of losing functional capacity and being subject to institutionalization.

The well-being of people with disabilities who have LTSS needs has always been closely intertwined with the well-being of the direct care workforce, including personal care attendants, home health aides, and nursing assistants, who can be employed in institutional, agency, and individual-pay community contexts. Due to the low rates of pay and difficulty with obtaining full-time positions, direct care workers can be holding multiple jobs at the same time,¹⁷ though doing so can inhibit close relationships with individual clients that are of mutual benefit.¹⁸ If people with disabilities are to realize their rights under *Olmstead* and avoid institutionalization, they must have access to a reliable HCBS workforce that is stable in all respects—pay, benefits, job satisfaction, working conditions, and availability. The availability of HCBS permitting persons with disabilities to live

When people without disabilities lose their jobs, their income, their housing, their health coverage, or their personal support network, they are not confronted with the specter of institutionalization as are people with disabilities . . .

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in the community is the alternative to living in CCFs, and Medicaid, which issues HCBS waivers to transition people out of institutions to the community, or to keep a person at risk

of institutionalization in their home with proper supports,¹⁹ is subject to all kinds of restrictions and policy disagreements among federal and state lawmakers. Well before the pandemic, the direct care workforce was already subject to

frequent turnover and a shortage of providers who could supply personal care services throughout the country, particularly as an aging U.S. population added to the demand. Direct care workers are often in short supply due to low wages, the difficulty of maintaining full-time work, and the lack of health insurance for many.²⁰ In 2019, one in six direct care workers

lived below the federal poverty level.²¹ The direct care workforce before 2020 was inconsistent because workers had the option of leaving their positions for better paying jobs; thus, people with disabilities have long been struggling to find and maintain direct care workers necessary

for their continued health and, for many, even their independence.

Education and employment opportunities are among the many opportunities that are lost when

a person is living in a CCF or community with insufficient HCBS to maintain health and critical function. When students with disabilities don't receive educational services that are guaranteed

under law, it can affect their social, physical, and emotional well-being and their greatest chances for economic self-sufficiency for the rest of their lives, as well as the lives of the family members who may have to act as unpaid caregivers for

extended periods. NCD reported in 2018 that the longstanding federal underfunding of the Individuals with Disabilities Education Act was already adversely affecting the ability of students with disabilities to receive Free and Appropriate Public Education (FAPE), placing many students with disabilities at a disadvantage.²² There was also a national shortage of special education providers, and qualified staff for in-home education can be wholly unavailable.²³

Coronavirus and the public health emergency have only exacerbated these existing disadvantages.

For years, people with disabilities have been chronically unemployed and underemployed despite the ADA prohibitions on discrimination in employment.²⁴ Though the ADA prompted a national increase in employment for people with disabilities when it was passed in 1990, there are still significant numbers of

people with disabilities "persistently locked out of employment," many of whom rely on federal public assistance programs.²⁵ For working-age people with disabilities prior to COVID-19, almost

"two-thirds of working-age Americans [were] left out of the labor market all together."²⁶ Despite the many opportunities for employment that an increasingly digital world may provide job-hunters with disabilities, the fastest-growing

and most dynamic technology-based industries have the poorest representation of people with disabilities.²⁷ Looking at employment in the context of education and healthcare for people with disabilities is instructive. The failure to fund the IDEA, discussed above, means that young people with disabilities entering the workforce are twice as likely as their peers without disabilities to have no high school diploma, leaving them unqualified for many jobs.²⁸ Young people with

disabilities (ages 20–24) were nearly 30 percent less likely to be employed than their peers without disabilities. Further, a certain portion of people with disabilities who are counted as employed are working for less than the minimum wage in sheltered workshops, as

a consequence of the Fair Labor Standards Act section 14(c).²⁹ For people with disabilities with significant chronic care needs, and especially for those with personal care assistance needs,

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Medicaid provides critical services and supports that cannot be easily replicated or afforded. However, the income limits on both Medicaid and the Social Security programs that are a gateway to Medicaid enrollment can also act as a reverse disincentive to employment and income. People with disabilities who get a job and earn too much or get too many hours can fall off the “Medicaid cliff” and find themselves losing the very healthcare services that enable them to work and thrive in their communities while still not earning enough to pay out of pocket for the HCBS that private insurance rarely covers. While federal Medicaid buy-in and work incentive programs can alleviate some of the problems raised by the Medicaid cliff, the programs are administratively challenging to understand and follow and usually offer limited employment supports.³⁰

People with sensory disabilities were met with barriers in communication during emergencies well before the COVID-19 pandemic. In 2014, in the wake of several devastating hurricanes, NCD reported that the communications needs of people with disabilities were not being met in emergency settings by either federal or local agencies.³¹ The failures of effective communication included, but were not limited to, a lack of American Sign Language (ASL) interpreters in televised announcements, web sites with emergency information not accessible to screen readers, inaccessible emergency

notification systems, and inaccessible shelter locations.³² Even outside of an emergency context, complaints and lawsuits continue to be brought as education,³³ state,³⁴ and private business entities³⁵ ignore basic effective communications for thousands of people with disabilities, failing to provide sign language in complex legal matters and only sending benefit eligibility and coverage information to blind persons in print letters. All too often, covered entities seek an easy way out of providing effective communication and place an ongoing

burden on the person with a disability to “make do” and adjust to the situation, rather than follow the dictates of federal law. For example, the National Association of the Deaf advises that qualified sign language interpreters are still often the best option in medical settings and that the use of Video Remote Interpreting (VRI) should be reserved

Failures of communication continued to be unsurprisingly pervasive during the pandemic, placing people with disabilities at an increased likelihood of danger, from the highest levels of public briefings from the White House when the pandemic began . . . all the way through to vaccination, a process that began almost a year into the public emergency.

for emergencies, reporting with concern that overreliance on VRI has detrimentally impacted Deaf and Hard-of-Hearing healthcare consumers.³⁶ Failures of communication continued to be unsurprisingly pervasive during the pandemic,³⁷ placing people with disabilities at an increased likelihood of danger, from the highest levels of public briefings from the White House when the pandemic began (see chapter 6, section E on Government Activities) all the way through to vaccination, a process that began almost a year into the public emergency.³⁸

People with a range of disabilities were already at higher risk of experiencing depression and suicidality before the pandemic, due in part to social isolation, abuse, and increased likelihood of living in poverty.³⁹ These facts were made worse by the lack of accessible mental healthcare for people with disabilities,⁴⁰ particularly for people with physical disabilities who found most counselors' offices in inaccessible buildings and tele-mental health services unavailable. Though the Affordable Care Act (ACA) made progress toward expanding mental healthcare for Medicaid coverage, millions of Medicaid-eligible Americans continued to lack access to behavioral health services.⁴¹ Medicaid services reimburse behavioral healthcare providers at lower rates, which contributes to a lack of mental healthcare providers serving people with disabilities who rely on Medicaid.⁴² Those with employment or private insurance face cost-control and other embedded gatekeeping barriers to obtaining the mental and behavioral health services they need to maintain well-being and functional capacity in their lives.⁴³ Stigma, ableism in society, and a lack of coordinated expertise in the medical field also exacerbated mental health problems for people with disabilities. People with co-occurring mental or behavioral health and other disabilities encountered a lack of experience and fragmented communication among their providers, leading to undiagnosed or untreated mental health symptoms.⁴⁴

One final thing to note in the 17 months since COVID-19 first appeared is the growing awareness

in the United States and globally of systemic racism and implicit bias against people of color, and how Black, Brown, and Indigenous persons have been subjected to authoritarian violence. In light of increasingly documented links between disability and race/ethnicity,⁴⁵ this report tries to note where and when compounded disparities of treatment and outcome occurred during the pandemic; for example, in the educational opportunities of Indigenous children with disabilities or in the application of crisis standards of care to significantly disabled Black persons.

The phrase "a rising tide lifts all boats" is generally used to explain how changes in

circumstance or policy that directly benefit some segments in society will nonetheless benefit all in society. Similarly, a pandemic is a great equalizer because the coronavirus's inherent capacity to infect, hospitalize, or kill does not change with a

given individual's personal characteristics. Such truisms disregard the extent to which people with disabilities, as with other identifiable groups such as Black and Brown persons or low-income female employees, have endured particular and avoidable harms during the pandemic that are rooted in longstanding physical and programmatic barriers as well as implicit bias and systemic discrimination. When an emergency hits, people with disabilities typically have fewer reserves to draw upon, their options for housing and healthcare are more limited, and it can be harder for them to recover once the immediate emergency has

When an emergency hits, people with disabilities typically have fewer reserves to draw upon, their options for housing and healthcare are more limited, and it can be harder for them to recover once the immediate emergency has passed.

passed. The pandemic has also revealed how much employees with disabilities are among those first to be let go and last to be rehired in an economic crisis. If we focus on the harms that have been universally imposed on all people, we pay insufficient attention to the loss of disability-specific programs and activities that were still needed to ensure effective and equal opportunities for people with disabilities. A rising tide might float all boats, but some of the boats were deep in the sea already, on top of schools of fish, while others were barely clear of sandbars or caught in shoals, far from economic opportunity and freedom from want. In a world where personal characteristics historically determine where one's boat is located in a sea of unequal opportunity, some will be no closer to recovery and well-being post-pandemic.

The pandemic has also revealed how much people with disabilities are among those “first to be let go and last to be rehired” in an economic crisis.

This report will provide data on major life areas where people with disabilities of all ages experienced fallout from the pandemic. We focus specifically on healthcare, congregate care facilities, the direct care workforce, mental health and suicide policy, education, employment, effective communication, and elements of transportation. Beyond data, which is not always available, we try to describe what people with disabilities have been living through as the coronavirus raced through the country. It is the story of disability communities forced to cope with historic systemic failures that continued to have implications for their economic, social, and educational well-being and recommends action to avoid leaving this population behind in a future pandemic or public health emergency.

Chapter 1: Healthcare

Context of COVID-19 and Disability Discrimination in Healthcare

The story of COVID-19⁴⁶ in the world and in the United States is one of loss: lost opportunities to prepare for the pandemic, lost time to institute contact tracing and testing, lost chances to rally behind population protocols that would lessen infection, and, ultimately, a terrible loss of physical, mental, emotional, and financial health and life. The global pandemic has raised a multitude of urgent national systemic issues involving the economy, education, employment, business, politics, culture, and race, but more than 17 months and 34 million cases later, the pandemic remains at its core a healthcare crisis. It is no surprise, then, that for people with disabilities who have long endured healthcare discrimination and barriers to equally effective healthcare, COVID-19 was not only a healthcare crisis but an extended test of the nation's recognition of their human and civil rights.

Early press reports on coronavirus cases and deaths in the United States stressed the virus'

outsized impact on older persons and people with preexisting conditions, giving the false reassurance that healthy younger people had little to fear. Practically, this approach placed pressure on people with disabilities to withdraw from society while simultaneously lulling the wider public into a false sense of security about relying on hand washing, social distancing, mask wearing, and other behaviors that would reduce community infection rates of a virus that is

transmitted through the air. It was an approach that cast people with disabilities and older persons as intrinsically distinct from the rest of society and portrayed them as inevitable victims of a new virus that the rest of us could just "shrug off" like a cold.⁴⁷ When reports of rapid infection and high

death rates exploded across the country and within LTCFs, the primary discussion was about the impact of age and rarely acknowledged that more than 14 percent of the residents in those facilities are people with disabilities younger than 65 years.⁴⁸ The idea that COVID-19 death rates could be diminished by rapidly diverting

When reports of rapid infection and high death rates exploded across the country and within LTCFs, the primary discussion was about the impact of age and rarely acknowledged that more than 14 percent of the residents in those facilities are people with disabilities younger than 65 years.

and deinstitutionalizing people with disabilities from nursing homes was not widely considered, seriously embraced, or explicitly included or funded in federal and state emergency measures. New York, New Jersey, Pennsylvania, and Michigan adopted the reverse policy, ordering nursing homes in the state to admit residents even if they were COVID-19 positive and irrespective of insufficient coronavirus testing, PPE, and infection control procedures in care facilities.⁴⁹

There is no question that the pandemic made it harder for many people with disabilities to be in the world, and equally no doubt that the pandemic exacerbated existing discrimination and inequities experienced by people with disabilities when they sought or received healthcare, as described in this report's introduction. This point was strongly noted in each stakeholder convening that we held. Stereotypes about people with disabilities, inaccessible diagnostic and treatment equipment, and systemic difficulties in obtaining needed accommodations have been documented for years, and led to healthcare disparities for everyone, from women with developmental disabilities seeking gynecological services to Deaf persons needing surgical interventions.⁵⁰ The dissemination and use of CSC by states and hospital facilities during the pandemic, which would allow delay or denial of care based on a person's disability or age, was a high-stakes example of long-standing disability stereotypes and implicit bias among healthcare systems and providers.

It is important to point out the fact that civil rights laws protecting people with disabilities apply broadly to the healthcare industry. Federal and state disability nondiscrimination laws have included healthcare entities for decades. Virtually

every hospital or healthcare facility is subject to disability rights law because they receive federal financial assistance through, for example, treating Medicaid or Medicare patients,⁵¹ they are part of the programs or activities of a state or local government,⁵² or because they are a private healthcare entity that is subject to Title III of the ADA.⁵³ Health insurers that offer insurance products, including managed care plans, on a federal or state health insurance exchange are subject to Section 1557 of the ACA, which incorporates the disability nondiscrimination protections of Section 504.⁵⁴ At this point, healthcare entities have no excuse for failing to recognize that they have nondiscrimination obligations that include requirements for physical accessibility, effective communication, and the obligation to make reasonable modifications in policies, practices, or procedures⁵⁵ for people with disabilities.

Key Healthcare Discrimination Issues During the COVID-19 Pandemic

Five aspects of COVID-19 affected the health and well-being of people with disabilities during the pandemic. In one sense, people with disabilities contended with the same challenges of avoiding infection, finding effective treatment in the event of infection, and obtaining vaccination once available that any nondisabled individual faced. But this view discounts how the U.S. healthcare system was rife with physical, communication, programmatic, and attitudinal barriers to healthcare for people with disabilities. People with disabilities were simply not at the same starting line in healthcare when the pandemic hit. The public health emergency led to a few possibly temporary healthcare delivery changes that may benefit some people with disabilities,

such as broader coverage and availability of telehealth.⁵⁶ For the most part, however, COVID-19 worsened existing barriers.

People with disabilities experienced multiple overlapping layers of healthcare discrimination during the pandemic in the following specific areas: access to personal protective equipment, COVID-19 testing, and the capacity to shelter in place and isolate; medical rationing, CSC, and DNR orders; visitation policies and other healthcare policy modifications and accommodations; and accessible vaccination and vaccination prioritization. Data collection on infection, hospitalization, treatment, and death rates of people with disabilities in the healthcare and public health context

is also addressed, as a decades-long dearth in the collection of detailed disability and functional status information has left people with disabilities facing not

only the burden of being overlooked, but also bearing the burden, as a group and sometimes individually, of trying to prove their capacity to respond to treatment or their higher susceptibility to COVID-19 before full treatment and vaccination prioritization would be extended to them.

At its worst, these and additional barriers during the pandemic led to people with disabilities losing their lives. Approximately one-third of reported COVID-19 deaths in the United States throughout the pandemic occurred in LTCFs, among a group that makes up only 1 percent to 3 percent of the nation's population depending on what is included in the LTCF category beyond nursing homes.⁵⁷ We still do not know if these statistics tell the true number

of deaths in these facilities or for those living outside facilities. While nursing home residents are generally thought of primarily as seniors, they are also people with disabilities and include residents aged 31 to 64 years who make up 14 percent of the nursing home population.⁵⁸

Long-term care statistics are likely undercounted for various reasons, including the fact that federal data requirements do not apply to the skilled nursing facilities where hundreds of thousands of people with disabilities live and the complete lack of standardized or historical gathering of death rates among LTCFs.⁵⁹

Unfortunately, even though data on the impact of the coronavirus in LTCFs is both incomplete and

unreliable, it is among the only data that is available on COVID-19 infection, hospitalization, and death rates of people with disabilities during the pandemic. That is largely because disability

status is not a recognized component of mortality data in this country.

The U.S. Standard Certificate of Death contains fields for a limited degree of personal information that the funeral director is responsible for filling in with information derived from an "informant" (usually a relative).⁶⁰ These fields include age/date of birth, sex, race, length of residence in a county/state, whether someone has served in the armed forces, marital status and occupation at time of death, names of spouse and/or parents, level of educational attainment, and the informant's name. There is no space for recording disability status as a demographic characteristic of a deceased person. The middle "cause of death" section on the

People with disabilities were simply not at the same starting line in health care when the pandemic hit . . . For the most part, . . . COVID-19 worsened existing barriers.

certificate must be filled out by the person who pronounces or certifies death, usually a medical examiner or coroner.⁶¹ This section requires an “underlying cause of death” and has room for “conditions, if any, leading to” the primary cause of death, as well as “other significant conditions contributing to death but not resulting in the underlying cause.” There are also a few questions concerning tobacco use, current or past pregnancy, and the manner of death that have public health value to the NCHS, which eventually receives and compiles death certificate information.

When organizations such as the Kaiser Family Foundation sounded the early alarm on how Black, Hispanic, and American Indian and Alaska Native populations were bearing a disproportionate burden of COVID-19 cases, hospitalization, and deaths,⁶² the analysis was grounded in state data on provisional death counts made available by the NCHS, as well as race/ethnicity population distribution information from surveys such as the American Community Survey.⁶³ Because disability status as a demographic fact is not required or asked on death certificates, it is extremely difficult to establish even the bare fact of how many people with disabilities died from COVID-19, and we know even less about the personal characteristics or health of those who have died. As a result, more time-consuming and original analytical research has to be conducted. The elevated risks of coronavirus infection and death among nonelderly people with disabilities who receive Medicaid HCBS, for example, was established

Because disability status as a demographic fact is not required or asked on death certificates, it is extremely difficult to establish . . . how many people with disabilities died from COVID-19 . . .

using source data from published private insurance data claims, Medicaid data, National Health Interview Survey data, and a gradually growing stream of medical research on specific “high-risk” health conditions and disabilities.⁶⁴ It is still not, however, an actual count of the numbers of COVID-19 infections or deaths of people with disabilities who have died directly as a result of contracting COVID-19, or indirectly as a consequence of being unable to gain access to needed care or losing necessary services

and supports during the pandemic.⁶⁵ CDC has reported, with regard to medical care, that:

Avoidance of both urgent or emergency and routine medical care because of COVID-19 concerns

was highly prevalent among unpaid caregivers for adults, respondents with two or more underlying medical conditions, and persons with disabilities. For caregivers who reported caring for adults at increased risk for severe COVID-19, concern about exposure of care recipients might contribute to care avoidance. Persons with underlying medical conditions that increase their risk for severe COVID-19 are more likely to require care to monitor and treat these conditions, potentially contributing to their more frequent report of avoidance. (Internal citations omitted)⁶⁶

For people with disabilities, the fact that they vanish as a demographic population when COVID-19 deaths are reported except in

so far as they overlap with the population of institutionalized persons raises an overarching discrimination issue that has persisted throughout the public health emergency. The Supreme Court’s 1999 decision in *Olmstead v. L.C.*⁶⁷ established that people with disabilities have the right to receive state or another public entity’s services in the most integrated setting. Yet, as the next two chapters on CCFs and the direct care workforce document, persistent systemic, economic, and legal barriers hinder the capacity of people with disabilities to live independently in the communities of their choice with appropriate supports and services. The “institutional bias” in Medicaid means public funding of institutional long-term care is mandatory, although states have the option of providing HCBS.⁶⁸ At the same time, the direct care workforce’s decades of poor pay and a lack of worker protections for physically and emotionally demanding work have contributed to a worsening shortage of the direct care workforce on which people with disabilities rely.⁶⁹ During the pandemic, the long-standing insufficiency of emergency direct service back-up systems for those living in the community also threatened people with disabilities as their usual personal care assistants became ill or had to take care of ill family members or supervise children when schools and daycares were closed.

The public health emergency starkly revealed how institutionalized people with disabilities are at risk of extreme isolation from family and

community and subject to infection and loss of life. Yet a number of states at the height of COVID-19 adopted policies that *required nursing homes to readmit COVID-19 positive residents from hospitals*, placing all residents and staff at heightened risk, rather than provide residents with safer community placements and HCBS using innovative practices such as those discussed in the following chapter. This disregard for the safety of people with disabilities is yet another example of the degree to which people with disabilities

[A] number of states at the height of COVID-19 adopted policies that required nursing homes to readmit COVID-19 positive residents from hospitals, placing all residents and staff at heightened risk, rather than provide residents with safer community placements and HCBS . . .

were discounted in the pandemic—left off of basic data gathering on death certificates, left out of emergency planning and distribution of supplies, and subject to ongoing stereotypes and assumptions about their health and quality of life by healthcare providers, which led to further

deadly consequences for people with disabilities who needed urgent intensive care at the height of the pandemic. Although the federal government funded programs in May 2020 to address some emergency preparedness issues related to the needs of people with disabilities, the results of that work could not be realized quickly enough to change the unnecessary deaths and general treatment of people with disabilities during this pandemic.⁷⁰

The life of a person with disabilities is neither more nor less valuable than the life of a person without disabilities. But when people with disabilities lost their lives because they were unnecessarily housed in CCFs where infectious diseases cannot be controlled, or COVID-19

treatment was denied because of discriminatory medical rationing, or because states failed to recognize that people with significant disability need priority for vaccination because they are subject to higher risks of infection and death, these were not only “pandemic losses.”

These lives were lost due to the devaluation of the lives of people with disabilities, a devaluation that is rooted in the medical establishment and that continues to pervade our educational, economic, cultural, and social systems.

Access to Personal Protective Equipment, COVID-19 Testing, Capacity to Shelter in Place and Isolate

Once the highly infectious nature of the coronavirus became widely known, federal agencies and infectious disease experts recommended key strategies for staying safe that included the consistent use of personal protective equipment, regular testing for COVID-19, and isolating in place as much as possible, including self-quarantine in the event of a positive COVID-19 test. People with a range of disabilities encountered numerous barriers to achieving these strategies.

The public demand for PPE such as fitted masks, gloves, and gowns, as well as hand sanitizer and wipes, quickly overwhelmed the U.S. supply, which was simultaneously subject to a worldwide shortage.⁷¹ Some individual market abuses and instances of PPE price gouging became almost legendary.⁷² Letting purchasing

and distribution responsibilities for PPE float freely in an overheated free market environment pitted states against the federal government and individual consumers against workplaces and healthcare facilities. Those individuals with the

time and resources to readily monitor for, drive to, and quickly snap up supplies were instantly at an advantage.

Individuals with disabilities who could not drive or carry packages on their own, or shop or assess their PPE needs independently, and who did not have internet access or funds

Individuals with disabilities who could not drive or carry packages on their own, or shop or assess their PPE needs independently, and who did not have internet access or funds to spare on unbudgeted expenses, found it extremely difficult to find and maintain a PPE supply.

to spare on unbudgeted expenses, found it extremely difficult to find and maintain a PPE supply. People with long-term care needs were especially vulnerable to coronavirus infection because the direct care workers who came to their homes to provide care were often the last in line to have access to PPE, as is documented in chapter 3.

Another shortage that left people with disabilities at a disadvantage was the inaccessibility of many COVID-19 testing sites, including the procedures for making testing appointments. The Federal Emergency Management Agency (FEMA) noted that people with disabilities nationwide encountered “[l]imited access to effective communication, facilities, transportation, and programs that allow for improved access to COVID-19 treatment, testing sites, and Alternate Care Sites. . . .” Drive-through testing sites became common in many parts of the country because they allowed for



greater social distancing between those seeking and those administering tests, but FEMA further warned that “[p]eople with disabilities may not be able to access COVID-19 testing sites which include, but are not limited to, community-based drive-through testing sites. Drive-through testing is especially inaccessible in urban areas, where fewer people have access to cars.”⁷³

Additional testing barriers included physical inaccessibility and procedural barriers such as long lines, inaccessible online portals for making test appointments, and a lack of sign language or other interpreters on-site given that anyone who has not taken a test could be shocked by the physical invasiveness of the procedure if an explanation for how the procedure works is not effectively communicated.⁷⁴

Though test manufacturer shortages, unclear information about the accuracy and interpretation of different types of tests, and delays in getting results affected every person who sought testing, the problems had a disproportionate impact on persons with disabilities who relied on personal care assistants. Given the low minimum wages common to direct care workforce jobs, as well as the fact that individuals with disabilities may typically need less than 40 hours per week of personal care attendance, many direct care workers work for more than one client or in both institutional and community settings. When PPE and timely testing are not consistently available in any one of those situations, it left the direct care worker with an elevated coronavirus infection risk and constant uncertainty about

their COVID-19 status. In turn, those negatively affected individuals with significant disabilities who received direct care assistance because they faced additional risks of death upon infection

from the way their disabilities could interact with the virus *and* the risk that they could be prioritized lower to receive treatment for COVID-19.

Barriers to Goods and Services

Multiple factors combined to turn “shelter in place” orders for persons with disabilities into an extended period of isolation with little access to needed COVID-19 resources or other needed goods and services. People with specific disabilities experienced the following barriers:

- The common use of opaque face masks diminished communication for Hard-of-Hearing and Deaf persons trying to meet their daily needs and get healthcare.
- Transit systems that stopped completely or cut routes and hours made it difficult for people with mobility, vision, and other disabilities to get beyond their immediate neighborhoods, not only because routes themselves were cut but because it was difficult to get timely, accurate, and fully accessible information about changed routes and times.⁷⁵
- Reduced accessibility to transportation in conjunction with lower income levels⁷⁶ and having high-risk conditions such as a compromised immune system or other chronic health conditions left some individuals with disabilities unable to get essentials such as groceries and medicines.⁷⁷ Food insecurity among U.S. households grew overall during the pandemic but “[a]dults who have a disability—in particular adults who have a disability and are not in the work force—also experience more than two times the rate of food insecurity as adults who do not have a disability.”⁷⁸ Some food banks began distributing food using a drive-through model, but not all food banks adapted to provide home delivery to people with disabilities who did not independently drive or lift groceries. In rural areas, grocery and food delivery options were already limited and were further limited by store policies that did not allow people with Supplemental Nutritional Assistance Program (SNAP) or food stamps to use those benefits for home delivery of groceries.⁷⁹
- Individuals at high risk of death from contracting COVID-19 had to risk exposure to receive necessary healthcare such as infusions or therapy, or forego the services and therapies that allowed them to maintain function and good health; some healthcare providers stopped certain treatments altogether.
- Individuals who needed assistance with activities of daily living and became infected with the virus faced being unable to keep or find new personal care assistants for their most basic needs, given the heightened risk of infection.

In short, people with disabilities who lived in the community were confronted daily with choosing between life necessities such as food and healthcare and high risks of infection with COVID-19, which led to the risk of forgoing personal assistance from a direct care worker who might not be able to access PPE or of losing assistants who became ill or stopped working because they were afraid of bringing the virus home to their families.

News media quickly covered the “perfect storm” of medically and/or cognitively vulnerable and often older residents living in facilities with well-documented infection control problems and tragic state policies that encouraged keeping or even returning infectious residents at some facilities, but similar attention has not been given to the situation of people with disabilities living in the community, for whom there is a dearth of detailed demographic data. Without this data and analyses, it is extremely hard to get a full picture of how much emergency Medicaid and other measures developed as a response to the pandemic benefitted people with disabilities in the community at large, and even more difficult to try and see, for example, if subpopulations within the disability community, such as Black or Brown persons, face discernible compound discrimination.

[T]esting barriers included physical inaccessibility and procedural barriers such as long lines, inaccessible online portals for making test appointments, and a lack of sign language or other interpreters on-site given that anyone who has not taken a test could be shocked by the physical invasiveness of the procedure if an explanation for how the procedure works is not effectively communicated.

One study that tried to determine if COVID-19 had a disparate impact among people with disabilities who are subject to sociogeographic disadvantage analyzed county-level data on confirmed COVID-19 cases from Johns Hopkins with a number of disability variables from the 2018 American Community Survey. What may be the first study published in the United States to look at disability from an explicit intersectional lens during the pandemic found that:

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

clustering. . . . Socio-demographically disadvantaged PwDs are significantly overrepresented in counties with higher COVID-19 incidence compared to other PwDs.⁸⁰

This study helps demonstrate the need for much better data collection on people with disabilities and their experiences during COVID-19 in ways that will allow for a nuanced look at how



Findings from Study of Disability from an Intersectional Lenses

Greater COVID-19 incidence rate is significantly associated with: (1) higher percentages of PwDs [people with disabilities] who are Black, Asian, Hispanic, Native American, below poverty, under 18 years of age, and female; and (2) lower percentages of PwDs who are non-Hispanic White, above poverty, aged 65 or more years, and male, after controlling for spatial clustering. . . .Socio-demographically disadvantaged PwDs are significantly overrepresented in counties with higher COVID-19 incidence compared to other PwDs.

disability, for example, makes a further difference to the health disparities that Black persons and people of color already face because of race.

Medical Rationing, Crisis Standards of Care, and Do Not Resuscitate Orders

The issue of medical rationing and how intensive care beds, treatment, equipment, and personnel would be made available during a period of widespread simultaneous virus infection emerged early during the pandemic. Stories of overwhelmed health systems and providers in Italy were soon followed by surge circumstances closer to home in places such as New York City. A medical surge occurs when the number of patients needing care is greater than a hospital or health system's capacity to

serve those patients. When a surge threatens, some facilities have policies to guide doctors and staff on the standards of care that should be applied when there are not enough beds, medical supplies or equipment, or trained staff to provide a normal level of care (i.e., doing everything possible to save every life) to every current or imminently expected patient. In response, some states revived or put out CSC guidelines in spring 2020.

The application of CSC guidelines during the pandemic profoundly affected people with disabilities, family members, disability advocates, and even many members of the public who were surprised that they could be denied medical care at the moment in which it was most needed. Why did a different set of rules evolve, and how could those rules apply when so few had provided input or even knew what the rules were?

What might be termed the “modern era” of CSC guidelines in the United States can be traced to the terrorist attacks of September 11, 2001, and subsequent fears of anthrax attacks. As the federal Agency for Healthcare Research and Quality (AHRQ) started to work on national plans to respond to bioterrorism and public health emergencies, it came to recognize that an event with mass casualties could at least temporarily overwhelm local or regional health systems and prevent the application of normal standards of medical care. AHRQ convened

experts in “the fields of bioethics, emergency medicine, emergency management, health administration, health law and policy, and public health” in August 2004, and eventually published “Altered Standards of Care in Mass Casualty Events.”⁸¹ The document states explicitly that the overall goal of altering standards of care in a mass casualty event is “to save as many lives as possible.”⁸² The Institute of Medicine subsequently held a series of workshops and published a 2009 letter report on developing CSC guidelines for disaster

situations.⁸³ The letter report concluded that:

“[i]n an important ethical sense, entering a crisis standards of care mode is not optional—it is a forced choice, based on the emerging situation. Under such circumstances, failing to make substantive

adjustments to care operations—i.e., not to adopt crisis standards of care—is very likely to result in greater death, injury, or illness.”

The committee also concluded that there is an urgent and clear need for a single national guidance for states with crisis standards of care that can be generalized to all crisis events and is not specific to a certain event.⁸⁴

This short background on CSC reveals that when CSC guidelines are triggered and how they apply are thought of as matters

The application of CSC guidelines during the pandemic profoundly affected people with disabilities, family members, disability advocates, and even many members of the public who were surprised that they could be denied medical care at the moment in which it was most needed.

for medical and policy experts. The Institute of Medicine letter report was written in response to a request by the HHS Office of the Assistant Secretary for Preparedness and Response. Subsequent publications by both AHRQ and the Institute of Medicine addressing CSC criteria similarly involved convenings of experts. It is unclear whether any of the federal or academic entities that worked on these CSC reports prioritized participation or engagement with members of the public who would be directly affected by CSC guidelines, though AHRQ describes “issues related to populations with special needs” as an “important nonmedical” issue. The tendency toward “expert delegation” is highlighted in a recent paper that analyzes how state and hospital CSC guidance changed over the course of the pandemic in response

to the assertion of disability rights and nondiscrimination.⁸⁵

CSC guidelines varied considerably among states, with some several years old and designed for an indeterminate public health emergency or a generic “flu” epidemic/pandemic, and others updated or developed specifically for the highly infectious novel coronavirus. As COVID-19 cases and hospitalizations spiked in several states in the spring of 2020, the disability community became increasingly aware of the impact that CSC guidelines could have on individuals with disabilities who sought medical treatment upon infection with the coronavirus. People with disabilities and disability advocates recognized how CSC language approved by medical and policy experts discriminated, both explicitly and implicitly, on the basis of disability in the following ways:

Methods of Discrimination in CSC Guidelines

1. *Categorical exclusion on the basis of specific diagnosis or categories of disability.* One example of a categorical exclusion is found in Florida’s 2011 CSC guideline that barred from hospital admission individuals with “complex disorders with significant neurological component and prognosis for imminent expected lifelong assistance with most basic activities of living (i.e., toileting, dressing, feeding, respiration).”⁸⁶ Another example is found in Colorado’s CSC guideline that lists “cystic fibrosis with post-bronchodilator FEV1 <30% or baseline PaO2 <55 mm Hg” as criteria for excluding an individual from admission or transfer to critical care.⁸⁷ The origins of the cystic fibrosis exclusion can be traced to a 2004 CSC guideline developed in Ontario, Canada, that based this diagnostic exclusion on a study published in 1992 that used cohort data derived between 1977 and 1989. In short, the categorical exclusion of people with cystic fibrosis who meet certain clinical criteria was based on 40-year-old mortality data.⁸⁸ There is no reason to think that other states

Methods of Discrimination in CSC Guidelines: *continued*

and hospital systems were or are using the most current or even more current medical research when developing criteria for deprioritizing individuals with certain disabilities or health conditions, especially where CSC guidelines were developed in the midst of an ongoing emergency situation. Individuals with intellectual or developmental disabilities and their families in Washington and Alabama raised strong allegations that those states' CSC guidelines discriminate against people with cognitive disabilities by deprioritizing their access to ventilators. Alabama's CSC guideline from early 2020 stated that "persons with severe mental retardation, advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support" and "persons with severe or profound mental retardation, moderate to severe dementia, or catastrophic neurological complications such as persistent vegetative state are unlikely candidates for ventilator support."⁸⁹ The state's CSC guideline was revised in April 2020 after disability rights groups filed a formal discrimination complaint with HHS OCR.⁹⁰

2. *Application of medical rationing or triage criteria that allow or encourage physicians to import their subjective assumptions about a patient's length or quality of life:* An example of this can be found in Washington State's CSC guideline that states that individuals can be considered for removal to out-patient or palliative care on the basis of "[b]aseline functional status (consider loss of reserves in energy, physical ability, cognition and general health)."⁹¹ Given that hospital physicians will be unfamiliar with the energy levels, physical ability, cognition levels, or general health of virtually every patient brought to the hospital with COVID-19, this appears to be an open invitation for physicians to make admission and treatment decisions that rest on how a physician interprets the current "functional status" of a person with disabilities.
3. *Relying on physician assessments of years of remaining life in the long or medium term, despite the notorious and established inaccuracy of such assessments:* Some CSC guidelines prioritize the goal of saving "life years" rather than saving lives. Pennsylvania, for example, considers a patient's "prognosis for long-term survival," assessing a patient's comorbid conditions with the goal to "save the most life-years."⁹² (See Pennsylvania Department of Health.) A goal of maximizing life years not only shortchanges the value of both people with disabilities and older persons, it invites physicians to make predictions about life expectancy even though they are notoriously bad at doing so.⁹³ It also penalizes people with disabilities with conditions that appear to have shorter life spans, regardless of whether that information reflects unequal medical treatment, physician stereotypes

(continued)

Methods of Discrimination in CSC Guidelines: *continued*

about a disability, or a dearth of medical research into a particular condition, or is simply outdated.⁹⁴

4. *Failing to recognize or make any kind of adjustment for the impact of disability on the clinical measures that were applied to determine patient priority for COVID-19 treatment:* Many CSC guidelines elevated the use of medical assessment tools such as the Sequential Organ Failure Assessment (SOFA), developed as a way to measure how likely patients' with sepsis were to survive in the near term, as a way to objectively assign a clinical priority score to individual patients for COVID-19 treatment. However, these tools commonly use variables that fail to take disability into account when they should. For example, the SOFA includes the Glasgow Coma Score as a component that measures a patient's consciousness level partly through their ability to articulate intelligible words. People with developmental, speech, hearing, or other disabilities may not be able to articulate intelligible words but that would not signal anything about their conscious functioning. As another example, clinicians should use clinical judgment to adjust SOFA scores downward (the higher the score the lower the chances of survival) as appropriate to account for chronic baseline levels of physiological functional impairment that are not caused by COVID-19, such as low oxygenation ratios for individuals with post-polio or complex neuromuscular conditions who use ventilation to support the muscles around the lungs rather than because of any functional incapacity in the lungs themselves. It is discriminatory to not adjust the application of SOFA or other tools so that they do not automatically and unjustly equate long-term functional impairments with lower survivability.⁹⁵
5. *Refusing to allow individuals to use their personal ventilators during hospitalization and maintaining the possibility of redistributing private ventilators:* People with a range of disabilities use personal ventilators to assist their breathing for some or all of their day. This equipment is personally calibrated to the individual user and medically necessary for maintaining that individual's life and function. Other persons with disabilities may use personal ventilators on a more intermittent "as needed" basis. Personal ventilator users became concerned that some CSC guidelines would allow hospitals to reallocate personal ventilators for the use of patients deemed to have a better chance of benefitting from COVID-19 treatment; some community members became fearful that not only would they be denied treatment if they arrived at a hospital with COVID-19, they risked active harm and death if their ventilator were taken from them.⁹⁶ Disability rights advocates in Kansas and in New York raised concerns about personal ventilator reallocation with the

Methods of Discrimination in CSC Guidelines: *continued*

HHS Office for Civil Rights last spring,⁹⁷ though the concern has been raised in New York since 2009.⁹⁸ New York’s Governor Cuomo issued an executive order in April 2020, calling upon nonhospital facilities to give up their ventilators as much as possible so they could be used in intensive care units (ICUs) for COVID-19 treatment.⁹⁹ Nursing homes were not captured in the executive order, but a nursing home in Long Island voluntarily lent 11 of its 16 ventilators out to a hospital when asked to do so.¹⁰⁰ This specific concern of personal ventilator allocation resonates strongly within the disability community and raised the specter of medical experts making decisions that would lead directly to the death of people with disabilities. Some of these experts have pointed out that “taking away someone’s PV [personal ventilator] is a direct assault on their bodily and social integrity, that PVs should not be part of reallocation pools, and that triage protocols should be immediately clarified and explicitly state that PVs will be protected in all cases.”¹⁰¹

We cannot know whether the above practices found in CSC guidelines were developed with discriminatory intent, but the practices, if acted upon, would deny life-saving care based on a preexisting disability. The presence or absence of individual or even systemic malice is neither relevant nor a defense. As disability rights advocates pointed out:

Congress intended disability nondiscrimination protections to reach not only discrimination that is the result of “invidious animus,” but also of “thoughtlessness,” “indifference,” and “benign neglect.” The implementing regulations make clear that illegal discrimination includes providing “an aid, benefit, or service that is not as effective

The CSC guidelines . . . and others like them are discriminatory when their application tends to automatically place people with disabilities in a lower priority category for receiving COVID-19 treatment.

in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement” as that provided to people without disabilities; and also “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities

from fully and equally enjoying any service, program, or activity.” No provision in the ADA, Section 504, or Section 1557 of the ACA nor in any other federal law authorizes the waiver

of these requirements during a public health emergency. [Internal citations omitted]¹⁰²

The CSC guidelines highlighted above and others like them are discriminatory when their

application tends to automatically place people with disabilities in a lower priority category for receiving COVID-19 treatment. The guidelines establish this priority if they do not require an individualized assessment of whether an individual with disabilities could benefit from the treatment, without consideration for whether a particular disability requires modification of the guideline's application to have an equal opportunity for treatment, and absent any examination of whether and how implicit disability bias influences physicians' clinical perceptions and policymakers' understanding of efficient and fair decision-making. This last point has implications beyond the immediate topic of CSC guidance.

Implicit disability bias was the common factor in pre-pandemic healthcare discrimination to early pandemic CSC guidelines that devalued the lives of people with disabilities to later vaccine prioritizations that ignored how people with disabilities receiving HCBS and their caregivers were at high risk from the coronavirus. CSC guidelines were developed by experts from many fields who are subject to many kinds of disability bias. Many CSC guidelines recommend a triage panel to make treatment prioritization decisions with a required bioethicist on the panel to provide ethical counterweight to

utilitarian concerns, but many bioethicists have utilitarian beliefs as well—that disabled lives are less valuable and, as such, it is ethical to devalue or even deny care when resources become scarce. Bioethicists are not immune from holding implicit

biases of their own. An examination of CSC guidelines developed or repurposed for the coronavirus pandemic makes clear that CSC drafters failed to understand the lived experience and goals of people with disabilities, especially those living in the community using HCBS; failed to understand the value

and quality of life of people with disabilities; failed to acknowledge the myriad barriers and failures to accommodate that people with disabilities commonly encounter in the healthcare setting; and assumed that medical providers will do what is best for people with disabilities even when there is a growing body of research confirming that

healthcare professions are rife with false assumptions about living with disability and uncomfortable with treating people with chronic conditions who cannot be “cured” or “fixed.”¹⁰³

A recent study of physician attitudes toward people with disabilities, released in early 2021, captured the pre-pandemic views of more than 700 U.S. physicians in active practice across the country.¹⁰⁴ More than 80 percent self-reported

Implicit disability bias was the common factor in pre-pandemic health care discrimination to early pandemic CSC guidelines that devalued the lives of people with disabilities to later vaccine prioritizations that ignored how people with disabilities receiving HCBS and their caregivers were at high risk from the coronavirus.

More than 80 percent [of over 700 U.S. physicians] self-reported the belief that people with significant disabilities have a worse quality of life than nondisabled people.

the belief that people with significant disabilities have a worse quality of life than nondisabled people. As the study's authors point out, it would be difficult to imagine four out of five physicians freely stating that Black people have a worse quality of life than white people, though some might indicate that Black people face significant challenges in their life from things such as police violence or systemic racism in housing, employment, and other major areas. However, only about 18 percent of this same group "strongly agreed that the healthcare system often treats [disabled] patients unfairly."¹⁰⁵

Taken together, these two findings indicate that physicians base the perceived lack of quality of life for people with disabilities on the fact of the disability, not in how people with disabilities are treated when they seek healthcare. At the same time, "only 40.7% of physicians were very confident about their ability to provide the same quality of care to patients with disability" and "just 56.5% strongly agreed that they welcomed patients with disability into their practices."¹⁰⁶ Interpreting these two figures together, it is clear that a minority of physicians do not feel fully confident in their ability to provide quality care to people with disabilities, and a small majority agree that they welcome patients with disabilities. This leaves about 16 percent of surveyed doctors who welcome patients with disabilities even though they are not very confident that they can provide those patients with the same quality of care that they give to nondisabled patients. This

discrepancy leads again to the inference that at least some physicians attribute the challenge of providing quality care to people with disabilities to the fact of disability, not seeing it as a problem that is sourced in doctors or that physicians should address by improving their abilities to provide quality healthcare individually or as a group.

CSC guidelines, whether issued by states, health systems, or hospitals, all make the physician a key decision maker and, sometimes, the sole decisionmaker. Findings such as those described in the physicians' attitudes study mean that people with disabilities are particularly

disadvantaged by CSC guidelines that give physicians discretion for using and determining "severity" of condition, "quality of life," and "healthy remaining years of life" to assess a patient's treatment prioritization. These same problematic attitudes

can be seen in how doctors talk about Do Not Resuscitate (DNR) orders with patients with disabilities and their families.

When approaching, or in, surge situations, some state CSC guidelines encourage doctors to ask their patients about DNR orders with the laudable goal of obtaining and honoring a patient's informed choice to forgo ventilation or other means of invasive care under certain circumstances. In England, stories emerged of hospitals unilaterally placing DNR orders in the files of patients with intellectual disabilities.¹⁰⁷ In the United States, there have also been media reports about physicians pressuring patients

"[O]nly 40.7% of physicians were very confident about their ability to provide the same quality of care to patients with disability" and "just 56.5% strongly agreed that they welcomed patients with disability into their practices."

and families to adopt DNR orders or rescind an existing POLST form that can express a patient's wish for full resuscitation attempts.

For example, when Sarah McSweeney, a 45-year-old woman with disabilities who lived in a group home in Oregon developed a high fever in April 2020, her support team and guardian brought her to the hospital and submitted her POLST form on her behalf.¹⁰⁸ Tests showed that McSweeney did not have COVID-19, but she developed life-threatening aspiration pneumonia during her stay. At one

point, two members of her support team were discussing the use of a ventilator with the lead doctor as the logical next treatment step when he surprised them and "pushed to rewrite McSweeney's care document. He wanted a new order that would say the disabled woman should not be resuscitated or intubated. That would be an order to deny McSweeney the ventilator the doctor

had just said she needed." The nurse manager at her group home, Kimberly Conger, recalled that the lead doctor "said intubating her was a matter of risk versus quality of life . . . I was like, 'But she has quality of life.' And he looked at me and goes, 'Oh, she can walk? And talk?'"¹⁰⁹ The doctor accompanied his words by scissoring his index and middle fingers in a simulation of walking. When the medical team looked at McSweeney, they saw a significantly disabled

nonverbal woman who used a feeding tube and needed assistance with multiple activities of daily living. Her guardians and friends saw a lively young woman who loved country music, "girly" activities, making her friends laugh, and was actively taking steps to get a part-time job. This difference in views especially clashed around the issue of DNR; the hospital viewed intubation as an extraordinary measure that could do more harm than good, but McSweeney had been intubated before and spent time with

good friends who used ventilators 24 hours a day and had tracheostomies. In the end, McSweeney died of aspiration pneumonia after her third week in the hospital. During her nearly three weeks in the hospital, "doctors and social workers had questioned why this disabled woman had medical instructions for full care, instead of a Do Not Resuscitate order. McSweeney's advocates had pushed back. Says Conger of

When the medical team looked at McSweeney, they saw a significantly disabled nonverbal woman who used a feeding tube and needed assistance with multiple activities of daily living. Her guardians and friends saw a lively young woman who loved country music, "girly" activities, making her friends laugh, and was actively taking steps to get a part-time job. This difference in views especially clashed around the issue of DNR . . .

McSweeney's care at the hospital: 'I don't feel like they—and this is my personal opinion—I feel like they didn't feel like she was worth that.'"¹¹⁰

McSweeney and her guardians experienced explicit pressure to formally adopt a DNR. In the case of Michael Hickson, a 46-year-old Black man with quadriplegia and other disabilities who was hospitalized in Austin, Texas, in the summer of 2020 with COVID-19, the hospital did not have to press for a DNR because the court-appointed

guardian agreed to the treating doctor's request to transfer Hickson from the ICU to palliative care. The treating doctor spoke to Mr. Hickson's wife in a disturbing conversation that she recorded. He evoked Hickson's quality of life, the fact that he did not walk or talk like others who had recovered after being placed on ventilators in the ICU, and the desire to make a "humane" decision for Mr. Hickson, but because Melissa Hickson was not her husband's legal guardian, her objections did not prevent the hospital's planned transfer of Mr. Hickson, who died after care and treatment were withdrawn.¹¹¹

McSweeney and Hickson had family or support persons present. The pandemic context moves even further away from that situation as a norm as pointed out by Arthur Caplan, New York University's chief ethicist.¹¹² Typically, people go to hospitals for help and see doctors as an advocate for their care. People with disabilities, however, have met with implicit bias in the provision of urgent care that links the potential withdrawal/withholding of medical treatment as "futile" to questions on the quality of the life led by a person who is disabled.¹¹³ Even accepting the premise that under surge conditions normal standards of care must be adjusted, this does not automatically lead to the further step of burdening individuals with disabilities with not only fighting for their lives should COVID-19 or another health emergency arise during the pandemic, but with simultaneously having to fight for medical treatment and to prove to one's own physicians that one's existence is "worth living."

According to Arthur Caplan, NYU's chief medical ethicist:

We're trying to go into not just who's coming in the door and triaging, but what

will we do if we can't resuscitate. Do I care what your living will says in a pandemic? I probably don't. I probably won't even read it. I probably don't even know where it is. Remember, many people are isolated in these units. Their loved ones may or may not be around to communicate something. It's not business as usual. Rarely do we find living wills that get read to guide treatment in normal times. It's usually your friends or family, your partner who speaks up and says, you know, they wanted everything or they didn't. But if they're in the hall far away and we don't want them in the intensive care unit, or surrounded by coronavirus patients, that isn't even going to happen.¹¹⁴

While most media coverage over the last year was on the development and actual use of state CSC guidelines, the situation where hospital administrators and staff know that they are rapidly approaching capacity but *before* a CSC policy is formally triggered and individual physicians are still in primary charge of their patients' care options is equally fraught. In this situation of "contingency capacity" where the hospital's resources are stretched but there is still some possibility of maintaining normal standards of care, disability implicit bias and stereotypes about disability are highly likely to influence care decisions as well as the advice providers give to patients and their families. The hospital that treated Michael Hickson did not have a triggered CSC even though he was admitted for COVID-19, leaving his doctor(s) free to decide whether to steer him toward a DNR order or hospice care instead of aggressive ICU treatment.¹¹⁵ In a convening held in furtherance of researching this report that included a range of adult and pediatric primary care and specialty

providers, both physicians and nurses, participants agreed that there is systemic ableism within the healthcare system. Bias is baked into the curriculum in medical school where quality of life is a major focus and disabilities are viewed purely as “medical conditions” that decrease quality of life. The entire group, which included family members of people with disabilities as well as bioethicists, strongly endorsed the need for implicit bias training in the healthcare context that especially focuses on disability.¹¹⁶

Understanding and addressing disability discrimination in healthcare as a systemic issue

will require investing in sustained action throughout the entire healthcare education, delivery, and funding system. A 2021 equity report and strategic plan by the American Medical Association appears to acknowledge this. The report focuses primarily on race and ethnicity, but also explicitly includes

women, LGBTQ+ persons, and people with disabilities as groups that have “experienced a history of harm and discrimination in medical settings.”¹¹⁷ Within the report, there is a page that focuses on structural violence and people with disabilities that mentions state sterilization laws, federal civil rights laws, and key court cases for the disability community such as *Holland v. Sacramento*¹¹⁸ and *Olmstead v. L.C.*¹¹⁹ There is also the statement that an equity model that simply treats everyone the same “fails individual patients and communities. For example, high-quality and safe care for a person with a disability

does not translate to ‘equal’ care. A person with low vision receiving the ‘same’ care might receive documents that are illegible, depriving them of the ability to safely consent to and participate in their own treatment.”¹²⁰ The American Medical Association’s report does not have cutting edge examples of ableism and, as a strategic plan, has been criticized for lacking bold commitments to inclusive changes in such specific areas as its prestigious research journals and boards, for example,¹²¹ but the clear inclusion of people with disabilities as a group that experiences redressable health and healthcare disparities signals an

opening for change.

Physicians and other healthcare providers enter their fields presumably because they want to provide care, not triage it. But healthcare providers cannot develop nondiscriminatory CSC guidelines and administer them fairly unless they are

Without interventions, such as training in disability cultural competency, health care providers will fall back on their own assumptions about the likely length and quality of life of people with disabilities, especially in conjunction with other factors such as age or race and income level.

supported in their ability to make nonbiased and nonableist treatment prioritizations when surge or contingency capacity is reached. Such support can run the gamut from encouraging ongoing professional education on what federal disability rights laws require in the healthcare context, a topic on which considerable ignorance appears to remain,¹²² to the active identification and dissemination of research that will inform clinical diagnosis and treatment of persons with disabilities during an emergency like the COVID-19 pandemic.¹²³ Without interventions, such as training in disability cultural competency,

healthcare providers will fall back on their own assumptions about the likely length and quality of life of people with disabilities, especially in conjunction with other factors such as age or race and income level. As one qualitative study of close to 100 physicians found, “[w]hile most clinicians did not feel that they had been in the position of having to ration scarce resources, some nevertheless described practices, such as selection by age or comorbidity, that may be subject to implicit biases and may not be supported by societal priorities for fairness in resource allocation.” [Internal citations omitted.]¹²⁴ This gap between physicians feeling like they are not engaged in medical rationing even as they engage in triage may be particularly relevant with emergency room specialists, who are expected to make rapid diagnostic and urgent care decisions, and who rarely have longer-term experience working with people who have disabilities and chronic conditions.

At the end of May 2021, the coronavirus appeared to be in retreat in the United States, and most signs indicated that both cases and death rates would continue to go down.¹²⁵ The subjects of medical rationing and CSC guidelines seemed less urgent than they had been a few short months before, but the disability community and the nation must retain an ongoing concern on this topic. The underlying biases that made medical rationing and triage so dangerous for people with disabilities during the

pandemic, and the potential for CSC polices to be applied in the future, will exist in any emergency whether caused by natural disasters, terrorist attack, or failings of critical infrastructure. Within the relatively short time period of the pandemic, there was an evolution of the language used in state CSC guidelines. Comparative research conducted on CSC guidelines across 35 states found that “CSC plans revised later in the pandemic were more likely to align with disability rights priorities than those revised early in the pandemic or never revised. This pattern is consistent with growth over time in

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both the familiarity of state policymakers with disability rights concerns and the capacity of disability activists to influence public policy on a topic that quickly moved from obscurity to prominence.”¹²⁶ Medical and legal authors are writing journal pieces that openly acknowledge the need for CSC

guidelines to be assessed for compliance with antidiscrimination laws as well as broader goals of social justice.¹²⁷ Advocates must be prepared to maintain momentum and repeat effective strategies for fighting discriminatory CSC guidelines now while also strategizing on what still needs to be done on a longer-term basis.

One helpful strategy pursued by state and national advocates was the coordinated effort to challenge discriminatory CSC guidelines by bringing administrative complaints with HHS OCR. HHS OCR was receptive to these complaints and early in 2020 bolstered disability advocacy efforts

by issuing nondiscrimination CSC guidance for healthcare entities in a civil rights bulletin,¹²⁸ and working with individual states that had some of the most egregious CSC policies.¹²⁹ HHS' early resolutions with Alabama, Pennsylvania, Tennessee, and Utah,¹³⁰ plus the ongoing work of disability advocates and community members to develop CSC principles, have prompted a number of states to incorporate explicit baseline protections for patients with disabilities who use personalized ventilators and/or require accommodations, and establish a framework of due process for medical rationing decisions. HHS OCR also worked with the state of North Carolina, the North Texas Mass Critical Care Guidelines Task Force, the Southwest Texas Regional Advisory Council, and the Indian

Health Service

to ensure that each entity's CSC guidelines contain best practices for serving individuals with disabilities and

older persons.¹³¹ In addition, some physicians, researchers, and bioethicists began to speak out and bolster the need for alternative best practices by questioning the accuracy and ethical assumptions behind common mortality prediction scores in existing CSC guidelines.¹³² Mainstream media support also pointed out the ethical and equitable shortcomings in medical triage approaches that, in practice, pushed people with disabilities and people from vulnerable populations to the back of the COVID-19 treatment line.¹³³

While some of the worst and older state CSC guidelines are using much improved language that eliminates discriminatory references to categorical disability exclusions from ICU care and a requirement for a prognosis of long-term

survival, disability advocates continue to meet continued resistance on CSC guidelines. Some states and many private healthcare entities fail to make their CSC guidance readily available to the public, and if the CSC guideline or policy is not known, it cannot be protested or potentially changed through advocacy. Not every CSC guideline includes a strong explicit commitment to nondiscrimination; nor does every guideline come with a clear set of due process instructions that would allow individuals and/or their families to question their prioritization for care or appeal the denial of care. The states and healthcare entities that work on CSCs need to proceed with less deference to "expertise" and more inclusion of people with disabilities in developing

updated CSC guidelines for any situation where surge conditions might arise. And critically, all stakeholders need to find ways to effectively implement and enforce

nondiscriminatory CSC guidelines in the urgent situations where people with disabilities face irreparable harm. For patients with disabilities who face the imminent potential for being taken off a ventilator or having their ICU admission delayed indefinitely, there are few or no viable options for immediate assistance, or at least, assistance to appeal or delay implementation of what could be a fatal decision. Finally, as a society we need a much greater understanding of how implicit biases are compounded in the case of specific individuals such as Michael Hickson who was both Black and disabled. Disability advocates, the federal government (e.g., HHS OCR), and ethicists who support the value of every life, must continue this work because even

The allocation of health care resources needs to be based on living with a disability, not dying with a disability.

when CSC guidelines are not triggered, their principles clearly influence the decisions that are made in “pre-surge” conditions, and the roots of medical rationing decisions lie in the same implicit bias that affected healthcare for people with disabilities long before the coronavirus came into existence.

Even if all states make their CSC guidelines nondiscriminatory, that may be only the substantial first step in protecting people with disabilities from medical rationing. State CSC guidelines are generally regarded as only guidelines. Individual hospitals and health systems may fail to formally adopt any CSC policy, and individuals with disabilities may find themselves subject to policies that are not publicly available even if they exist, and that look very different from those developed in their state. In addition, public health and other state agencies that typically have authority over hospitals and health systems may lack the experience, legislative mandate, sufficient personnel, or the will to enforce disability and other civil rights laws in the arena of CSC, instead, treating medical rationing and triage decisions as purely medical decisions to be made by healthcare professionals. For the sake of every stakeholder, from patients with disabilities to doctors, from family members to medical educators, we must find ways to work together on developing nondiscriminatory standards of care, and to do so before we are actually in the midst of the next crises or emergency shortage. The allocation of healthcare resources needs to be based on living with a disability, not dying with a disability.

Visitation Policies and Other Healthcare Policy Modifications and Accommodations

People with a range of disabilities often develop a close and trusted relationship with their support person(s), who gain specific expertise in their employer, client, or family member’s physical, communicative, social, and emotional needs. The no-visitor policies adopted by hospitals, healthcare facilities, and ambulatory clinics/offices since the pandemic began have been challenging for primarily adult people with disabilities¹³⁴ (most hospitals recognize an exception for minors that allows them to be accompanied by at least one adult for both inpatient and outpatient hospital procedures). Some professional provider

associations such as the American Academy of Developmental Medicine and Dentistry also recognized the need and the capacity for no visitor policies to be modified.¹³⁵ The American Academy

Throughout the pandemic, many health care facilities and plans seemed unclear on the critical point that civil rights laws apply during a public health emergency . . .

of Developmental Medicine and Dentistry statement “recommended that hospitals provide reasonable accommodations in accord with the Americans with Disabilities Act in their visitor policies for persons who need support from known and acknowledged support persons” and recognized that “policies should permit a caregiver to be present to the greatest extent possible,” while also recognizing the hospital’s responsibility to develop appropriate infection control protocols for the presence of support persons.¹³⁶

Throughout the pandemic, many healthcare facilities and plans seemed unclear on the critical point that civil rights laws apply during

a public health emergency. As explained earlier in this chapter, healthcare entities have been subject to federal and state disability civil rights for decades. With the declaration of a public health emergency, however, many hospitals and urgent care systems seemed to assume that they could adopt blanket policies that would apply throughout the pandemic. Moreover, some hospitals did not publicly acknowledge any obligation to make individualized assessments of the needs of people with disabilities or to consider disability-related policy modifications or exceptions in care for people who contracted the virus. HHS OCR identified “[a]voiding separating people from their sources of support, such as service animals, durable medical equipment, caregivers, medication and supplies” as a practice needed to help ensure that people with disabilities have equal access to emergency services,¹³⁷ and emphasized that “government officials, healthcare providers, and covered entities should not overlook their obligations under federal civil rights laws to help ensure all segments of the community are served.”¹³⁸ As the following examples show, covered healthcare entities around the country have been slow to publicly acknowledge disability-based accommodations to their no-visitor policies, and even where policies exist, frontline hospital staff may not know or understand them or may implement them in overly narrow ways.

HHS OCR was directly involved in this issue after receiving several distinct complaints about hospital facilities denying the support persons needed by patients with disabilities. In May 2020, Disability Rights Connecticut and other disability rights groups filed a complaint with HHS OCR

against a Connecticut hospital that refused to modify its no-visitor policy to allow the support person of a 73-year-old generally nonverbal patient with aphasia and severe short-term memory loss; the complainant’s support person provided assistance with communication and comprehension.¹³⁹ Connecticut state was also included in the complaint because the state’s visitation guidance only recognized a narrow exception to no-visitation policies, limiting support person modifications to those “individuals with disabilities receiving certain services from the state Department of Developmental Services.”¹⁴⁰ Individuals with very similar functional limitations to those with developmental disabilities were arbitrarily denied their support persons merely because their disabilities first manifested in adulthood or were the result of an accident, and therefore fell outside eligibility criteria under the state’s Department of Developmental Services funding stream.

Later in 2020, HHS OCR received three distinct complaints about MedStar Health’s denial of a disability-related exemption to its no-visitor policy. MedStar Health operated health facilities that operated in more than 100 locations throughout Maryland, Virginia, and Washington, D.C., including hospitals and urgent care centers. The three complainants had sought surgical or emergency care unrelated to COVID-19 but were confronted with the no-visitor policies that MedStar Health hospital facilities had adopted because of the coronavirus. Each of the complainants had physical disabilities and either cognitive or memory impairments, and two complainants also had hearing or vision loss. The complainants alleged that MedStar Health’s visitation policy denied them effective

communication with their treating providers, denied them the ability to provide informed consent, and subjected them to physical and pharmacological restraints that would have been unnecessary if their support persons had been allowed.¹⁴¹

A close look at the complaint brought by Disability Rights D.C. and other disability organizations in September 2020 on behalf of William King¹⁴² shows numerous common discriminatory elements in the hospital visitation policies brought to HHS OCR's attention:

These common elements of visitation policies that are not in compliance with disability civil rights obligations can be found in the Connecticut complaint and also in other visitation policies that were the subject of complaints brought from around the county.¹⁴³ In a series of complaints filed with the California Department of Public Health (CDPH) in August 2020 against five separate hospitals across the state, encompassing four different health systems,¹⁴⁴ family members and support persons detailed a trail of ignorance

Discrimination in Hospital Visitation Policies

- Narrowly or exclusively defining a subgroup of persons with disabilities (e.g., people with developmental disabilities or specific diagnoses) as patients who can receive an exception to the no-visitor policy;
- Narrowly or exclusively defining who the hospital will accept as a support person (e.g., someone with legal decision-making authority over the patient, or a paid disability service provider) and limiting the disability-related functions that will be recognized as tasks that a support person undertakes (e.g., direct interpretation is recognized but recognizing and alleviating anxiety so effective communication can take place is not recognized), and/or limiting when and how a support person can be present;
- Little emphasis on communicating policies and policy changes to frontline hospital staff, ultimately leaving discretion for the admittance of support persons in the hands of untrained staff who might not know exceptions to no-visitation even exist;
- No clear obligation on the part of hospitals and urgent care facilities to make their policies *and the disability-related exceptions to those policies* publicly available on websites, physically displayed at entrances, or handed out upon hospital admission;
- State departments of public healthcare that provided only advisory rather than mandatory guidance, did not mention civil rights or nondiscrimination obligations, and gave individual hospitals unfettered discretion to create individualized visitation policies without any consideration for elevating or appealing frontline decisions.

concerning the needs and rights of people with disabilities.¹⁴⁵ One 68-year-old person with a disability was hospitalized for a week and her support person, her daughter, was excluded every night for 12 hours.¹⁴⁶ As the complaints show, many hospitals disregarded CDPH’s statement that “‘recommends that one support person be allowed to be present with the patient when medically necessary;”¹⁴⁷ or would interpret “medically necessary” in the narrowest possible way; frontline hospital staff were unfamiliar with and disregarded even their own hospital’s policy exceptions to a no-visitation rule.

When a needed support person is denied, the health and well-being of the person with a disability can quickly deteriorate, and the initial failure to accommodate will be compounded by an extended stay and a resulting increased risk of being subject to medical rationing if crisis standards of

care are triggered or close to being triggered. Even when a support person is not a requested accommodation, people with various disabilities can need modifications in policy: someone with quadriplegia may need extra assistance during meals or frequent visits for repositioning because of existing pressure sores, someone who is developmentally disabled may require additional checks to ensure that intravenous and monitoring connections stay in place, and someone with limited vision may need initial assistance using unfamiliar technology

for online visitation. A person with mobility disabilities needs an accessible toilet and may need assistance with any needed transfers. A failure to meet these needs is not only likely to result in unequal care, it can lead over time to complications and worsening health that then also raise the threat of medical rationing during surge or near-surge conditions. This is why a common lack of accommodations, policy modifications, and individualized care assistance related to disability needs can lead directly to patient concerns about staying in a hospital. As one well-known disability researcher and

doctor who is a person with disabilities herself has noted:

Each of us makes choices about the care that is confronting us, and especially at the height of the COVID crisis, it would have been rational for a person with disabilities to decide to remain at home and receive care

at home—even if it ultimately resulted in their death. We didn’t understand the virus well back then.¹⁴⁸

Policymaking that did not consider the need for disability modification of pandemic-motivated policies or individualized assessment of the healthcare needs of individuals with disabilities led to discriminatory CSC, and also prompted hospitals to adopt strict “no-visitor” policies as an infection control measure without considering the need for exceptions. A central part of the

When a needed support person is denied, the health and well-being of the person with a disability can quickly deteriorate, and the initial failure to accommodate will be compounded by an extended stay and a resulting increased risk of being subject to medical rationing if crisis standards of care are triggered . . .

problem is that there was already a preexisting assumption by many physicians and the general public that when a person with a disability goes to the hospital, hospital staff will be equipped to meet all of their healthcare-related needs. During the pandemic, this assumption shortchanged both support persons' expertise and hospital staff, who during the best of times may not have the training or capacity to meet the assistance needs of multiple significantly disabled adults, much less during a pandemic. A majority of healthcare providers working in hospitals, and especially those in emergency rooms and intensive care units, focus on urgent care. They are not necessarily trained to recognize how people with intellectual or developmental disabilities may not give straightforward answers to questions about their pain levels, or how people who use personal ventilators will deteriorate mentally and physically without their ventilators, or how preexisting disabilities or conditions, including mental health medications, may require additional assistance during a hospital stay. One professor of nursing has agreed that visitation has become an ethical dilemma for nurses, who "are often disadvantaged, forced to act as 'gatekeepers' without sufficient direction or training on disability-related exceptions to general policy, and expected to deal with additional care requirements when someone with significant disabilities is admitted without the experienced support person who would willingly perform many of these care functions." By refusing to admit support persons or provide other needed policy modifications during a pandemic or similar health crisis, hospitals hurt people with disabilities as well as the very staff who would benefit most from having support persons on site.

It is difficult to conceive of any public health emergency, natural disaster, hostile act, or infrastructure failing that would not place a significant strain on the health system in the affected geographic area. Once that occurs, it is entirely foreseeable that healthcare providers and administrators will deny needed policy modifications and accommodations because they will assume that emergency conditions dictate common rules for every patient, without exception. But disability-based policy modifications are required in healthcare under federal and many state laws. Those laws are not neutralized or diminished in an emergency, as this chapter has repeatedly stressed.

Accessible Vaccination and Vaccination Prioritization

The first Emergency Use Authorization (EUA) for a coronavirus vaccine in the United States was granted for individuals aged 16 years and older on December 11, 2020.¹⁴⁹ The second EUA followed one week later for individuals aged 18 years and older.¹⁵⁰ The third vaccine, which required only a single shot rather than two spaced weeks apart and did not need storage at ultra-cold temperatures, was approved at the end of February 2021, again for individuals aged 18 years and older.¹⁵¹ And on May 10, 2021, the EUA granted for the first vaccine was expanded to include persons aged 12 to 15 years old,¹⁵² while both the first and second EUA grantees applied May 7 and June 1, respectively, for full use authorization and not just EUA status.¹⁵³ Even though the full authorization process is likely to take months, the applications showed the developers' confidence in their product. Full authorization allows each developer to market its vaccine directly to consumers and reassure those

with vaccine hesitancy because of concerns that the vaccines were insufficiently tested in a rushed process.

Vaccination was described by federal administration and state governors as the light at the end of COVID-19's long dark tunnel. Vaccination helped the nation reach a crucial turning point of both falling case and death rates¹⁵⁴ and economic recovery,¹⁵⁵ though not all of these positive changes happened evenly across all states.¹⁵⁶ Vaccination itself can be a divisive subject, but monthly polling showed that even though the percentages of the public who said they will definitely not get the vaccine or will only get vaccinated if required to do so stayed consistent for months at approximately 13 percent and 7 percent respectively, the percentage of the public who received shots steadily increased, reaching 62 percent in May 2021 with only 4 percent indicating they had not yet been vaccinated but would like to be as soon as possible.¹⁵⁷ The proportion of people who said they would "wait and see" if they would get vaccinated steadily dropped from 22 percent in January 2021 to 12 percent in May 2021.¹⁵⁸ By August 2021, about 52 percent of U.S. residents were fully vaccinated.¹⁵⁹ Nonetheless, the vaccine success story should not obscure the fact that the *same* preexisting foundational problems that made PPE and COVID-19 testing so hard to get for those needing or providing HCBS, made medical rationing fearful, and made the denial of needed policy modifications so common for people with disabilities, also plagued the equitable and accessible inclusion of people with disabilities in COVID-19 vaccine distribution across the country.

Generally speaking, the groundwork for vaccination can be placed into three overlapping

categories of work that had to be done before any shot was given: outreach, prioritization of population groups (assuming at least some period[s] during which demand outstrips supply) and establishing the mechanics of eligibility sign-up and delivery. The needs of people with disabilities must be considered in all these categories or many will be left out. Equitable outreach and education efforts focused on race and ethnicity, as is appropriate, but they also had to consider effective communication requirements and the need to reach and reassure groups, such as Deaf persons, who may be experiencing vaccine hesitancy because breaking public health news is full of technical jargon and often only available through error-prone automatic captioning,¹⁶⁰ or they are reluctant to place themselves in situations where they are unsure that full communication access will be provided.¹⁶¹ In Rochester, New York, which has one of the largest per capita communities of Deaf persons in the world, the full communication access provided to refugees who are Deaf and seeking vaccination exemplified how effective communication was integral to both equitable vaccination and achieving public health goals.¹⁶² Vaccine information and outreach written in plain language benefits Limited English-speaking populations, persons with intellectual or developmental disabilities, and people with lower literacy levels.

In the category of vaccine sign-up and delivery, there were numerous reports across the country of inaccessible online registration forms, physically inaccessible vaccination sites, lack of ASL interpreters and alternative formats, and the failure of vaccine personnel to recognize direct care workers and unpaid support persons

as frontline healthcare workers.¹⁶³ Both HHS OCR and ACL made attempts to address some of these barriers by developing legal guidance on how vaccine providers needed to ensure that people with disabilities had equal access to vaccine processes¹⁶⁴ and on best practices and strategies for providing that access on the ground.¹⁶⁵ Another key accessibility factor was having sufficiently reliable internet access to reach vaccination sites. Analysis of 2019 American Community Survey data established that people with disabilities, older persons, and people of color had lacked internet access in higher proportions.¹⁶⁶

The two categories of outreach and vaccine delivery also affected other populations that include and/or directly intersect with the well-being of people with disabilities. For example, states were not equally effective in early efforts to proactively target outreach and vaccination to low-income counties with racial and ethnic groups that had multiple social vulnerability indicators; Arizona and Montana were notably successful, while California ran into problems of misuse when special vaccination codes intended for communities of color circulated among wealthier nonresidents.¹⁶⁷ A majority of direct care workers are low-income women of color, as explained in chapter three, and vaccine hesitancy deeply influenced uptake of the COVID-19 vaccines among healthcare workers—those who put off the vaccine comprised at least 40% of healthcare workers at some historical points and was most prevalent among lesser-paid healthcare workers of color.¹⁶⁸ Some states, such as Virginia and Missouri appeared to have reached Latino populations effectively, but nationally “a dearth of transportation options, an inability to take off from work to get a vaccine,

and concerns about documentation and privacy dampened uptake among Hispanics, according to experts.”¹⁶⁹ These same accessibility barriers concerned organizations such as the National Medical Association and other Black healthcare professionals, who emphasized that “the fear of Covid-19, which is this invisible looming foe, that fear does not always outweigh the very clear and well-documented danger of going to a system that has proven itself to be as deadly as disease,” and pointed to “the forced sterilization of poor, disabled, and Black women through much of the 20th century as just one of many examples.”¹⁷⁰ People with disabilities were therefore disadvantaged by vaccination barriers they encountered themselves, as well as barriers that lowered vaccination rates among current and potential direct care workers who provide necessary personal assistance.

As problematic as vaccine outreach and delivery have been for people with disabilities, however, the most revealing systemic difficulties occurred in the category of vaccine prioritization. Given multiple reports emerging in 2020 on the unequal impact of the coronavirus on racial and ethnic population groups in particular, the federal government took steps to address the potential inequalities in how COVID-19 vaccines would be distributed once approved. In the late summer of 2020, the National Institutes of Health and CDC asked the National Academies of Science, Engineering, and Medicine (NAEM) to form a committee of experts who would create a consensus statement on how to equitably allocate COVID-19 vaccines. Vaccine supply would almost certainly be less than demand, both domestically and globally, for a period likely to be months or even years for some poorer countries. The committee, largely made up of

individuals with medical, scientific, bioethics, or legal expertise, was asked to:

consider what criteria should be used to set priorities for equitable distribution among groups of potential vaccine recipients, considering factors such as population health disparities; individuals at higher risk because of health status, occupation, or living conditions; and geographic distribution of active virus spread. In addition, the committee will consider how communities of color can be assured access to COVID-19 vaccines in the U.S. and recommend strategies to mitigate vaccine hesitancy among the American public.¹⁷¹

The NASEM committee's equitable framework for vaccination gave limited recognition to disability as a factor in prioritization, and *it failed to recognize people with disabilities* as a group subject to identifiable risks of coronavirus infection and severe COVID-19 illness. Instead, the committee paid almost exclusive attention to age and medical factors and failed to grapple with multiple high-risk factors that affect people with disabilities, such as reliance on HCBS, living in smaller CCFs such as group homes whatever one's age, the historical and ongoing impact of being a health disparity population, and the existence of discriminatory CSC that would ration people with various significant disabilities out of COVID-19 treatment in surge conditions.¹⁷² People with disabilities were not specifically consulted or asked about the unavoidable risks of infection and severe consequences from COVID-19 that they live with because of disability-related needs. The final framework noted the risks of infection experienced by people with disabilities

who could not forego or socially distance from their direct care workers, but the committee's prioritization recommendation pointed only to CDC's then-current listing of comorbid conditions associated with increased risk of severe illness or death from COVID-19: cancer, chronic kidney disease, chronic obstructive pulmonary disease, immunocompromised state from solid organ transplant, obesity (body mass index ≥ 30), serious heart conditions (e.g., heart failure, coronary artery disease, cardiomyopathies), sickle cell disease, and type 2 diabetes mellitus. Recognizing the limited initial vaccine supply, Phase 1c proposed setting a priority on individuals with two or more of these conditions, recognizing that these priorities could be refined as better evidence emerges.¹⁷³

CDC's list of conditions, not intended to be used as a way to distinguish between people with disabilities who were or were not at high risk from COVID-19, was not a particularly timely or efficient way of keeping up with emerging evidence about comorbid conditions.¹⁷⁴ At the simplest, comorbid conditions are two or more conditions or diseases that exist at the same time in a person. Scientists researched comorbid conditions in those individuals who were infected with the coronavirus or who were hospitalized or died most often from COVID-19. Researchers could then make reasoned conclusions about whether people with certain health conditions were at higher risk of becoming seriously ill or dying from COVID-19 if they were exposed to the coronavirus.¹⁷⁵ The idea that national or state guidance on vaccinations would equitably include people with disabilities by consistently and constantly incorporating the very latest scientific investigations into what constitutes

a comorbid condition, in the middle of a pandemic, was flawed to begin with. Medical researchers gravitated toward more common conditions among the general population such as type 2 diabetes or chronic obstructive pulmonary disease, tended to focus on specific diagnostic conditions rather than the functional impairments that reveal more about disability status and healthcare needs, and relied on death certificate information that incompletely captures a deceased person's health conditions. Scientists and institutions conducting research also tended to overlook persons with rarer health conditions

because it is harder to find enough subjects to make statistically significant findings.¹⁷⁶

Nonetheless, as NCD highlighted in its February 2021 letter to the National Governors' Association, the NASEM equitable vaccination framework as well as the federal Advisory

Committee for Immunization Practices (ACIP) Updated Interim Recommendations for Allocation of COVID-19 Vaccine¹⁷⁷ explicitly included at least some people with disabilities in their recommendations and did not impose additional arbitrary age divisions on those with high-risk medical conditions. Each recommendation "proposed persons of all ages with comorbid and underlying conditions that put them at significantly higher risk be included in Phase 1b or Phase 1c."¹⁷⁸ But the NASEM framework was purely a model. Even ACIP's recommendations to CDC on who should get vaccinated and when

only served as "guidance" for states. Most states adopted ACIP's 1a prioritization of healthcare personnel and residents of LTCFs, but as time progressed, states increasingly established their own prioritizations with varying degrees of specificity.

The degree of specificity in a state's vaccine priorities can and did become a barrier in and of itself. Washington, D.C., and Ohio indicated by January 11, 2021, that inpatient psychiatric patients should be included in phase 1a as residents of LTCFs,¹⁷⁹ but in states that were unclear on this point, psychiatric patients could

be completely overlooked or only included in the event that some advocate at the facility had connections with a state or federal vaccine provider. On the other hand, some states were narrowly specific in ways that could result in prioritized individuals being turned away. For example:

The idea that national or state guidance on vaccinations would equitably include people with disabilities by consistently and constantly incorporating the very latest scientific investigations into what constitutes a comorbid condition, in the middle of a pandemic, was flawed to begin with.

- Massachusetts included "home-based healthcare workers, including: Personal Care Attendants (PCAs) and Home-Based Respite and Individual/Family Support staff (DDS and DDS Self Directed)" among its 1a category of healthcare workers, but Illinois stated that "those providing "Home Health" or serving as a "Home Aide/Caregiver" for a relative with a disability include those who care for people with any of . . . : Cerebral Palsy, Down Syndrome, Epilepsy, Specialized healthcare needs, including

dependence upon ventilators, oxygen, and other technology.”¹⁸⁰ Even though the Illinois priority list indicated its list of stated conditions was not exhaustive, a list makes it that much harder for caregivers of individuals with disabilities that are not specified on the list to establish their prioritization.

- Maryland and Ohio included people with developmental disabilities in its phase 1b, a deliberate and explicit inclusion that necessarily excludes people with other disabilities from vaccination unless they happen to be institutionalized or over 75 years old and fit into the age prioritization.¹⁸¹
- Florida appeared to broadly include people deemed to be “extremely vulnerable to COVID-19” in phase 1a but the determination had to be made by a hospital physician using a specific form.¹⁸²
- Pennsylvania was one of the few states to explicitly and early mention people receiving HCBS and include them in phase 1b.¹⁸³

Once Phase 1a was underway, some states such as California, Colorado, Kentucky, Montana, New Hampshire, New Jersey, New Mexico, and Ohio quickly pivoted in early January to an age-based framework that included age limits as young as 50 years in phase 1c. However, only some of these same states, such as Montana, New Hampshire, New Mexico, and Oklahoma *also* included people 16 years and older with high-risk medical conditions in phase 1b. Montana

went so far in phase 1c as to include people 16 years and older with medical conditions that were not included in phase 1b. Even among these four states, however, one state required people to have two or more underlying health conditions while the other three states explicitly or implicitly required only one condition. States also changed their own prioritizations over time, especially in the first weeks of 2021. New Jersey, for example, did not include people with high-risk medical conditions on January 11 but by January 19 included persons 16–64 years with high-risk medical conditions in phase 1b.¹⁸⁴ By March 9, the situation had reshuffled with at least thirty-seven states including at least some residents with high-risk conditions in their vaccine prioritization, but “the health issues granted

higher priority differ from state to state, and even county to county.”¹⁸⁵ In marked contrast, California moved to a primarily age-based

framework in January, placing people aged 65–74 years in phase 1b and those aged 50–64 in phase 1c. Phase 1b also included essential workers, defined in terms of agriculture/food services, education/childcare, and emergency services.¹⁸⁶

The above review of vaccination among states through the first months of 2021 reveals that vaccine prioritization was the “Wild West” of COVID-19. States talked about equity and tried to achieve speed, but a great deal of vaccination procedures on the ground were determined by local public health authorities and vaccine providers who seemed to have default discretion to interpret state rules that could change weekly. The needs of people with disabilities and older individuals, especially those who could not leave

... [T]he first months of 2021 reveals that vaccine prioritization was the “Wild West” of COVID-19.

their homes for vaccination, were partially met if there happened to be a strong local advocate, a healthcare decision maker, or even just a single provider who saw the need,¹⁸⁷ but heroic individual efforts should not have been required and cannot redeem systemic failures. The degree of seemingly arbitrary variance in how people with disabilities as a population group were treated when it came to COVID-19 vaccination cannot be overstated. Such treatment, coming after people with disabilities were seemingly left to die in nursing homes and subject to discrimination under some CSCs, left members of the disability community fearful that governments and public health authorities simply didn't care if some of them died during the pandemic.¹⁸⁸ It is foreseeable that in a free-for-all environment, people with disabilities will get pushed to the back of the line virtually every time, with their rights obscured and forced to be dependent upon charity.

California is a case study in how people with disabilities and high-risk conditions had to battle to be included in the state's vaccine prioritization, irrespective of a public commitment to equity in the vaccination process. The state had established a "Community Vaccination Advisory Committee" (CVAC) in November 2020 with nearly 80 advocates and representatives from racial, ethnic, and underserved communities, with the state goal of ensuring that COVID-19 vaccines would be distributed equitably, and the hope of avoiding exacerbation of existing health and healthcare disparities.¹⁸⁹ The CVAC met frequently and tried to achieve consensus results on the population groups that would be prioritized once vaccination began. However, demand far outweighed supply for many weeks and as reports of a slow vaccination pace and unused spoiled doses spread across the state,

California moved away from nuanced attempts to balance exposure, infection, and death risks among California communities. The state instead adopted age as a prioritization factor that is logistically easy to administer and widely acknowledged as a strong risk factor for dying from COVID-19.¹⁹⁰ A few CVAC members worked together bringing original data verifying how younger Medicaid-enrolled people who require HCBS usually have a range of health conditions and are at high risk of infection, hospitalization, and death from COVID-19.¹⁹¹ These members also circulated breaking studies and information to the CVAC on how COVID-19 placed people with various disabilities at higher risk, such as those with intellectual and developmental disabilities,¹⁹² people with schizophrenia,¹⁹³ and those for whom other countries gathered data.¹⁹⁴ Mainstream state and national media also played a useful role by reporting on rates of coronavirus infection and death from COVID-19 among people with specific disabilities¹⁹⁵ and providing a forum for younger people with disabilities to express their personal concerns on vaccination and the impact of COVID.¹⁹⁶

In the end, younger people with high-risk disabilities or conditions were not included in phase 1b or 1c until February 12, 2021, at which time CDPH issued a bulletin to vaccine providers advising them that people with high-risk conditions or disabilities would be eligible for vaccination as of March 15.¹⁹⁷ High-risk conditions were defined primarily through CDC's finite list of health conditions, but high-risk disability encompassed circumstances in which:

- an individual is likely to develop severe life-threatening illness or death from COVID-19 infection;

- acquiring COVID-19 limits the individual's ability to receive ongoing care or services vital to their well-being and survival; or
- providing adequate and timely COVID-19 care will be particularly challenging as a result of the individual's disability.¹⁹⁸

The more open-ended nature of high-risk disability was a victory for California's disability community.¹⁹⁹ California was experiencing near-surge conditions at the end of 2020 through the first few months of 2021, making this period a particularly anxious time, and once people with high-risk conditions and disabilities were included within California's vaccine priority populations, state representatives and disability advocates had to consider how vaccine providers could confirm that individuals belonged within this group. If the verification process called for "a doctor's note," people with disabilities and advocates were concerned that the requirement would become yet another barrier to low-income people of color who were disproportionately less likely to have a regular healthcare provider who could write such a note, and primary care doctors did not always know when their patients received HCBS or understand its significance for coronavirus infection.²⁰⁰ In the end, CPHD agreed that people with high-risk medical conditions and disabilities could self-attest to that fact to establish their vaccination priority.²⁰¹

Now that the United States has reached a point where supply seems to match or even outstrip remaining demand in at least some parts of the country, it is easy to look back and characterize the inaccessibility and uneven treatment of people with disabilities in vaccination as just one of many flawed

government responses during an emergency. But vaccine problems persisted for some people with disabilities as states reopened and vaccination totals are celebrated. Individuals with disabilities who had difficulty leaving their homes remained unvaccinated months after they were first eligible because of their age or having a high-risk condition/disability.²⁰² There was a sharp contrast between states like Ohio, New York, and Colorado initiating vaccination lotteries with large cash prizes to incentivize vaccination among those who remain hesitant²⁰³ even as unvaccinated people filled COVID-19 wards in Cleveland, New York City, and Denver, including people who were unable to get vaccinated because "[c]ities and states have slowly been rolling out programs to reach some of the nation's estimated 4 million homebound Americans, but the programs tend to have modest goals and target only a fraction of the people who likely need outreach."²⁰⁴

When states, local governments, and public health authorities made decisions in or after May to use narrow definitions of "homebound" to gatekeep the house call vaccination process and consequently missed people with disabilities who face multiple barriers to leaving their homes,²⁰⁵ they were not deciding something in the heat of an emergency. They were making deliberate decisions about where to expend resources and who is worthy of those resources. Even as states fully reopened their economies and modified social distance and mask rules, persons with disabilities of all ages who still could not get vaccinated were left to weather a profound social isolation that is even longer than the period of isolation that nursing home and congregate residents had to endure when they quarantined in their

own rooms. Ironically, institutional residents were told that they could not be placed into alternative housing because they would be lonely, while nursing home residents and their families were told they had to endure loneliness to remain healthy. But as poignantly observed by the adult daughter of a memory care facility resident, “Is physical health so important that we deny social isolation as potentially furthering illness and death?”²⁰⁶ Six months after the first vaccine was authorized, we had unvaccinated people with disabilities who fought to remain in the community who had to continue curtailing visitors, maintaining social distance, and enduring anxiety when they received personal support services or other medical services in their homes. Their deprioritization for COVID-19 vaccination was also a choice of sorts, but one that was imposed upon them rather than a decision they got to make.

The common thread that ran from inadequate PPE to discriminatory medical rationing of COVID-19 treatment to failing to be accounted for in vaccination schemes is rooted in how many levels of public health and emergency decision makers fail to recognize the lives of people with disabilities, and particularly those with significant disabilities living in the community. The failure to collect relevant health data on those lives—where people with disabilities live, where they get healthcare, how they are or are not accommodated, the health and healthcare disparities that they experience,

the intersection of disability characteristics with racial, ethnic, LGBTQ+ and other personal characteristics—constitutes ignorance that was systemic, and at this point in history, willful. This idea will be addressed more fully in the following section.

Even though several states were approaching 70 percent vaccination rates of adults 16 and over, vaccination-related issues continued to be relevant for some time for a number of reasons. These reasons include the fact that experts could not pin down exactly when herd immunity will be achieved in the United States, vaccination rates remained uneven across states and

identifiable population groups, COVID-19 variants continued to evolve and spread across the globe, vaccine use was not yet granted for children 12 years and under, and there was still much discussion and uncertainty around how proof of vaccination would play out in such

contexts as employment, travel, and attendance at mass events held in music or sports venues. So many of the problems outlined throughout this chapter occurred because governments, public health entities, and healthcare providers failed to take account of the disparate needs of *all* persons when planning and executing pandemic and emergency response measures. The cycle of insufficient data, inadequate accommodations and modifications, untrained frontline responders, and implicit bias cannot be left to trap people with disabilities in an endless loop of actions that come “too little, too late.”

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COVID-19 Data Collection—Infection, Hospitalization, Treatment, and Death Rates of People with Disabilities, Collected in Conjunction with Race, Ethnicity, Age, and Other Demographic Characteristics

The dearth of disability-specific COVID-19 information has left the nation uncertain of such basic figures as how many COVID-19–related deaths of people with disabilities occurred in the United States and where they occurred; the number of people with disabilities younger than 65 who died in long-term care and other congregate settings; the functional disabilities among those who have been infected with the coronavirus and those who received treatment in hospitals; and how many people with disabilities were vaccinated to date.

Without this data, it is challenging to make tailored legal and policy recommendations to reduce disparities in COVID-19 testing, receipt of treatment, and vaccination among people with disabilities because it is difficult to even establish that disparities exist. It is also almost impossible to make a cross-analysis of how disability intersects with age, race, ethnicity, income levels, LGBTQ+ status, and other personal characteristics.

When disability advocates and communities sought vaccination prioritization for younger people with disabilities, they were confronting a complex application of disability rights. People with disabilities can clearly evoke disability rights laws when they face physically or programmatically inaccessible vaccination locations, for example, or if they are explicitly excluded from vaccination because they are disabled. In such cases, they face targeted barriers that prevent their equal access to vaccines to which they would otherwise have

the same right as everyone else. It is a less straightforward argument to say that people with disabilities are being discriminated against when a state establishes vaccination priorities that give higher priority to groups of individuals on the basis of a characteristic other than disability, for example age. Infection and death rates have established that the coronavirus is having a greatly disproportionate impact on older individuals. If people with disabilities who also fit the age criteria are being vaccinated, it is difficult to establish that younger people with disabilities are actively discriminated against just because disability in and of itself is not being prioritized above age. Similarly, a state’s prioritization of other equity or social factors such as emphasizing frontline healthcare workers or essential workers is difficult to impugn as inherently discriminatory. Arguably, a governing entity is free to prioritize saving older lives that are disproportionately at risk or people working in occupations that are particularly needed for maintaining population health and infrastructure. If advocates could establish similarly high rates of risk of infection, severe illness, and death from the coronavirus for younger people with disabilities to those cited for older persons, but the state nonetheless refused to prioritize on the basis of disability, then the presence of discrimination becomes more probable.

Ultimately, the country must achieve finely detailed or “granular” collection of health data on people with disabilities because it cannot achieve equitable well-being in healthcare and public health for people with disabilities without it. The U.S. government must recognize the need for the data, information collection must be mandated, and a variety of health entities must agree to develop and use validated methods

for collecting data both at the point at which a service such as hospitalization or vaccination is administered and through the use of national surveys such as the American Community Survey or the Behavioral Risk Factor Surveillance System (BRFSS). Though the surveys are national some are administered by and through states. The BRFSS, for example, has “a standardized core questionnaire, optional modules, and state-added questions” and is administered by state health departments through telephone surveys using random digit dialing to landlines and cell phones; the BRFSS is administered throughout the year and is particularly important for detecting trends that can point to emerging illnesses such as COVID-19.²⁰⁷ The ACS, on the other hand, is conducted directly by the U.S. Census Bureau through paper or online surveys sent out randomly every month to addresses in any of the 50 states, the District of Columbia, and Puerto Rico in five-year cycles, and “provides information about the social and economic needs of your community every year.”²⁰⁸ It is particularly important in helping all levels of government to plan spending and infrastructure for educational, housing, healthcare, transportation, and other needs in American communities.

Disability data collection efforts and standardization in healthcare and in programs and activities conducted or sponsored by federal HHS were not broadly required until Section 4302 of the ACA was enacted in 2010.²⁰⁹ An interagency committee had developed a six-item set of functional disability questions that had undergone extensive cognitive and field testing and was being used in the ACS and some other major national surveys, but it had not been officially adopted as a minimum standard or uniformly required by HHS;²¹⁰ but the Section 4302 mandate

covers only national population-based surveys and does not extend to “administrative data (such as data captured at the time of enrollment in a program or data collected from a medical record), clinical data (collected as part of clinical care), and research data (collected from participants in research studies)” that would allow analysis of disparities in the public health inclusion of people with disabilities.²¹¹ The adequacy of inclusion of people with disabilities in state health surveillance, public health, and emergency measures is also not captured. There has not been any attempt to extend Section 4302’s minimum data standards to private entities, even to entities that receive federal financial assistance through their participation in federal and state insurance exchanges, for example.

For the most part, private health providers and insurers treat diagnostic information as disability information. This tends to obscure functional disability status because someone with a diagnosis of multiple sclerosis, for example, can have a range of symptoms from nonvisible fatigue to loss of mobility requiring use of a wheelchair; a diagnosis in itself fails to reveal a patient’s accommodation needs or their likelihood of experiencing disability-related healthcare disparities. Nonetheless, private health insurance claims data helped to establish how persons with certain health conditions were at high risk of severe consequences after contracting COVID-19²¹² and could be even more helpful if claims data included demographic data from the ACS disability set.

Given the current limited state of granular disability health data collection, it is useful to trace how granular data on race, ethnicity, and language (REL) has come to be widely embraced as an important component for measuring health and healthcare disparities in the United States.

The information we now have on health and healthcare disparities experienced by racial and ethnic groups is due to government policies that date back decades. Starting with “the landmark 1985 Secretary’s Task Force on Black and Minority Health,” HHS reports came to recognize how timely and reliable data could be used to identify racial and ethnic health disparities and the factors that cause and accompany disparities and to monitor progress in reducing disparities.²¹³ In 1997, HHS finally adopted a “Data Inclusion policy that “required the collection of uniform standard data on race and ethnicity in all HHS-sponsored data collection activities.”²¹⁴ Years later, the Institute of Medicine issued its seminal report in 2003, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, that acknowledged how racial and ethnic disparities are “significant predictors” for of the quality of care that a person of color receives even after accounting for other socioeconomic differences.²¹⁵

Almost 20 years of advocacy later, we see far greater awareness among experts and the general public of health and healthcare disparities related to race, ethnicity, and language (REL). During the pandemic, all levels of government openly accepted that systemic racial/ethnic discrimination and implicit bias contributed to COVID-19 infection, treatment, and vaccination disparities among people of color, particularly Black, Hispanic, and Indigenous persons, a response that was likely heightened by cultural and social changes in the wake of George Floyd’s death in 2020. Media sources established regularly updated dashboards that showed disproportionate infection and death rates among people of color and the racial and ethnic demographic characteristics of vaccinated individuals.²¹⁶ CDC providing national rates of vaccination by race and ethnicity, stated that “[i]mproving COVID-19 vaccination coverage in

communities with high proportions of racial/ethnic minority groups and persons who are economically and socially marginalized is critical because these populations have been disproportionately affected by COVID-19–related morbidity and mortality.”²¹⁷ The great majority of states are also reporting state vaccination rates by race and ethnicity.²¹⁸

Even with far greater awareness and intentionality, though, state-level collection of race and ethnicity data remains highly imperfect. Some states’ existing Immunization Information Systems still lack capacity to track REL data, and adding that capacity could take months, while other states have the capacity to record race and ethnicity data but the fields are not required during data entry.²¹⁹ Moreover, those states that track race and ethnicity have not uniformly adopted the clearly defined racial and ethnic categories used in federal census data or committed to a minimum set of data collection standards.²²⁰ Inconsistencies and gaps can also compound across states and further impede any attempt to get a clear national picture of vaccine equity; for example, South Carolina “lumps together Asians, Native Americans, and Pacific Islanders in one category,”²²¹ while “data gaps and separate reporting of data for vaccinations administered through the Indian Health Service [further] limit the ability to analyze vaccinations among American Indian and Alaska Native and Native Hawaiian and Other Pacific Islander people.”²²² With race and ethnicity information known for only 53 percent of those vaccinated as of March 29, 2021, numbers still consistently showed that Black and Hispanic populations across states received proportionately less vaccine than their percentage share of cases, of deaths, and of the state’s total population.²²³ As pointed out by one population health expert, incomplete and inconsistent data makes it

“harder for us to hold ourselves accountable to our own work and to stand up and say to the public ‘Here’s the evidence that we are trying and we’re making progress.’”²²⁴ Not all states agreed that improving data collection and transparency was crucial to accountability

for achieving greater equity in the pandemic’s impact. “Only about half of US states still provide daily updates on key Covid-19 metrics—such as new cases, deaths, hospitalizations and vaccinations—a trend that worries some public health experts.”²²⁵

Lessons Learned on Data Collection

The ways in which race and ethnicity data collection was elevated, carried out, and reported during the pandemic provide valuable lessons for disability advocates.

- **Persistence Paid Off:** REL communities and advocates developed evidence for decades on the existence of health and healthcare disparities across multiple delivery contexts and argued that without granular REL data and uniform collection standards, there was no way to effectively hold providers accountable and encourage measurable quality improvement for delivering equitable healthcare. During the pandemic, most government and healthcare entities took steps to track race and ethnicity data that confirmed the inequitable impact of COVID-19 and showed that states fell far short of achieving vaccination equity.
- **National Leadership is Critical:** Federal standards facilitate regional and national data analysis and information technology interoperability. The Office of Management and Budget (developed a federal government-wide standard for REL data collection in 1997 after holding a wide-ranging public process of engagement and field testing. This early standard grounds the REL minimum data collection standard under Section 4302 of the ACA and paved the way for further work by federal agencies such as the AHRQ when it suggests ways for REL data collection to take place.²²⁶
- **The Pandemic Exposed Data Gaps:** Many experts agree that the pandemic “has shined a light on racial data problems that have persisted in U.S. public health for far too long. . . . [the hope] is that our lessons from COVID really cause all of us to think about the infrastructure we need within our state and nationally to make sure we are prepared next time. Data is our friend.”²²⁷
- **Data Collection Needs Will Continue:** pandemic data collection cannot end prematurely, particularly while disparities in vaccination rates persist among specific populations and herd immunity has not been achieved in the country. Moreover, the public health reporting systems that states have built or improved since the pandemic started do *not* have to be limited to use with COVID-19. “States have spent 15 to 18 months building up this infrastructure By winding down, the question is what will happen to this new infrastructure and skill set. By putting this genie back in the bottle, we lose the capacity to take advantage of them.”²²⁸

The disability community has made significant strides in establishing itself as a population group that is subject to health and healthcare disparities,²²⁹ but it clearly has not reached the point where health and government entities will put out disability-specific statistics related to coronavirus infection, treatment, deaths, and vaccination or search for ways to do so. Even at the height of CDC and state reporting of COVID-19 cases and deaths, there was no attempt to capture the full extent of the virus's toll on people across a range of disabilities, except for people with disabilities who happened to intersect with characteristics that were already tracked, such as age. Even when the pandemic eased, some people with disabilities, including those who are immunocompromised, adults with disabilities who have difficulty leaving their homes, or young children with disabilities who are not yet eligible for vaccination, could be harmed by the decision to cut back on vaccination reporting as "[d]aily data reporting provides critical "backup" information to help people and public officials alike make decisions about the safety of engaging in various social activities,"²³⁰ and especially until the nation reaches herd immunity.

The fragmented nature of healthcare delivery and insurance coverage in the United States makes it particularly difficult to compile complete data on where, how, and under what

circumstances COVID-19 circulated among and killed people with disabilities. Without common ways to identify people with functional disabilities, common standards for data collection, and a common mandate to collect this information across states and healthcare systems, people with disabilities will remain shut out of policymakers' increased commitment to emergency interventions that account for disparities and to equitable healthcare overall. As one prominent healthcare research organization

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observed, the "wide variety in state reporting makes it difficult to compare between states or have a complete understanding of how people with disabilities have been affected by the pandemic."²³¹

The best tools we have for baseline granular identification of people with disabilities, the six-disability question set in the ACS and the Washington Short

Set on Functioning²³² are not in broad use, and this shortcoming makes it difficult to even begin thinking about how those tools can be further refined to better capture people with communication disabilities, mental health or behavioral health disabilities, and people with HCBS needs. All these factors proved to be relevant to the high risk borne by people with disabilities during the pandemic, but potential users of disability identification tools have little current incentive to find effective ways to obtain additional information.

Surveillance tools such as the BRFSS offer another opportunity to gather vaccination information, albeit some time after vaccination. The BRFSS's focus on noninstitutionalized adults will leave out some people with disabilities residing in CCFs, but that is a population for which additional demographic information on functional disability, race, ethnicity, and other characteristics can and should be obtained in any event. CDC requested approval on March 12, 2021, to add an optional module on COVID-19 vaccination to BRFSS

that would be available by mid-2021. The proposed questions include when the respondent received their vaccination shot(s) and "what kind of place" the shot(s) were received.²³³ By early June, Alaska, Illinois, Missouri, New Jersey, and North Carolina

had reported their intention to administer the optional COVID-19 vaccine-related module, and North Carolina intended to include an additional question: "What is the MAIN reason you have NOT received a COVID19 vaccination?"²³⁴ These questions have great potential for providing important information about the vaccine barriers that people with disabilities encountered and the set will be coupled with the six-question disability set used in national surveys. The downside is that the vaccine module is optional, and any given state that chooses to include it may have insufficient sample sizes of people with specific functional limitations to provide reliable and meaningful analysis. If all states administered the vaccine module or went so far as to include

vetered disability-specific data questions, it might be possible to combine disability samples across states or within a geographic region that included a number of states.

Another data collection option is the administration of independent, state-specific polls or surveys that could be tailored and achieve results quite quickly when offered by such entities as state or local public health departments, health policy groups, university research entities, and media, or even large

healthcare systems such as a managed care entity, but such surveys can be costly, which in turn tends to limit sample size.²³⁵ And again, the lack of mandated disability inclusion in state surveillance means that disability is easily excluded from data gathering. Even with

REL data, none of the many public and private players in healthcare "has the capability by itself to gather data on race, ethnicity, and language for the entire population of patients."²³⁶ Some individuals, including people with disabilities, may have sporadic contact with the healthcare system for various reasons, such as the lack of a regular source of healthcare or being homeless, making the gathering of standardized data for quality improvement across all health and healthcare entities even more important.

The evidence that people with disabilities comprise a population group that experiences health and healthcare disparities continues to grow. The pandemic has established higher rates of coronavirus infection, and serious illness

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and death upon infection, for at least some persons with specific disabilities. But attempts to establish the overall impact of the coronavirus on people with disabilities are continually stymied by the failure to collect functional disability as a demographic characteristic and not just an individual medical need or a patient diagnosis. Health information technology interoperability rules provide yet another potential way for patients with disabilities to disclose functional disability information, but neither version 1 of the U.S. Core Data Set for Interoperability put forth by the U.S. Office of the National Coordinator for Health Information Technology, nor version 2 which is in draft form, asks for disability-related demographic information.²³⁷ A category called “functioning” is included in the health record and includes questions relating to mental function, mobility, and self-care among other elements, but its placement in the electronic health record among purely medical questions indicates that it is likely not a field that could be used to help identify or verify people with disabilities as a group subject to health disparities. The “missed policy opportunity to advance health equity” through the inclusion of more granular race, ethnicity, disability, and gender identity demographic information was noted when the Core Data Set was first being adopted: “CMS declined to adopt disability status or sexual orientation and gender identity because of the lack of consensus on definitions, lack of agreed-upon standards, data collection and reporting challenges, and disagreement over where and how to collect this information in an [electronic health record].”²³⁸

At some point, the fact that federal and state governments continually overlook the need for functional disability data begins to cross the line from simply being overlooked in prioritization to

negligence. It is virtually impossible to provide real-time accurate data about the impact of COVID-19 on people with disabilities or the healthcare disparities they experienced during the pandemic if state, public health, health plan, and provider databases fail to identify someone as a person with a disability. This simple fact has become increasingly clear over the past couple of decades as the U.S. healthcare system has come to gradually recognize REI-related health and healthcare disparities, and concentrated effort has been put into transitioning to electronic health records. The fundamental failure of healthcare data collection to recognize people with disabilities must be decisively changed on multiple levels, or policymakers, researchers, and the public will never know whether people with disabilities are disproportionately dying in the next pandemic or emergency, and they will assume that any disproportionate impact is purely attributable to the presence of disability or a health condition rather than a matter of systemic or implicit bias.

Summary of Findings

- Needed PPE was widely unavailable to both those providing and receiving long-term services and supports, placing people with disabilities, both those living in congregate care situations and those living in the community, at higher risk of infection, severe illness, and death during the pandemic.
- Implicit bias about living with a significant disability is widely prevalent among healthcare providers, hospital administrators, bioethicists, and healthcare decision makers and likely influenced denials of treatment and inappropriate referrals to hospice care of

- people with disabilities, including people of color with disabilities who are also subject to intersecting stereotypes and systemic racism.
- There is some awareness among healthcare providers and professional associations of how people with disabilities have suffered historic harm, structural discrimination, and unequal care in the delivery of healthcare, but this awareness has not yet translated into concrete commitments to changing healthcare education, professional accreditation, and academic research policies.
 - Many of the CSC policies established or used by states and hospitals during periods when medical beds, equipment, and personnel were first strained by high levels of coronavirus infection and hospitalization discriminated explicitly and implicitly against people with disabilities.
 - Longstanding failures of healthcare providers and administrators to know and follow federal and state disability nondiscrimination laws resulted in patients with disabilities being denied critical policy modifications and accommodations during the pandemic.
 - Basic physical and programmatic inaccessibility was widespread in many public health responses to the emergency, from the establishment of drive-in testing sites to procedures for making vaccine appointments and providing vaccination.
 - Policymakers have limited data or understanding about people with disabilities who live in the community and receive HCBS, some of whom cannot maintain access to the necessities of life while sheltering in place and practicing strict social distancing.
 - Current restrictions on how SNAP benefits can be used exacerbated the food shortages experienced by people with disabilities who need assistance with Complex Activities of Daily Living or who live in remote rural areas, particularly when public transportation is also restricted or unavailable.
 - The rollout of COVID-19 vaccines in the United States raised competing priorities for achieving equitable distribution and achieving speedy and efficient vaccination, which left out people with disabilities who were at high-risk from COVID-19 but who did not have health conditions already established as medically high-risk or who needed logistically complex accommodations, such as vaccination in their homes.
 - Federal and state healthcare data collection practices failed to capture baseline information about the functional disability status of patients and the public, leaving people with disabilities uncounted during and after public health emergencies, and healthcare workers and policymakers unaccountable for both failing to include people with disabilities during crises and improving quality and inclusion for people with disabilities in the aftermath of crises.
 - Private health insurance claims information contains valuable data on health and healthcare disparities experienced by people with disabilities, but this information cannot be fully accessed or effectively analyzed unless these insurers collect demographic functional disability information in addition to standard information about medical diagnoses and health conditions.

Recommendations

To ensure the United States is prepared to swiftly recognize healthcare discrimination and appropriately monitor and enforce disability civil rights laws on behalf of people with disabilities in

a future pandemic or similar national health crisis, NCD recommends the following actions based on our findings about the impact of COVID-19 on people with disabilities:

Recommendations for Congress

Congress should:

- Include functional disability status among any bills that propose improved demographic data collection relating to testing, infection, injuries, hospitalizations, and fatalities that are related to pandemics, natural disasters, climate change–related emergencies, or any other public health emergencies, both within every type of congregate care setting (e.g. psychiatric facilities, facilities for people with intellectual and developmental disabilities, board and care homes, group homes, and so forth) as well as community settings.
- In any legislation that addresses shortfalls in the nation’s supply of healthcare providers (physicians, nurses, therapists, and so forth) through changes to training programs, inclusive recruitment for a diverse healthcare workforce, loan forgiveness that encourages healthcare providers to work with underserved populations, or other innovative targeted incentive measures, include healthcare providers who are familiar with the needs of disability communities such as Deaf and Hard-of-Hearing people, people with complex rehabilitative needs, people with intellectual and developmental disabilities, people with serious mental illness, and so forth.
- Require state collection of healthcare demographic data relating to functional disability and HCBS use for all Medicaid enrollees, including better data collection across the full range of long-term care, group homes, and congregate settings licensed, certified, or approved by the state.

Recommendations for Federal Agencies

HHS should:

- Require all hospitals, hospital systems, and managed care plans that receive federal financial assistance to increase public transparency of, and nondiscrimination and due

Recommendations for Federal Agencies: *continued*

process within, CSC guidelines and medical rationing policies adopted during public health emergencies and emergency surge situations. These guidelines and policies should be clearly posted on all the entity's websites and hospital and appropriate provider network websites.

- Conduct a national convening of experts, including disability advocates and people with disabilities to review how discriminatory CSC and medical rationing policies developed and may continue to influence healthcare decision making in future public health emergencies, and to make further recommendations for alleviating the impact of CSCs and medical rationing on people with disabilities, people of color, older persons, and other groups that experience health and healthcare disparities.
- Include functional disability status among the demographic data that must be collected by the Secretary of HHS and posted on Nursing Home Compare on COVID-19 cases and deaths under the COVID-19 Nursing Home Protection Act (S.333) or other bills introduced to improve demographic data collection on nursing home infections, illnesses, deaths, or resident transfers to hospitals
- Expand on the data collection standards and requirements laid out in Section 4302 of the ACA to require any healthcare or public health program, activity, or survey (including population surveys conducted by the Bureau of the Census) that is federally conducted or that receives federal financial assistance to collect and report data on functional disability status for applicants, recipients, or participants (though the provision of such information from individual applicants, recipients, and participants should always be voluntary).
- **HHS OCR and DOJ** should work with state civil rights counterparts to issue early general guidance clarifying that there is nothing in federal or state law that automatically relieves covered entities from their preexisting disability nondiscrimination obligations, including the obligation to provide reasonable modifications and accommodations to people with disabilities, in the event of an epidemic, pandemic, natural disaster, climate change disaster, or other public health emergency.
- **HHS OCR** should:
 - Develop a Patient Bill of Rights for People with Disabilities, written in plain language, and including information on the following rights that pertain to healthcare: effective communication, policy modifications, treatment without discrimination, access to personal support persons, use of personal medical equipment, physical accessibility,

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Recommendations for Federal Agencies: *continued*

choice of less invasive reasonable treatment or health maintenance alternatives; having an advance directive, POLST, or DNR orders without undue influence, information on and assistance for returning to the community from hospital or institutional care, and freedom from assumptions about one's quality of life and capacity to benefit from treatment or survive treatment because of the presence of a disability or particular condition.

- Initiate an ongoing process for reviewing crisis standards of care and medical rationing policies of states, healthcare systems, and hospitals in anticipation of other public health emergencies that will strain local, regional, or national resources, and provide technical assistance for compliance with disability nondiscrimination in the formulation of CSC and rationing policies.
- **HHS and FEMA** should require disability expertise and representation on federal pandemic planning committees, and ensure true inclusivity in all local, state and federal emergency responses for a wide range of disabilities and co-occurring conditions, including lesser known or nonvisible disabilities such as multiple chemical sensitivity, and disability-specific concerns such as including personal care assistants and direct support professionals in federal emergency measures for strengthening Medicaid and frontline healthcare workers during an emergency (e.g., authorization of overtime hours or hazard payment if providing assistance to a person with disabilities who is sick or has other direct care workers who are sick, distribution of virus tests and PPE, and so forth).
- **HHS, U.S. Census Bureau, FEMA**—Interagency Cooperation: Federal agencies including CDC, CMS, FEMA, and the U.S. Census Bureau, should collaborate and form a broader interagency work group to identify methods to efficiently collect functional disability information during public health and other emergencies in order to identify how many people with disabilities are affected (e.g., infection, illness, injury, hospitalization, death), whether they live in a type of congregate care facility or in the community or transition between them during the emergency, and whether they have HCBS needs. They should also develop methods to identify how HCBS workers are affected by public health or other emergencies (e.g., infection, illness, injury, hospitalization, death) to inform policies and actions that will be needed to maintain necessary HCBS during and after these emergencies. Data should be published on regularly updated publicly available websites.
- **HHS** should assume primary responsibility for implementing, monitoring, and enforcing the data collection requirements in Section 4302 of the ACA. Data should be collected at

Recommendations for Federal Agencies: *continued*

the smallest geographic level such as state, county, zip code, or institutional levels, using disability data collection tools such as current population survey questions included in the ACS, those recommended by the Washington Group on Disability Statistics, or other equivalent data collection measures developed through interagency cooperation. Disability data collection tools should also be further developed to better capture people with intellectual and developmental disabilities, communication disabilities, and other diagnostic or functional limitations that may be currently excluded from or undercounted by the ACS or Washington Group survey questions. The U.S. Census Bureau, the HHS, CMS, and the CDC should aggregate the data on a common website for use by researchers and the public.

- **HHS, working through the Health Resources and Services Administration** should assume primary responsibility for implementing and appropriately funding Section 5307 of the ACA,²³⁹ including establishing and developing criteria for grants, contracts, or cooperative agreements for developing and evaluating research, demonstration projects, and model curricula in cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities. HHS should identify effective best practices and model curricula identified through projects initiated under Section 5307 and mandate their use in health professions schools and continuing education programs to address systemic and implicit disability bias in the health professions.
- **NCHS** should work with state vital statistics offices to initiate revisions in the U.S. Standard Certificate of Death to include functional disability and HCBS consumer information in the demographic section of death certificates and obtain the approval of completed revisions from the HHS Secretary.
- **HHS/ACL, HHS/OCR, and DOJ** should work together to establish and fund a national healthcare technical assistance center to inform a range of healthcare providers on civil rights issues regarding patients with disabilities. The Center would provide healthcare providers, medical educators, professional associations, and public health authorities with information and trainings on implicit disability bias, the importance of policy modifications and reasonable accommodations to providing effective healthcare, and the critical role that support persons play in maintaining the health and functional capacity of people with disabilities. ACL could play a central coordinating role over the Center, either as an

(continued)

Recommendations for Federal Agencies: *continued*

independent entity or as an adjunct component of existing entities that provide disability expertise such as the regional ADA Centers, while both HHS OCR and DOJ can provide technical and legal expertise, given their overlapping regulatory authority over the gamut of healthcare entities and providers.

- **Department of Agriculture** should monitor and enforce physical, website, and procedural accessibility to ensure that people with disabilities are able to enroll in SNAP and fully use their SNAP benefits, including modifications needed by people with disabilities who may require grocery delivery and assistance during pandemics and public health emergencies. In addition, rather than require all persons with disabilities to meet the strict asset tests imposed on Supplemental Security Income and Social Security Disability Insurance payments, recognize persons with disabilities through broad-based categories for eligibility, for example, HCBS consumers as they are likely to have higher disability-related household expenses that make it harder to meet food expenses.

Recommendations for States

States should:

- Specify and adequately fund a designated state agency or entity that will take individual complaints, provide real-time technical assistance, and initiate investigations on allegations of discrimination and accessibility barriers by healthcare entities during public health emergencies, including communication accessibility, access to support persons and needed policy modifications and accommodations, and nondiscrimination in medical rationing and crisis standards of care.²⁴⁰
- Require hospitals, managed care entities, and healthcare systems operating in the state, including university teaching hospitals and systems, that are licensed, regulated, or certified in the state or that receive any state funding or that serve any Medicaid enrollees to include people with disabilities or disability advocates on their medical ethics committees and in the development, adoption, or revision of crisis standard of care or medical rationing policies.

Recommendations for States: *continued*

- State Departments of Public Health must strengthen ties with disability and community-based organizations such as independent living centers and aging and disability networks to build capacity to reach people with disabilities through trusted messengers if outreach is needed on newly developed or repurposed medications or treatments, and to strengthen the department's capacity to ensure full accessibility, including threshold languages, in its own outreach, emergency guidance, and logistical operations.²⁴¹

Recommendations For Additional Entities

- **Association of State Governors:** Develop a set of strategies, best practices, and data collection standards (including privacy concerns and addressing interoperability needs) for collecting functional disability information on residents across the full range of congregate living facilities that are licensed, certified, or otherwise recognized or funded by a state (e.g., psychiatric facilities, intermediate care facilities, board and care homes, group homes, and so forth).
- **American Medical Association:** Develop and disseminate mandated requirements and standards relating to disability rights and implicit bias training for physicians and related healthcare professions involved in setting public health emergency procedures, medical rationing, and standard setting. Such training should be a required component of continuing professional education. The American Medical Association should also encourage reporting and academic investigation that reveals health and healthcare disparities experienced by people with disabilities, including people of color with disabilities.
- **National Association of Insurance Commissioners:** Develop model disability data collections standards and best practices that state departments of insurance could enact as part of Market Conduct Annual Statement reporting requirements on healthcare insurers licensed or practicing in the state.

Chapter 2: Impact of COVID-19 on People with Disabilities in Congregate Care Facilities

COVID-19 Had a Devastating Impact on People with Disabilities in Congregate Care Facilities

No demographic in the United States experienced COVID-19 more dramatically than people living in CCFs. The way people in congregate settings live and receive care made the pandemic especially difficult to contain and, as a result, greatly increased the risk of exposure for residents and staff.

CCFs include LTCFs like nursing homes and assisted living facilities, and other congregate settings such as state psychiatric hospitals, intermediate care facilities for individuals with intellectual and developmental disabilities, board and care homes, and group homes. On the front lines of a fast-changing pandemic, CCFs reported staff shortages, inadequate PPE, inconsistent and slow testing, and limited space for resident isolation and

quarantine. Residents of CCFs also experienced extreme isolation due to COVID-related restrictions on visitors, and many died alone.

Most significantly, due to the difficulty of ensuring physical distancing, isolation, and quarantine in CCFs, rates of transmission and death from COVID-19 in these facilities were extraordinary. As of March 2021—a year into the pandemic—over one-third of all COVID-19

As of March 2021—a year into the pandemic—over one-third of all COVID-19 deaths in the United States occurred in LTCFs, including nursing homes and assisted living facilities. One hundred and eighty-one thousand individuals in LTCFs died from COVID-19, accounting for more than one-third of all COVID-19 deaths in the United States, from a group of individuals constituting less than 3 percent of the nation’s population.

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LTCFs, with nearly 35,000 facilities reporting known cases.²⁴³

However, these numbers do not account for cases and deaths in other types of CCFs for people with disabilities, like state psychiatric hospitals, intermediate care facilities for individuals with intellectual and developmental disabilities, board and care homes, and group homes.

Data from these other types of CCFs is less available, but what data exists indicates that residents and staff who lived and worked in other types of CCFs also had a heightened risk of contracting COVID-19 and of dying from the virus. One would expect the data in these facilities to be comparable to that in LTCFs, given the similarities in how they operate.

Living in a CCF exposes people with disabilities to the many individuals who enter the facility on a regular basis—including caregivers, other residents, and staff. A study of Connecticut nursing homes found that those with “more residents at the beginning of the pandemic and with greater shares of beds filled had significantly more cases and deaths per licensed bed than facilities operating at lower capacity . . . speak[ing] to the importance of density and intrafacility spread.”²⁴⁴ Moreover, nursing homes with higher staffing rates and a lower staff-to-resident ratio had fewer COVID-19 incidences and deaths.²⁴⁵ The risk of transmission based on density and traffic in and out is similar in all types of CCFs.

The high frequency with which residents and staff interact and the difficulty of practicing physical distancing within these facilities contribute to transmission.²⁴⁶ Consistent with these observations, a July 2020 report found

that people with intellectual disabilities residing in group homes were four times more likely to contact COVID-19, twice as likely to die than people with intellectual disabilities receiving care in noncongregate settings, and eight times more likely to die than the general population.²⁴⁷ Further, a recent study found that individuals admitted to a psychiatric inpatient setting faced an increased risk for infection and death compared with similarly situated individuals in the community.²⁴⁸

These risks may be heightened where residents have certain types of impairments that make them particularly vulnerable. For example, studies have shown higher rates of COVID-19 and death in people with intellectual disabilities,

including a recent study showing that people with intellectual disabilities are 2.5 times as likely as others to be diagnosed with COVID-19 and 5.9 times as likely to die

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from it.²⁴⁹ Similarly, a recent study published in the *Journal of the American Medical Association* found that individuals with a diagnosis of schizophrenia were 2.7 times as likely to die from COVID-19 as individuals without psychiatric diagnoses, controlling for demographic factors such as age, race, and sex and for known medical risk factors.²⁵⁰

Staffing shortages further exacerbated the vulnerabilities of CCF residents and staff. As one state human services official explained, “Pre-COVID, we have had staffing shortages in [congregate care and group home] settings across Minnesota, but what we’re experiencing right now is something different . . . as staff test positive for COVID-19, they’re having to

quarantine, which leaves care facilities in a precarious position.”²⁵¹

All types of CCFs reported experiencing the same unprecedented staff shortages due to COVID-19. A state-run psychiatric hospital in Pennsylvania was so short-staffed that even after closing a patient ward on weekends and some weekdays, the hospital still could not meet a 1:4 aide to patient ratio, the professional recommendation.²⁵² Some states looked to staffing agencies to recruit emergency workers, others called in the National Guard as a last resort.²⁵³

Where visitation restrictions combined with staff shortages, facilities altered the provision of care, including fewer therapies and greater restrictions on the mobility of residents within facilities. As a result, CCF residents experienced increased rates of isolation, depression, and physical deterioration.²⁵⁴ In Connecticut, “despite differences in methods and frequency of visitations, nearly all family members reported the physical and emotional health of residents declined significantly without frequent, in-person interactions with the family members and caregivers who had provided critical support for activities of daily living.”²⁵⁵

Limited access to testing and PPE worsened the already dire situation in CCFs. A fall 2020 investigative report from Senator Elizabeth Warren (D-MA) found that none of the 10 large behavioral health treatment program operators surveyed “conduct[ed] routine daily or weekly testing of staff or patients at all their facilities” and “experie[n]d turnaround times of a week or more for test results.”²⁵⁶ These facilities were “generally not able to perform routine testing of asymptomatic individuals” in line with CDC recommendations for CCFs. Only two of the 10

providers reported testing new patients upon admission. One provider attributed limited testing to the “difficulty of obtaining testing supplies” and reliance on “local health departments.”²⁵⁷

Another provider shared that “as a sub-acute provider, our company facilities and staff seemed to be near the bottom of the list to receive both assistance with emergency supplies or financial assistance,” so they had to rely on “their own supply chains for PPE, without the assistance of local health or emergency response officials.”²⁵⁸ The report also found that “most providers reported shifting care into telehealth formats and using technology to arrange virtual visits and group meetings,” yet difficulties “obtaining reimbursement from commercial insurers for services provided by telehealth” remained a large barrier to care.”²⁵⁹

In sum, the COVID-19 pandemic exposed anew many vulnerabilities of our congregate care systems, including that congregate settings placed people with disabilities at a high risk of infection, serious illness, and death. While vaccinations greatly reduced the death tolls in CCFs across the country, the unpredictability of the virus, difficulties of getting vaccines to some facilities, and high rates of vaccine hesitancy among many facility staff led to outbreaks at dozens of facilities even after vaccinations occurred at the facilities.²⁶⁰

People with Disabilities were Stuck as Diversions and Transitions from CCFs Slowed to a Near Halt

While the dangers imposed by the pandemic in CCFs created an urgency to transition residents to their own homes or other noncongregate community settings to keep people safe and to allow for distancing within facilities, the opposite

happened. Due to the pandemic’s impact on community service providers like direct support professionals, assertive community treatment team staff, case managers, employment services providers, and peer support workers, transitions and diversions in most places ground to a halt, even as unprecedented efforts were made to reduce the census of many jails and prisons due to COVID-19 transmission risks.²⁶¹ The National Governors Association observed that while at least some states continued facilitating discharges from state psychiatric hospitals, others “halted or slowed discharges.”²⁶²

Among other things, community service providers were unable to enter CCFs to engage and assist residents

with transitions to the community, and in many cases had fewer staff available due to staff illness, quarantining after exposure to the virus, or family or childcare issues. While Centers for Medicare & Medicaid

Services (CMS) guidance allowed essential workers into nursing homes and other LTCFs, many states did not designate community service providers and individuals conducting “in-reach” to engage people with disabilities in institutions and assist them with transition as essential workers. In North Carolina, in-reach workers helping people with psychiatric disabilities transition out of adult care homes were designated as essential workers able to enter the facilities as a result of advocacy by the court monitor in an *Olmstead* settlement, but that designation took four months to accomplish.²⁶³

Complicating the situation, many nursing homes and group homes for people with IDD/DD could not safely readmit people who needed to be temporarily hospitalized during the pandemic. In New York, for example, the “OPWDD [Office for People with Developmental Disabilities] issued guidance instructing providers to accept individuals only if they could safely accommodate them in the group home” such that “people who could not be safely accommodated either remained at the hospital or were served in one of the over 100 temporary sites established for COVID-19 recovery efforts.”²⁶⁴

While telehealth was used to facilitate communication between community providers

and individuals in many CCFs, CCFs often lacked reliable internet access, tablets and other devices were often difficult for individuals to use, and residents were often not trained in how to use them. This lack of technology and

training impaired provider access to residents, and isolated residents from communication with loved ones and other forms of social interaction. Moreover, many activities essential for community transition that could have been conducted virtually were often not—for example, in-reach activities, assessments and service planning by community providers, and tours of community housing.²⁶⁵

In response to deaths in CCFs from COVID-19, advocates filed lawsuits seeking to quickly move people out of state psychiatric hospitals in the District of Columbia, California, Connecticut, and Massachusetts where high rates of COVID-19

[A]dvocates filed lawsuits seeking to quickly move people out of state psychiatric hospitals in the District of Columbia, California, Connecticut, and Massachusetts where high rates of COVID-19 transmission and deaths were occurring.

transmission and deaths were occurring.²⁶⁶ A mental health expert in one of these cases observed:

State psychiatric wards are typically designed to hold between twenty to forty patients per unit. Having that many people living in rooms with two or more other patients and interacting in a confined area with a large number of staff is obviously not consistent with “social distancing.” . . . Even if congregate care facilities could be rendered safe by observance of CDC guidelines, it would not happen. There is no effective way to enforce social distancing in a psychiatric ward. . . .

Psychiatric units are designed to facilitate staff and patient interaction. Patients are encouraged with a variety of incentives to attend group treatment, eat, socialize, and watch television together in an open area, attend community meetings, and exercise as a group. Avoiding the isolation that is compelled by the virus is so ingrained in treatment protocols that licensing standards typically prohibit staff from requiring patients to stay in their room unless they are an imminent danger to themselves or others.”²⁶⁷

Some of this litigation resulted in better infection control practices in the hospitals. It did not, however, succeed in securing facility census reductions, in part because vaccination efforts and decreases in COVID-19 outbreaks made this relief more difficult to secure.²⁶⁸

These cases demonstrate the difficulty that disability advocates have experienced in trying to secure relief that would increase the pace of discharges from institutional settings, even where deaths from COVID-19 in institutions reached alarming rates.

COVID-19 Exacerbated Existing Civil Rights Violations Involving Needless Institutionalization and Segregation

The disability community and disability advocates have long fought to reduce the use of congregate settings for people with disabilities. Individuals with disabilities overwhelmingly thrive in the

[S]erving people at home rather than in a CCF, along with other safety precautions, such as PPE, helps to control the spread of the virus.

community when they are provided HCBS. The ADA and its integration mandate require that public entities administer services to people with disabilities in the most

integrated setting appropriate, unless doing so would fundamentally change their service systems.²⁶⁹ HCBS provides people with an opportunity to live full lives in the communities where they and their support systems are located, and, as we learned during COVID-19, serving people at home rather than in a CCF, along with other safety precautions, such as PPE, helps to control the spread of the virus.

In 1999, the U.S. Supreme Court affirmed that people with disabilities have a legal right to community-based care. The Court found that needless institutionalization “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”²⁷⁰ In addition, “confinement in an institution severely diminishes the everyday

life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”²⁷¹ As such, the needless segregation of people with disabilities in institutional settings is a form of disability-based discrimination. *Olmstead* established that people with disabilities have the right to receive a public entity’s services in the most integrated setting.

The impact of COVID-19 on CCFs meant that people with disabilities not only experienced needless segregation on a widespread basis, but now that segregation also came with serious risks of infection and death from COVID-19. Moreover, the pandemic’s impact in slowing down discharges and diversions from CCFs and hampering the community service system meant that people with disabilities had little chance of achieving their right to community integration and were stuck in CCFs that in many cases had become dangerous.

Even for individuals who were class members in *Olmstead* settlement agreements that afforded them specific rights to transition out of CCFs, enforcing those rights became an enormous challenge as states fell far behind on the obligations in these settlements and were unable to conduct certain activities required by the settlements due to the pandemic, including activities that required face-to-face contact or that could not be conducted through telehealth because of poor internet access, lack of equipment, the inability to train individuals in how to use the equipment, or other issues.

In one state, community providers advocated for the state to halt diversion and transitions under two *Olmstead* settlements because they said they could not maintain adequate staffing and considered all individuals transitioning out of these

institutions as “high-risk” for community living in light of the providers’ capacity concerns. Providers also expressed concerns about the impact of loneliness on individuals living in the community if providers were not spending as much time with them, even though isolation was even more dramatic in CCFs, particularly with staff reductions during the pandemic, and some facilities prohibited residents from even going outside.²⁷² Despite budget increases to support diversion and transition, including the hiring of additional staff and allowing telehealth for services, and despite the fact that hundreds of individuals died of COVID-19 in the nursing homes at issue in one of these settlements, transitions under the settlements were largely halted. During 2020, the rate of transitions of individuals from these institutions was the lowest since the settlements had begun more than 10 years earlier.²⁷³

The Biden Administration DOJ is reinvigorating the federal government’s *Olmstead* enforcement efforts. In June 2021, it entered an *Olmstead* settlement with Maine’s Department of Health and Human Services requiring an “exceptions process” allowing individuals to show that modifying Maine’s caps on HCBS Medicaid waiver costs and/or service amounts is necessary to ensure that people with intellectual disabilities or autism spectrum disorders can receive adequate and appropriate services in the most integrated setting appropriate to their needs. The settlement resolved a complaint by a man with intellectual disabilities who, as a result of the state’s waiver caps, was at risk of having to move to a congregate setting to access needed services.²⁷⁴ One month earlier, it issued a findings letter detailing *Olmstead* violations by Alameda County, California, in placing people with psychiatric disabilities at risk of institutionalization

and incarceration by failing to provide needed community-based services.²⁷⁵

More Could Have Been Done to Discharge and Divert People with Disabilities from CCFs during the Pandemic

While the pandemic created real challenges for transitioning and diverting individuals from CCFs, in most instances many steps could be taken to work around these challenges. For example, North Carolina, to promote compliance with an *Olmstead* settlement, developed protocols for local management entities in order to quickly transition people out of state psychiatric hospitals, including challenging providers to report barriers to the state for remediation. As a result, the state successfully diverted 40 percent of people from entering board and care facilities called “adult care homes.”²⁷⁶ Though transitions out of these facilities did not reach prepandemic levels, they continued despite barriers and obstacles with visitation and transportation. The state transitioned and diverted 331 individuals into supported housing between March 1 and December 31, 2020, and the number of people who stayed in the community after exiting adult care homes remained steady.

In addition, a number of individual Centers for Independent Living led efforts to transition individuals out of CCFs. These centers took advantage of funds directed to independent living centers through the Coronavirus Aid, Relief,

and Economic Security Act of 2021 (CARES) as well as other emergency resources to quickly set up temporary housing and transition people out of congregate settings. These innovative partnerships provided potential solutions to long-standing problems with transition and diversion, and investments should continue beyond the pandemic.

In Denver, Atlantis Community, Inc., an independent living center, launched a pilot program called “the Emergency Relocation of People with Disabilities out of Congregate Settings” to transition people out of CCFs including acute care hospitals, assisted living

facilities, nursing homes, congregate shelters for people experiencing homelessness, hospitals, and physical rehabilitative hospitals. The program “started with the basic idea of gathering a group of 9 people and moving them into a hotel for a minimum 14 day

quarantine period while services, supports, and housing are set up with the individuals for more permanent housing in the community.”²⁷⁷ Using a combination of funds from CARES Act, Medicaid, state housing vouchers, and private foundations and donors, Atlantis also hired and trained (and housed) people experiencing homelessness as caregivers for the individuals transitioning. Every person who participates in the pilot program is set up with a state housing voucher and supported in finding long-term, sustainable housing. Roads to Freedom independent living center in Pennsylvania used a similar model of moving people from nursing homes to hotels and

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then to more permanent housing, using CARES Act, FEMA funds, grants, and other funding. Both of these programs found that once individuals were transferred to a hotel, they were able to secure permanent housing of the person's choice within approximately a month or one and a half months.²⁷⁸ In the Denver program, state rental subsidies paid for community housing. The Pennsylvania program used federal subsidies, including Section 8 Housing Choice Vouchers, Section 811 supportive housing for people with disabilities, and public housing. In both programs, Medicaid paid for supportive services.

Experts in one of the cases seeking to reduce the census of institutions during the pandemic stated: "Based on our years of experience managing psychiatric hospitals and other facilities, planning for the successful transition of individuals with serious mental illness from state psychiatric hospitals can be accomplished, even under these circumstances, through individualized planning and using all available resources, including natural supports."²⁷⁹ Experts in these cases recommended that discharge determinations be made using a different standard than in ordinary times, ensuring that individuals' basic needs will be met in the community; that facilities explore whether residents have family or friends who could house them if provided with appropriate supports; that available capacity in community programs be used to permit discharges; that temporary housing in hotels be used if more permanent housing options are not immediately available; that community providers be included in

the process of assessing discharge potential and planning for transition; and that additional funding to enhance community services be considered.²⁸⁰

Concerns about isolation and loneliness in the community should not be used as an excuse to keep people institutionalized; similar concerns exist in institutional settings, particularly during a pandemic.²⁸¹ Providing individuals with technology to more easily communicate can reduce isolation and can also help with telehealth services and virtual transition efforts.²⁸² For example, the California Foundation for Independent Living Centers purchased and distributed laptops to people with disabilities living in the community and agreed to pay

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internet costs for several months.²⁸³ These tablets "allow[ed] people to take cooking classes, peer classes, and even attend a disability athletics fair."²⁸⁴ Similarly, many peer support providers have transitioned

efforts to Zoom to continue engagement during the pandemic. In North Carolina, community providers used Zoom to communicate with psychiatric facility social workers to facilitate quick discharges of individuals to the community.²⁸⁵ One North Carolina community service provider employed robots to assist individuals in the community with medication and case management during the pandemic.²⁸⁶

Unfortunately, efforts to move people into the community remained sparse because little was done on a state level to facilitate discharges and diversions from CCFs, and most people in congregate settings at the start of the pandemic remained there.

Limited Federal Guidance for CCFs Hindered Responses During Early Days of COVID-19

As the federal government wrestled with the COVID-19 pandemic in its early days, the CDC issued general guidance instructing how nursing homes and healthcare settings should control infection and ensure equitable delivery of care but not for other CCFs, like group homes. CDC reports issuing general guidance for nursing homes and healthcare settings as early as January 2020 and on March 1, 2020.²⁸⁷ CMS issued a memo on March 13, 2020, and a toolkit on April 4, 2020, with best practices for nursing homes, and, together, CMS and CDC issued recommendations on April 2, 2020, concerning COVID-19 transmission in nursing homes.²⁸⁸ A March 30, 2020, CMS guidance concerning intermediate care facilities for people with intellectual disabilities and psychiatric residential treatment facilities addressed infection control and prevention practices to prevent the transmission of COVID-19 in these facilities.²⁸⁹ These guidance documents focused mainly on infection control, including recommendations for visitor restrictions, and emphasized the importance of social distancing.²⁹⁰ In many facilities, compliance with this distancing guidance would require the facilities to discharge and divert people, but CDC did not specifically discuss the need to increase discharges and diversions to community settings.

CDC also published guidance to administrators of assisted living facilities on April 16, 2020.²⁹¹ This guidance, again, focused almost exclusively

on basic infection control within facilities—including recommendations that facilities mandate residents wear cloth face masks, regularly disinfect, cancel group activities, implement social distancing, “restrict . . . all non-essential personnel,” and “ask residents not to leave the facility except for medically necessary purposes.” The guidance also instructed facilities to isolate suspected positive individuals in their rooms or, where facilities could not provide adequate care, to transfer individuals to another location (e.g., alternate care setting, hospital) that was equipped to adhere to recommended infection prevention and control practices.²⁹²

Despite the widespread deaths of individuals with disabilities in CCFs during the first weeks of the pandemic—by April 23, 2020, more than 10,000 deaths had been reported in LTCFs in the 23

By April 23, 2020, more than 10,000 deaths had been reported in LTCFs in the 23 states that publicly reported death data for these facilities.

states that publicly reported death data for these facilities²⁹³—it was not until May 28, 2020, that CDC released targeted guidance for community-based congregate settings. In CDC’s “Guidance for Group Homes for Individuals with Disabilities” and, later, its “Guidance for Shared or Congregate Housing,” CDC acknowledged that some individuals with disabilities may be unable to socially distance or wear face masks and recommended that facilities consult with local “Departments of Behavioral Health and Developmental Disabilities” for “information on and resources for behavioral techniques.” The guidance recommended that facilities “plan for essential outings,” but focused only on resident use of public transportation to continue working

or attending medically necessary medical appointments, not to partake in diversion or transition efforts. CDC also recommended that CCF residents “continue to receive medical care for underlying conditions and evaluation or new symptoms or illnesses,” including by investigating where “providers . . . have new ways to be contacted or new ways of providing appointments,” like telehealth.

Though CDC revised its prior recommendations to fully restrict the mobility of CCF residents, it continued to recommend that CCFs only allow “essential” visitors, which contributed to limited access for necessary direct support workers and community service providers.²⁹⁴ The dividing line between essential and nonessential visitors proved murky, and, in practice, was often a difficult one for facilities to manage.²⁹⁵ While facility staff and personal care attendants were considered essential and therefore allowed into facilities to provide necessary care to residents, community transition support workers were not always considered essential, which slowed transitions out of CCFs. CDC also said facilities should “avoid transferring residents with disabilities to alternate settings, whenever possible, as a solution to staffing issues,” which contributed to the hampering of moving individuals into lesser density community-based settings.²⁹⁶

Similarly, states offered little guidance for CCFs beyond infection control procedures within the facilities. For example, New York issued guidance for congregate residential settings, but the guidance focused on policies for group environments, social distancing, infection control, visitation, and testing.²⁹⁷ Pennsylvania

issued guidance for individuals in personal care homes, assisted living residences, and private intermediate care facilities.²⁹⁸ The guidance mostly provided guidance for infection control, but also detailed the allowance of compassionate care visitation if a resident has a “significant change” in condition.²⁹⁹

Until the early months of 2021, under the Biden Administration, there was little public recognition that without efforts to move people out of crowded institutional or congregate settings, infection control efforts that relied primarily on social distancing would continue to leave CCF residents and staff at risk.

Initial federal guidance for emergency use vaccines also failed to prioritize all residents of CCFs equitably. The National Academies of Science, Engineering, and Medicine’s “Framework for Equitable Allocation of COVID-19 Vaccination” tiered groups for vaccine distribution in priority order, including as key populations “people who live and/or work in congregate settings,” “older adults living in senior facilities,” and “long-term care facility residents.”³⁰⁰ Phase 1a, making vaccination available to the highest priority group, included “high-risk health workers” that “are involved in direct patient care.”³⁰¹ Phase 1b, the next phase, “focuse[d] attention on two groups that [we]re particularly vulnerable to severe morbidity and mortality due to COVID-19: (1) people of all ages with comorbid and underlying conditions that put them at significantly higher risk and (2) older adults living in congregate or overcrowded settings.”³⁰² However, even though the guidance recognized the risk in congregate settings, the guidance left until Phase 2 “group homes . . . for people with

disabilities, including serious mental illness, developmental and intellectual disabilities, and physical disabilities or in recovery, and staff who work in such settings” despite similarities in transmission rates and population risks across these congregate settings.³⁰³ Moreover, the guidance did not detail whether staff or residents should be prioritized first, how residents with different disabilities in different types of CCFs should be prioritized based on underlying risk, or how facilities could ensure the continued availability of vaccines for new residents. In response, many states vaccinated CCF staff much earlier than residents, similarly to the manner in which some states made COVID-19 testing available more frequently to CCF staff than residents.³⁰⁴

The Biden Administration Brought New Focus to People with Disabilities in CCFs, Though Many Steps Came Late and Others Remain Undone

President Biden issued a National Strategy for the COVID-19 Response and Pandemic Preparedness immediately upon assuming office. Among other things, it included a commitment to make “significant investments in home and community based services,” and, through HHS, CMS, and ACL, identify “opportunities and funding mechanisms to provide greater support for individuals receiving home and community based services, with particular attention to people with disabilities and the home care workforce crisis.”³⁰⁵

On January 21, 2021, President Biden issued an Executive Order directing the federal government to take a more active role in providing assistance to CCFs.³⁰⁶ The Executive

Order requires the Secretaries of Defense, HHS, and Veterans Affairs to “provide targeted surge assistance to critical care and LTCFs, including nursing homes and skilled nursing facilities, assisted living facilities, intermediate care facilities for individuals with disabilities, and residential treatment centers in their efforts to combat the spread of COVID-19.”³⁰⁷ Since then, CDC has updated its guidance for LTCFs to include procedures for handling PPE, visitation, and physical distancing with “a description of quarantine recommendations including resident placement, recommended PPE, and duration of quarantine,”³⁰⁸ and updated its guidance for individuals with disabilities in group homes,³⁰⁹ but neither recommends facilitating transitions out of these facilities or describes strategies to do so.

HHS’s Office for Civil Rights issued a guidance prohibiting discrimination in COVID-19 vaccination programs on April 13, 2021,³¹⁰ and around the same time, the Administration for Community Living issued strategies for improving equitable vaccine access for older adults and people with disabilities.³¹¹ These guidance documents were helpful but did not specifically address individuals in CCFs.

The Biden Administration engaged in significant interagency coordination to identify ways to pair services and housing resources to promote transitions and diversions of people with disabilities and older adults from institutions, particularly in light of the virus transmission that occurred and could recur in the future.

The federal government first addressed legal requirements to transition individuals from CCFs during COVID-19 almost a year into the pandemic. On December 17, 2020, CMS issued guidance stating that community service providers “should

have direct access to service recipients prior to discharge;" that facilities should use telehealth strategies to engage outside providers in transition planning, developing relationships, and facilitating transition if visitation restrictions are in place for these providers; and that institutional settings should work together with community providers to ensure that individuals who no longer need or want facility-based care can transition to the community, including through the use of virtual technology for team meetings, client engagement, service planning, and apartment walk-throughs.³¹² On February 10, 2021, CMS issued guidance noting that federal disability rights laws *may* require facilities to permit entry of support staff to facilitate an individual's transition from an institutional setting to the community.³¹³ The guidance, later updated on June 3, 2021, says that under federal law, "facilities may be required to permit entry of a designated support person to meet an individual's disability-related needs, including, as may be appropriate in some cases, supporting an individual's transition from an institutional setting into the community, and offering strategies as well for allowing safe outdoor visitation."³¹⁴ Despite CMS's acknowledgment that visitation restrictions should not impede community providers from entering facilities to provide transition support, the guidance could be clearer that these providers

Despite CMS's acknowledgment . . . , the guidance could be clearer that these providers should be considered "essential care providers."

[T]he federal government has not fully addressed the need for federal guidance to facilitate transitions and diversions from CCFs.

should be considered "essential care providers." The guidance also could have clarified what newly available funding sources could help fund transition-related costs.

On April 2, 2021, DOJ issued a statement

recommending "services in home- and community-based settings instead of in long-term care facilities" and requiring "governments" to "comply with the ADA

and Section 504."³¹⁵ Moreover, the guidance acknowledged that these HCBS services "can satisfy the ADA integration mandate by preventing unnecessary institutionalization . . . [and] also reduce COVID-19 risk."³¹⁶

Though the spring 2021 guidance documents from CMS and DOJ were necessary, they came too late; the worst of the pandemic had already occurred and had taken the lives of thousands of CCF residents during the previous year. Furthermore, by the time they were released, the United States had made vaccines widely available to this population. An earlier investment

in infrastructure and guidance to move people out of these high-density settings and requiring compliance with *Olmstead* during the pandemic could have

prevented mass casualties and infection.

Moreover, the federal government has not fully addressed the need for federal guidance to facilitate transitions and diversions from CCFs. While rates of COVID-19 transmission in CCFs

have dramatically decreased, such guidance is important for the future. No federal guidance has detailed with specificity how HCBS could facilitate transitions and diversions of individuals from CCFs during a pandemic, nor how states could reduce census within facilities by enhancing HCBS, despite similar CDC guidance recommending release of individuals from correctional and detention facilities to prevent intrafacility transmission.³¹⁷ Guidance could have detailed how providers could use telehealth for transition services and could highlight temporary discharge options like motels or other housing.

For example, to speed up transitions amid staff and provider shortages, CMS guidance could have identified strategies for discharging individuals with disabilities from CCFs to temporary housing—possibly with a lower but critical level of support initially, affording additional time to secure permanent housing and full supportive services. Guidance could have considered subsidies or financial stipends for friends and family of persons in CCFs to provide short-term housing and care while permanent supports were found. It could also have given states a framework for innovative ways to use emergency funds and existing resources to fund other short-term, emergency housing like hotel stays, so people could be safely moved from CCFs while providers were given a window to find stable housing.

The full extent of vaccinations among CCF residents is not known due to inadequate data

collection for facilities other than LTCFs. Around 3 million people in LTCFs were fully vaccinated, but, even so, the federal program bringing vaccines to nursing homes missed around half of the staff working within those facilities, according to a March 2021 report.³¹⁸ More data is needed to understand where and how vaccines should have been prioritized differently.

On May 13, 2021, CMS issued an interim final rule requiring intermediate care facilities for individuals with intellectual and developmental disabilities, along with LTCFs, to offer residents and staff vaccinations and to

collect and report data on these vaccinations to CDC.³¹⁹ CMS solicited public comment on whether it would be feasible to impose similar requirements on other facilities including psychiatric hospitals, psychiatric residential treatment facilities, forensic hospitals, adult

foster care homes, group homes, assisted living facilities, supervised apartments, and inpatient hospice facilities. NCD believes that all of these facilities should be required to comply with these rules.

During future pandemics and national emergencies, guidance is needed at every step of the way for *all* types of CCFs, not just nursing homes and LTCFs. The guidance must detail how facilities can accelerate discharges and ensure diversion and how states can pay for those efforts—both by increasing the availability of funds and detailing ways in which

During future pandemics and national emergencies, guidance is needed at every step of the way for all types of CCFs, not just nursing homes and LTCFs. The guidance must detail how facilities can accelerate discharges and ensure diversion . . .

those funds can be used most efficiently to provide equitable care.

Financing Community Services and Housing to Enable Transitions from CCFs

Understanding the key funding sources available to expand community services and housing is critical to accelerating discharges and diversions from CCFs. Medicaid is the primary payer of HCBS for people with disabilities. Key Medicaid authorities for financing these services include HCBS waiver services, the Medicaid rehabilitation option (which covers assertive community treatment, peer support services, mobile crisis, and other crisis services), personal care services, home health services, intensive case management, transition services, tenancy support services, and supported employment.

The Medicaid “Money Follows the Person” program also funds HCBS for people with disabilities who have been institutionalized for at least 90 days, but states have had difficulty relying on it due to short reauthorization periods,³²⁰ and features of the program have made it largely unavailable to people with psychiatric disabilities.

HCBS services were already in short supply before the pandemic. For example, most states’ HCBS wait lists averaged around three years,³²¹ and community mental health services were in similarly short supply. Additionally, the Trump Administration weakened its enforcement of the Medicaid HCBS “Settings Rule,” which is designed to ensure that scarce resources

designated for HCBS are provided in integrated community settings, and not in segregated settings that isolate people.³²² The Settings Rule has been important in expanding opportunities for individuals with disabilities to live, work, and receive services in integrated settings and thus in reducing some COVID-19 risks. CMS’s enforcement in recent years has been less assertive, however, and its new policies have weakened the impact of the rule. In 2017, CMS extended the deadline for states to come into full compliance with the rule by three years, from March 2019 to March 2022,³²³ and in 2020 CMS extended the timeline by another year due to COVID-related issues.³²⁴ In 2019, CMS issued guidance making a number of changes

Medicaid is the primary payer of HCBS for people with disabilities. . . . [A]s of July 2021, there are more than 850,000 people with IDD/DD on waiting lists for HCBS services.

allowing states to avoid federal scrutiny of whether federal HCBS funds are appropriately used for settings that are presumptively institutional in nature but for which states seek

HCBS funding.³²⁵ Had the Settings Rule been in full effect during the pandemic, persons with disabilities may have had more opportunities to secure community-based services to transition from or avoid placement in a CCF. The Trump guidance should be reversed, and CMS should take a more active role in scrutinizing which settings meet the requirements of the rule.

As described above, the pandemic’s impact on community service providers made HCBS services even more difficult to access. In addition to these services, housing subsidies are critical to ensure that people with disabilities can transition or be diverted from CCFs. A lack of housing is often the biggest barrier to

transition. Many states have programs providing state rental subsidies as part of supported housing. In addition, federal housing funding streams are often used, including HUD’s Housing Choice Vouchers (formerly known as “Section 8” housing), “Section 811” supportive housing vouchers for people with disabilities, “Mainstream vouchers” for nonelderly people with disabilities, and Continuum of Care subsidies to house homeless individuals. The availability of both federal and state rental subsidies falls far short of the need. As a result, there are nearly 400,000 people with disabilities living on the streets, in shelters, and another 200,000–300,000 people with disabilities in institutional settings.³²⁶ Further, as of July 2021, there are more than

850,000 people with IDD/DD on waiting lists for HCBS services.³²⁷

According to one report, “federal rental subsidy programs administered by the U.S. Department of Housing and Urban Development (HUD) currently reach only 35 of every 100 extremely low-income (ELI) households. . . . This shortfall translates into long waiting lists at Public Housing Agencies (PHAs) and affordable housing developments, and a critical shortage of permanent supportive housing (PSH) opportunities for people with significant disabilities who have SSI-level incomes.”³²⁸

Congress has made available new funding available for HCBS and housing in its COVID-19 relief legislation, most significantly in the American Rescue Plan Act (ARPA).³²⁹ However, it is incumbent upon state and local governments to take advantage of these funds to expand their ability to transition and divert people with

disabilities from CCFs. States also have the ability to use certain Medicaid flexibilities during an emergency to cover services that would otherwise not be reimbursable—including “Appendix K” waivers for Medicaid HCBS waivers as well as waivers permitted under Section 1135 of the Social Security Act.

Enhanced Medicaid Funding for HCBS

Increased funding for HCBS is critical to speed up the rate of transitions out of congregate settings for people with disabilities. HCBS are health services “designed to enable people to stay in their homes, rather than moving to a facility for care.”³³⁰ For community providers who were hit hard by the pandemic including with staff

shortages, expenses of acquiring PPE, telehealth equipment, vehicle shields, and other necessary supplies, additional funding that

could be used to provide HCBS and cover such supplies and extra staffing was key to shore up their ability to function and to expand. ARPA provided \$12.7 billion to states for HCBS—including home healthcare, personal care, habilitation services, supported employment, and rehabilitative services, among other services. Congress provided a 10 percent increase in federal Medicaid reimbursement for these services for one year, from April 2021 through March 2022. If states choose to use this newly available funding, they must use it to supplement current HCBS spending.³³¹ This ensures that states do not reduce their financial investments in HCBS as they receive an influx of federal funds; the funds must be used to add to the state’s existing investments. The Act also provided enhanced federal Medicaid

A lack of housing is often the biggest barrier to transition [to the community].

reimbursement for mobile crisis services for a three-year period beginning in April 2022.

Congress also extended the Money Follows the Person program for three years in the Consolidated Appropriations Act in December 2020.³³² Money Follows the Person “provides states with enhanced federal matching funds for services and supports to help . . . people with disabilities move from institutions to the community” and “was designed to . . . increase the use of home and community-based, rather than institutional, long-term care services.”³³³

Using Medicaid “Appendix K” and Section 1135 Waivers to Cover Family Caregiver Support

Many states have used “Appendix K” waivers, which may be used to modify Medicaid HCBS waivers during an emergency, to cover services that they ordinarily would not cover. Appendix K waivers, which must be approved by HHS, enable

states to “pay legally responsible relatives to provide care that is ‘extraordinary’” and that is “necessary in order to prevent the beneficiary from being institutionalized.”³³⁴ For example, states could expand eligibility for community services by increasing flexibility for payment to family caregivers and by temporarily modifying minimum provider qualifications. States could also use these waivers to increase the amount they currently pay home caregivers and to provide them with PPE. As of April 19, 2021, 39 states were using Appendix K waivers to pay family caregivers.³³⁵ The use of Appendix K has helped to prevent the transmission of COVID-19.

Likewise, “Section 1135” waivers can be used during emergencies to temporarily halt certain requirements for providers of home healthcare. As of April 19, 2021, 14 states were using Section 1135 waivers to pay for personal care provided by legally responsible family caregivers.³³⁶ By keeping family members together and out of congregate settings, the use of Section 1135 to pay for family caregivers, like Appendix K, has helped to prevent transmission of COVID-19.

One flexibility that CMS commonly granted in Section 1135 waivers is a waiver of preadmission screening (PASRR) requirements to ensure that individuals with psychiatric and intellectual disabilities are not inappropriately admitted to nursing homes. As it is, these requirements have had limited effectiveness in stopping nursing home admissions of individuals who could live in

more integrated settings, and waiving them only increases needless institutionalization and exposes more

people with disabilities to risks of coronavirus transmission.

FEMA Reimbursement for Emergency Housing

The Federal Emergency Management Agency (FEMA) quickly became a leading source of funding for housing assistance grants. The main source of FEMA funding for housing relief is Category B Public Assistance under the Stafford Act.³³⁷ The CARES Act added supplementary funding to Category B Public Assistance and enhanced Emergency Food and Shelter Program grants. By an Executive Order dated February 2, 2021, President Biden increased the federal

match to 100 percent of approved expenses (up from the usual 75 percent rate) for work through September 30, 2021.³³⁸ FEMA Category B grants can be made to states, territories, tribes, and local governments if the area is under a public health order that recommends noncongregate housing to address COVID-19 in a target population. According to FEMA, target populations may include, for example, people who test positive for COVID-19 but do not require hospitalization, people who have been exposed to COVID-19, and individuals who are high-risk and require physical distancing as a precautionary measure.³³⁹ Localities may then use Category B funds to reimburse the cost of renting hotels, motels, and “other forms of non-congregate sheltering” to house individuals at risk of homelessness.³⁴⁰

At least four states—California, Pennsylvania, Connecticut, and North Carolina—received approval for FEMA Category B funds to provide noncongregate housing to a target population during the pandemic, which could include, “those who test positive for COVID-19 who do not require hospitalization but need isolation (including those exiting from hospitals); those who have been exposed to COVID-19 who do not require hospitalization; and asymptomatic high-risk individuals needing social distancing as a precautionary measure, such as people over 65 or with certain underlying health conditions (respiratory, compromised immunities, chronic disease).”³⁴¹ California and Pennsylvania applied

for and were granted funds for noncongregate sheltering for the groups outlined in FEMA’s target populations.³⁴² North Carolina expanded the target population to also include “those whose living situation makes them unable to adhere to social distancing guidance.”³⁴³ Finally, Connecticut’s approved application broadly extended to cover noncongregate housing for individuals currently living in “at-risk facilities such as group homes, nursing homes, long-term care sites, and alternative care facilities” and “homeless individuals in congregate shelters.”³⁴⁴

In the fall of 2020, independent living centers

reported that FEMA funds were difficult to access during the pandemic, sometimes because they were allocated to other entities early on and also because independent living centers would have to contract with a local agency or a county than directly with a state, to access Category

Category B funds offer an important temporary solution for moving people out of CCFs and into supported housing quickly while more permanent housing is found, but recipients cannot use the funds for the wrap-around services that individuals in temporary housing need.

B funds covering the areas in which they worked.³⁴⁵ As an example, Roads to Freedom, the Center for Independent Living of North Central Pennsylvania, entered into an agreement with the county to receive FEMA Category B funds to transition people with disabilities from congregate settings. FEMA acknowledged that these funds could be used to transition people with disabilities from congregate settings to noncongregate settings about seven months later.

While Category B funds offer an important temporary solution for moving people out

of CCFs and into supported housing quickly while more permanent housing is found, but recipients cannot use the funds for the wrap-around services that individuals in temporary housing need. For example, FEMA explicitly disallows subsidies for case management and mental health counseling, and states must apply separately for sheltering subsidies and crisis counseling funds. Additionally, Category B funds provide only for *temporary* housing. Other federal subsidies are needed to ensure permanent, supportive housing for individuals with disabilities.

The CARES Act also provided \$200 million to FEMA's Emergency Food and Shelter Program (EFSP), which is not contingent on a local disaster declaration.³⁴⁶ Emergency Food and Shelter Program grants reimbursed 30-day stays in noncongregate housing and sheltering transportation costs.

New Funding for Housing

Congress also appropriated significant new funding for federal housing programs in its COVID-19 relief packages. Most of these funds are targeted to individuals who are homeless or at risk of homelessness, but some may be used for people with disabilities being discharged or diverted from CCFs to the extent that they meet the criteria for the funds.

For example, ARPA included \$5 billion for emergency vouchers that can be used by people who are homeless or at risk of

homelessness, recently homeless, or fleeing domestic violence. These vouchers should be able to be used by people with disabilities discharged from CCFs who do not have access to stable housing.

CARES Act provided nearly \$4 billion in new funding for HUD Emergency Solutions Grants (ESG).³⁴⁷ These grants, authorized by the McKinney-Vento Homeless Assistance Act, provide funding to cities, counties, states, and territories to provide services to individuals at risk of homelessness (typically through subgrants to nonprofit organizations).³⁴⁸

They can be used for individuals exiting an

institution who meet certain qualifications—having income below 30 percent of the median family income and having spent 90 days or less in an institution and lived in an emergency shelter or were homeless prior to entering the facility.³⁴⁹ Upon discharge, qualifying

individuals leaving institutions are eligible for short-term rental assistance as well as housing relocation and stabilization. Funds can only be spent “to the extent that the assistance is necessary to help the program participant regain stability in [their] current permanent housing or move into other permanent housing and achieve stability in that housing.”³⁵⁰

The only housing funding targeted directly for people with disabilities in the COVID-19 relief legislation to date has been \$15 million for Section 811 supportive housing and \$65 million

The only housing funding targeted directly for people with disabilities in the COVID-19 relief legislation to date has been \$15 million for Section 811 supportive housing and \$65 million for the Housing Opportunities for Persons with AIDS (HOPWA) program. . . .

for the Housing Opportunities for Persons with AIDS (HOPWA) program, both included in the CARES Act. However, Section 811 funds did not include any requirement to provide new housing units, but only to ensure maintenance of operations of existing Section 811 units during the pandemic. The HOPWA funds can be used to maintain existing housing assistance or to respond to COVID-19, including isolation and relocation expenses to protect people living with HIV/AIDS,³⁵¹ but most HOPWA funds tend to serve individuals who are not coming out of CCFs.

Since the vast majority of funding that can be used for new housing subsidies is targeted at people who are homeless or at risk of homelessness, guidance indicating that these funds can be used for purposes of transitioning eligible individuals with disabilities out of CCFs is important to ensure that some of this funding is directed to that purpose.

Likewise, in any future health crisis, legislation establishing emergency funding should make clear that funds may be used for transition purposes.

[T]he Better Care Better Jobs Act . . . would make states eligible for a 10 percent increase in federal Medicaid reimbursement for HCBS services if they take certain steps to expand HCBS services, strengthen the HCBS workforce . . . , and demonstrating improved availability of services and competitive wages for workers.

CMS routinely collects data on nursing homes and therefore had built-in channels to begin requiring nursing homes to track and report on incidences of COVID-19 in their facilities; but neither CMS, the CDC, nor any other federal agency required reporting of this data in other types of CCFs, including CDC's COVID-19 Data Tracker.

Forthcoming Infrastructure Investments

On March 31, 2021, the Biden Administration released its \$2.3 trillion infrastructure plan, the American Jobs Plan.³⁵² Among the plan's

provisions are a proposal to spend \$400 billion to shore up the HCBS workforce and expand HCBS services for people with disabilities and older adults, as well as a proposal to further extend the Money Follows the Person program. Congressional enactment of new funding for HCBS would

be an opportunity to extend the American Rescue Plan's important incentive for expansion of HCBS into the future. On June 24, 2021, the Better

Care Better Jobs Act was introduced in the House and Senate.³⁵³ This legislation would make states eligible for a 10 percent increase in federal Medicaid reimbursement for HCBS services if they take certain steps to expand HCBS services, strengthen the HCBS workforce including by raising HCBS payment

rates and ensuring that rate increases are passed through to direct care workers, and demonstrating improved availability of services and competitive wages for workers. The

legislation would also make the Money Follows the Person program permanent.

Better Collection and Analysis of the Impact of COVID-19 on People Living and Working in Congregate Care Facilities

Data capturing the spread and transmission of COVID-19 in CCFs outside of LTCFs (and, especially, nursing homes) is sparse. CMS routinely collects data on nursing homes and therefore had built-in channels to begin requiring nursing homes to track and report on incidences of COVID-19 in their facilities; but neither CMS, the CDC, nor any other federal agency required reporting of this data in other types of CCFs, including CDC's COVID-19 Data Tracker.³⁵⁴ This left gaps in critical information and an unclear picture of the impact on people with disabilities living in other CCF's, such as group homes and assisted living facilities.

To track the spread of the pandemic in CCFs, advocates had to piece together data from news reports on specific facilities, state databases and reports (where they existed), narratives from providers and caregivers, and private insurance data. The lack of federal data collection efforts stymied efforts to monitor compliance with federal disability protections and intensified civil rights concerns. Motivated by these grave consequences, in every Congressional negotiation on COVID-related packages, advocates pushed for federal collection of data to track the impact of COVID-19 on residents and staff of CCFs and to compare it to the impact on similarly situated individuals living at home. Such data requests included, for example:

Data Requests in Federal COVID Legislation

- Numbers of tests and rates of testing for COVID-19 of people with disabilities and staff in nursing homes, psychiatric facilities, facilities for people with intellectual and developmental disabilities, board and care homes, group homes, and other congregate facilities for people with disabilities in supported housing and other community settings.
- Numbers of people with disabilities and staff testing positive for COVID-19 and rates of positive tests in each of these settings.
- Numbers of COVID-19–related hospitalizations of people with disabilities and staff in each of these settings.
- Numbers of COVID-19–related deaths and death rates among people with disabilities and staff in each of these settings.
- Numbers of people who have recovered from COVID-19 and recovery rates among people with disabilities and staff in each of these settings.
- Numbers of people who have been transferred from community settings to institutional settings as a result of COVID-19.
- Numbers of people with disabilities who have been discharged from institutions as a result of COVID-19.
- Analysis of the data to identify trends and factors such as facility type, disability type, location or geographical area, or other factors that correlate with rates of testing, positive cases, or outcomes.”³⁵⁵

Though the House-passed Health and Economic Recovery Omnibus Emergency Solutions (HEROES) Act included a provision requiring the Secretary to work with covered agencies to support the modernization of data collection to increase data related to “health inequities, such as racial, ethnic, socioeconomic, sex, gender, and disability disparities,” the bill did not ultimately become law.³⁵⁶

The primary provision in the various pieces of COVID-19 relief legislation that could be used to require expanded data collection and analysis concerning people with disabilities is in the Paycheck Protection and Healthcare Enhancement Act. This Act included a provision requiring HHS to report incidences of COVID-19 diagnoses, hospitalizations, and deaths, broken down by several factors including race, ethnicity, age, sex, region, and “other relevant factors,” but did not specifically require reporting by disability.³⁵⁷ HHS should issue guidance indicating the “other relevant factors” provision includes disability, and data should be separated by housing status, including community care. Data is needed on community care to compare the difference in outcomes for people who experienced the pandemic in congregate settings and those that were able to receive care at home.

ARPA included provisions calling for the Secretary, acting through the Director of CDC, to provide funds to be used for data related to vaccine distribution and vaccinations, and funds for activities to support data collection systems. While the provisions are not currently disability-specific, these provisions might be a tool to track vaccination data for people with disabilities in and out of CCFs.³⁵⁸ Further, as noted above, CMS issued an interim final rule requiring nursing facilities and intermediate care facilities

for people with intellectual and developmental disabilities to collect and report vaccination data for residents and staff.³⁵⁹

In January 2021, President Biden released the “National Strategy for the COVID-19 Response and Pandemic Preparedness,” which included a call for increased data collection.³⁶⁰ The strategy recognized that “the fragmented and limited availability of data by race, ethnicity, geography, disability and other demographic variables delays recognition of risk and a targeted response,” and called upon HHS to “optimize data collection from public and private entities to increase the availability of data by . . . disability . . . and other demographic variables, as feasible,” and established that CMS “will work to report Medicare and Medicaid data on COVID-19 testing, cases, vaccinations, hospitalizations, therapeutic utilization, and deaths by . . . disability and other sociodemographic factors.”³⁶¹ Additionally, President Biden issued an Executive Order directing federal agencies to “expand their data infrastructure to increase collection and reporting of health data for high risk populations.”³⁶²

Summary of Findings

- COVID-19 exposed many of the worst vulnerabilities of congregate care systems and emphasized the weaknesses in existing efforts to move individuals out of these settings. In the face of the century’s worst public health crisis, states had dramatically less capacity to fund and implement legally required diversion and transition initiatives. As a result, people with disabilities residing in congregate settings experienced disproportionate rates of severe illness and death due to COVID-19.

- Without adequate data to track the rates of transmission, testing, morbidity, mortality, and vaccination in each category of CCF, it is hard to say whether the federal government’s prioritization of older adults and disabled persons, facility adherence to visitation restrictions, and provider hesitancy to move people out of congregate settings had a positive net effect on controlling the spread of COVID-19 in congregate settings (as claimed), despite the negative impact on transitions and diversion and the isolation that people experienced in these facilities. More information is needed to understand the full experiences that people with disabilities had during the pandemic. Moreover, CDC and CMS must build systems and capacities to track future public health emergencies in CCFs.
- Two positive gains from the pandemic include added investments in HCBS and housing for people with disabilities—including enhanced Medicaid reimbursement

for HCBS, Medicaid flexibilities to reimburse family caregivers, a three-year extension of the Money Follows the Person demonstration project, and FEMA funding for emergency housing. Yet, it is not clear how fully states used these new funding streams, and if they did not, whether such oversight was intentional or a result of limited guidance and/or a lack of awareness of potential uses. Even with these positive steps, more investments are needed to expand Medicaid HCBS services, make permanent the Money Follows the Person program, strengthen enforcement and interpretations of the HCBS Settings Rule, and to expand the availability and affordability of housing units.

Recommendations

To ensure that diversions and transitions from CCFs continue prior to a future health crisis or pandemic, and to ensure quality standards of care for those who prefer or need to reside in CCFs, NCD recommends:

Recommendations for Federal Agencies

CMS, ACL, SAMHSA, HUD, FEMA, and DOJ should:

- Develop a multi-agency national strategy to mitigate the risks of COVID-19 transmission in CCFs and address the civil rights concerns that continue to impact the lives of people with disabilities in CCFs. The agencies should clarify how community services can be paired with housing resources to ensure that people with disabilities have the opportunity to receive services in the most integrated setting and avoid needless risk of infection and death. They should also issue guidance identifying strategies and resources available to state and local governments to facilitate transitions and diversions from CCFs, flexibilities

Recommendations for Federal Agencies: *continued*

that may be used, and how these resources factor into public entities' *Olmstead* obligations in future crises; for example:

- **CMS** should issue guidance explaining how states can combine HCBS funding with housing resources to facilitate transitions and diversions from CCFs; and ensure that temporary funds are available in future emergency settings with an explicit directive to transition people with disabilities out of CCFs.
- **CMS** should encourage states to use Appendix K and Section 1135 waivers to support family caregivers.
- **CMS** should rescind Trump-era guidance that weakens the interpretation of the HCBS Settings Rule and ensure that HCBS funding is used to fund services in integrated community settings.
- **CMS** should rescind its approval of PASRR waivers and HHS should prohibit their use in any future health emergency except under very limited circumstances.
- **HUD** should issue guidance clarifying that federal housing funds made available through ARPA and the CARES Act, as well as Emergency Solutions Grant funding more generally, may be used for individuals with disabilities transitioning or being diverted from CCFs.
- **HUD** should increase the availability of additional housing vouchers so states can curtail lengthy waiting lists, increase housing options—including accessible units—and speed up the process of transitioning people with disabilities into the community.
- **FEMA** should issue guidance clarifying that Category B funds and the Individuals and Households Program may be used for individuals with disabilities transitioning out of CCFs.
- **DOJ** should issue guidance concerning public entities' *Olmstead* obligations and how those entities should take advantage of specific federal resources to facilitate transition and diversion from CCFs, including emergency resources. The guidance should clarify that *Olmstead* and the ADA's integration mandate require that transitions and diversion from CCFs continue even during pandemics and other emergencies and offering strategies and examples of how that can be accomplished.
- **CDC and CMS** should work together to emphasize census reduction in all CCFs as an infection control strategy. Accordingly,
 - **CDC** should expand its guidance beyond LTCFs to include all CCFs and emphasize that reducing the census of CCFs through accelerating discharges and diversions as a

(continued)

Recommendations for Federal Agencies: *continued*

critical strategy to ensure that the physical distancing required for infection control can be effectively done in CCFs. CMS guidance should explain ways to reduce the level of services required for discharge when needed to speed up transitions amid staff and provider shortages during an emergency. In many cases, minimally necessary services and supports could, in an emergency setting, simply include medication and case management.

- **HHS** should improve disability data collection: The Paycheck Protection and Healthcare Enhancement Act required HHS to report incidences of COVID-19 diagnoses, hospitalizations, and deaths, broken down by several factors including “other relevant factors,” but not specifically disability.³⁶³ For data collection purposes, the Secretary of HHS should define “other relevant factors” to include data points that capture people with disabilities in CCFs. Future legislation should also require the collection of this data for each type of congregate care setting as well as for individuals with disabilities living in their own homes (specific data recommendations for Congress are addressed in the recommendations in chapter 1). Further, the CDC’s COVID-19 Data Tracker should release COVID-19 data separated by housing status—for each type of CCF and for individuals who live independently in the community.³⁶⁴
- **CMS** should prioritize all CCFs to receive equipment such as test kits and proper PPE from federal, state, and local governments that is necessary to follow CDC guidelines in any similar health emergency. CMS should recognize and clarify that community providers conducting in-reach transition support to facility residents are “essential care providers,” not “visitors,” and should not be restricted from entering facilities during future pandemics or crises. All CCFs should receive priority designation for vaccine allocation. Federal and state investments to expand telehealth infrastructure to ensure continuity of care are likewise needed.
- **FEMA** should issue guidance to regional administrators reiterating their ability to approve broader eligibility definitions for sheltering-related Public Assistance reimbursements and to state governments explaining how they can access upfront FEMA Public Assistance payments in line with President Biden’s January 21 executive order. It should:
 - Expand Reimbursement to Cover Expenses for Supportive Services and Personal Assistance Services (PAS) To Ensure Accessibility: Supportive services can be necessary to ensure that people experiencing homelessness, residents of CCFs, and other individuals with disabilities have access to noncongregate sheltering. To ensure greater

Recommendations for Federal Agencies: *continued*

access to the Public Assistance program, FEMA should expand the types of expenses eligible for reimbursement to include supportive services and encourage states and localities to provide supportive services alongside noncongregate shelter.

- Allow Independent Living Centers and Homeless Service Organizations to Apply for and Receive Direct Public Assistance Reimbursements: Currently, FEMA allows Public Assistance program reimbursements to be applied for and received by PNPs. The standing definition of PNPs, however, often exclude facilities such as independent living centers, homeless service centers, and similar nonprofits that operate in an open and public manner to ensure that certain populations have the services they need to survive. FEMA must issue guidance expanding the definition of PNP to include these organizations, ensuring they can continue operating after a disaster—including the current pandemic.

Recommendations for States

- **State Medicaid agencies** should expand Medicaid HCBS services including through taking advantage of new HCBS funding made available through ARPA and use Appendix K and Section 1135 waivers to support family caregivers.
- **State housing authorities and disability services agencies** should support the expansion of available housing to enable people with disabilities, including by increasing requests for federal housing assistance through HUD programs and targeting housing resources to people with disabilities, as well as expanding the use of state housing subsidy programs to support people with disabilities.
- **States**
 - Should ensure that requests for FEMA emergency housing assistance include the needs of people with disabilities to move from congregate settings from CCFs.
 - Should collect and make public, data concerning the numbers and rates of infections, hospitalizations, and deaths from COVID-19 or other viruses among residents and staff of all CCFs.

Chapter 3: The Direct Care Workforce

Overview of Direct Care Workforce

The direct care workforce, including personal care assistants, home health aides, and nursing assistants, is critical to the independence and well-being of any person with long-term care needs. Similarly, unpaid family caregivers assist family and friends who have chronic or other health conditions, functional limitations, or disabilities, allowing them to remain living at home and, for some, avoid institutionalization in nursing homes. As the coronavirus pandemic spread across the United States, direct care workers, primarily women and people of color, continued to shoulder responsibility for providing essential care and assistance for people with disabilities and older people. Yet they often received little or no training on the risks of COVID-19 and were not provided with adequate coronavirus testing or PPE and supplies that could shield them from infection and death.³⁶⁵ Moreover, for these workers, the pandemic laid bare other long-standing inequities, including low wages, lack of comprehensive employee benefits such as paid family and medical leave, adequate

unemployment insurance benefits, and hazard pay, and limited training and advancement opportunities.

Family caregivers met unforeseen challenges arising from COVID-19, including uncertainty about the likely impact of the disease on themselves and their families, the impact of shelter-at-home restrictions, lack of access to routine medical care, school, childcare, adult day program closures, potential job loss, income

insecurity, and restricted access to prescriptions and home care supplies. The pandemic caused hardship and loss, yet it brought the essential and undervalued role of direct care workers

The pandemic caused hardship and loss, yet it brought the essential and undervalued role of direct care workers into the national conversation.

into the national conversation. It also shined a light on urgently needed reforms, including improvements in compensation, career development, care team integration, training, and improved employee benefits. Similarly, the pandemic heightened public awareness of the invaluable role family caregivers play in maintaining people with disabilities and older adults at home³⁶⁶ and focused on reforms that would support and enable unpaid workers to continue in these critical roles.³⁶⁷

Direct Care Workforce and Family Caregiver Characteristics

An estimated 4.6 million individuals make up the direct care workforce in the United States, with a subset of more than 2.4 million who provide home care for people with disabilities and older individuals. An estimated 1 million home care workers are employed directly by people with disabilities and older people who receive services through publicly funded, consumer-directed programs. Other workers are hired privately in the “gray market,” however, workforce data is not available for this group.³⁶⁸ The direct care workforce assists an estimated 17 million people with disabilities and older people living in the community who require help with daily activities. It also assists an additional 1.5 million people

living in nursing homes and 1 million people living in residential care facilities such as assisted living facilities and group homes.³⁶⁹

DC workers include personal care assistants, home health aides, and nursing assistants. People who work with individuals with intellectual and developmental disabilities are referred to as direct support professionals. Personal care assistants typically assist people with disabilities living in community settings and homes of their own with Activities of Daily Living (ADLs) such as bathing, dressing, eating, and toileting, and Instrumental Activities of Daily Living (IADLs) such as shopping, preparing meals, housekeeping, and handling finances. Home health aides and nursing assistants who work in institutional and community settings are



allowed to perform some clinical tasks, such as medication management, that some personal care assistants may not be allowed to carry out. An estimated 53 percent of direct care workers come into close, frequent contact with the individuals they assist, which placed them and the people with whom they worked at risk of contracting COVID-19 during the pandemic.³⁷⁰

The direct care workforce is comprised mostly of women (87 percent) and people of color (59 percent). Immigrants—noncitizens living in the United States, including lawful permanent residents, “nonimmigrants,”—such as visitors, students, and temporary workers, and undocumented immigrants—make up about 27 percent of the direct care workforce. The median age of the workforce is 45 years of age.³⁷¹ The direct care workforce in the United States, especially home health and personal care assistants, is projected to grow 34 percent from 2019 to 2029, according to the Bureau of Labor Statistics, as the baby boom generation ages and demand for home health and personal care assistance increases.³⁷² Even as millions of people with disabilities and older people rely on the care they provide, these undervalued and undercompensated workers were affected by structural racism, gender inequality, and anti-immigrant sentiments in the United States.³⁷³

Before the coronavirus pandemic, the workforce as a whole was subject to consistently low wages, challenging work conditions, and limited workplace protections and employee benefits.³⁷⁴ Because they earned a median hourly wage of only \$11.57, nearly 20 percent of direct care workers lived in poverty, and more than 40 percent depended on public assistance, including Medicaid and the Children’s Health

Insurance Program (CHIP).³⁷⁵ Sixteen percent did not have any form of health insurance.³⁷⁶ These factors also contributed to high job turnover.³⁷⁷ During the height of the pandemic, one study revealed that home care workers felt invisible and forgotten when it came to hazard pay, health insurance, paid leave, and lack of child care when schools were closed. Moreover, many direct care workers who lived in multigenerational households where most adults continued to work, often as essential employees, expressed fear of bringing the coronavirus home to their families.³⁷⁸ Other studies revealed that direct care workers in nursing homes and assisted living communities were statistically more likely than home care workers to report COVID-19–related workplace challenges including increased workload demands and understaffing. Thirty-seven percent of nursing home direct care workers and 33 percent of assisted living workers reported understaffing as a challenge, compared to 13 percent of workers in agencies that provide HCBS including home healthcare agencies.³⁷⁹ Staffing shortages placed additional pressure on already overburdened workers.

As the coronavirus spread, direct care workers continued to shoulder responsibility for providing essential care and assistance for people with disabilities and older people. Moreover, in light of the disproportionate impact of the virus on communities of color, direct care workers who were members of racial, ethnic, and immigrant groups also faced more significant health and economic risks during the pandemic.³⁸⁰ Long-standing healthcare inequities left them more likely to experience severe COVID-19 illness if they become infected. Yet they often received little or no training beyond narrowly focused COVID-19 safety measures and

were not provided with adequate coronavirus testing or PPE and supplies that could shield them from infection and death. Moreover, they lacked employee benefits that could help them avoid a financial crisis if they contracted the virus, lost their jobs, chose to isolate to protect themselves or their families, or left jobs to care for their own family members.³⁸¹ While we lacked accurate COVID-19 death rates for all direct care workers, high rates of nursing home staff and resident infection and death had been reported and are referenced in chapter 2 of this report.³⁸²

DC workers were acutely affected by the inadequacy of the federal response during the early days of the pandemic. COVID-19 precipitated an extraordinary and widespread human rights and public health crisis in nursing facilities, but direct care workers caring for people with disabilities and older adults living in home- and community-based care settings also experienced threats to their jobs and difficulty protecting themselves and their clients from the danger of coronavirus infection and death. The most effective methods to avoid contracting the coronavirus—social distancing and working remotely from home—were not options for direct care workers whose jobs in nursing facilities and community-based settings required close and sometimes intimate contact with clients. Lack of PPE and training on its use, worker and client fear of infection, and personal, economic, and family demands and stress led to an estimated loss of 232,000 homecare jobs during just the first three

months of the pandemic in 2020.³⁸³ However, the fragmented systems that pay for and facilitate HCBS also could not generate a coordinated response as the pandemic swept across the country. And notably, the lack of accurate data on the prevalence of COVID-19 illness and death among home care workers and the people they cared for also made it impossible to understand with any accuracy the true scope of the national COVID-19 disaster. Even as some data was available on the devastating effects of COVID-19 on people with intellectual and developmental disabilities, and states and the CDC reported nursing home infections, illness, and deaths for

[D]irect care workers caring for people with disabilities and older adults living in home- and community-based care settings also experienced threats to their jobs and difficulty protecting themselves and their clients from the danger of coronavirus infection and death.

staff and residents, age-adjusted data was not available on COVID-19 infections, illness, and death based on disability status alone or the combined characteristics of race, ethnicity, and disability status.³⁸⁴ Lack of this critical information meant that

policy advocates had to base recommendations mostly on anecdotes and early qualitative research. A dearth of accurate occupational data on the direct care workforce also obscured a full understanding of COVID-19's impact on these workers. Existing data did not consider the varied roles, job duties, work environments, and titles of direct care workers, which led to undercounting certain workers and excluding others entirely.³⁸⁵

A direct care workforce that makes a living wage, has access to comprehensive healthcare, appropriate employment protections, benefits, job security, and career track opportunities is a matter of racial, ethnic, and gender equity.

These employment rights also ensure that the disability community has consistent access to services and supports needed to maintain health and live full, independent lives. The pandemic created new and distinct employment and health threats and challenges for direct care workers in addition to those they were already experiencing. While these threats eased somewhat, especially for residents and staff of nursing facilities, as vaccinations and PPE became more readily available, longstanding inequities remained. Direct care workers and home care agencies providing HCBS still reported PPE shortages and barriers to being vaccinated. For the foreseeable future policymakers must continue to recognize that the direct care workforce is made up of essential workers who are eligible for free coronavirus testing and vaccinations, who must have sufficient PPE and training in PPE use and infection control. They must also recognize that these workers are entitled to living wages and employment benefits that incentivize continued employment in the field, especially in light of threats posed by COVID-19.

In addition to the paid direct care workforce, research suggested that more than 50 million caregivers are currently providing unpaid help for adults or children with disabilities in the United States.³⁸⁶ A family caregiver is generally defined as an adult family member or another individual who has a significant relationship with a person who has a chronic or other health condition, a functional limitation, or a disability. These caregivers represent all ages, racial and ethnic groups, and socioeconomic backgrounds. They assist with ADLs, IADLs, medication management, and emotional and other support for family members or close friends. Among people caring for adults, almost 90 percent care for an adult relative, while about 10 percent care for a friend or neighbor. As the U.S. population

lives longer with more chronic and complex functional limitations and medical conditions, the prevalence of unpaid caregiving will increase.

Family caregivers provide care for people with long-term physical conditions and emotional, mental health, or memory problems, including dementia or Alzheimer's. Recent studies suggested that not only are more people in the United States taking on unpaid caregiver roles; they also are caring for people who have increasingly complicated support requirements or medical needs. Even before COVID-19, some family caregivers reported experiencing emotional stress and short- and long-term financial consequences to devoting significant time to caregiving, and a decline in self-reported health status.³⁸⁷ Furthermore, studies reported that over 50 percent of family caregivers had jobs that pay hourly wages, including some direct care workers, suggesting that taking unpaid time off threatened their economic stability.³⁸⁸

The coronavirus pandemic added additional stress and uncertainty for family caregivers, many of whom experienced new and unforeseen challenges arising from COVID-19. After the pandemic began, millions of family caregivers were forced to shelter in place, and some had to take a leave from their jobs to care for family members. Many had little or no paid leave while they struggled to fill caregiving gaps for their family members with disabilities when scheduled workers contracted COVID-19 themselves or choose to stay home to avoid either contracting the virus or passing it on to clients and their families. Caregivers also encountered difficulties coordinating care for family members living in nursing homes and other facilities that closed to visitors.³⁸⁹ COVID-19 hit communities of color especially hard, and reports indicated that 16 percent of Latino and 13 percent

of Black adults left their jobs to care for family members during the pandemic.³⁹⁰ Many of these individuals held low-paying jobs and lacked paid leave even as they needed to shelter in place to avoid contracting the virus or to care for a person with a disability or an older adult.³⁹¹ Refining the focus even more to women of color, 28 percent of Latina women and 27 percent of Black women indicate that they have taken days off without pay or quit a job to care for either a child or an elderly relative, compared to 12 percent of white women and men of all ethnicities.³⁹²

Federal and State COVID-19 Responses to Direct Care Workers

After the pandemic began, Congress and state legislatures enacted significant COVID-19 relief measures and approved

specific short-term solutions for the most pressing threats and problems brought on by the pandemic. These legislative and policy

actions rolled out during 2020 and 2021 as advocates, researchers, the media, and those directly affected reported the COVID-19 landscape and associated workforce challenges. Even as federal COVID-19 relief bills did not seek to reform the long-standing structural problems that direct care workers experienced, they afforded a glimpse into what was possible and practicable.

PPE and COVID-19 Testing

Lack of timely coronavirus testing and PPE, including gowns, masks, gloves, and face shields, placed many direct care workers in increased danger of becoming infected and spreading the virus to clients and family

members. COVID-19 testing was limited in the early days of the pandemic, and people who were able to be tested had long waits for test results. Provisions of the Paycheck Protection Program and Healthcare Enhancement Act,³⁹³ signed into law on March 18, 2020, allocated funds to scale up coronavirus surveillance and testing capabilities. However, the direct care workforce, especially those serving people with disabilities and older people living at home or in other community-based settings and at high risk for infection, found testing challenging: limited availability of testing during the early months of the pandemic and other barriers such as lack of transportation, difficulty taking time off from work, concerns over the cost of testing, and fear of revealing their immigration

status to authorities were common barriers to testing. A survey of states conducted by Health Management Associates and the Kaiser Family Foundation

for fiscal years 2020–2021 confirmed these problems. The survey found that nearly three-quarters of states indicated concerns about access to COVID-19 tests for direct care workers, and almost all states reported that access to PPE for direct care workers was a serious concern. Several states reported the length of COVID-19 test processing times as a particular challenge. A small number of states reported limited testing due to lack of transportation to testing sites, which remained problems for rural areas.³⁹⁴

Confusion over who was responsible for payment of testing also persisted for months during 2020. Two federal COVID-19 relief bills,

16 percent of Latino and 13 percent of Black adults left their jobs to care for family members during the pandemic.

the Families First Coronavirus Response Act (FFCRA)³⁹⁵ and the CARES Act,³⁹⁶ signed into law during the onset of the pandemic, in March 2020, required most private health plans, Medicare, and Medicaid to pay for the COVID-19 testing procedure, the test itself, and other related costs, with no cost sharing required.

Some resources were also made available to finance free testing for uninsured people. However, the CARES Act limited access to free testing for immigrants and temporary workers, although states could provide testing for these groups through Medicaid programs. The CARES Act provided \$1 billion for free coronavirus testing and treatment at federally supported community health centers where many immigrants sought care, regardless of citizenship status or insurance coverage. Immigrants who would have been eligible in some states to enroll in Medicaid during the pandemic and thus eligible for free testing were reluctant to do so, due to the Trump Administration's "public charge" rule that would make immigrants who applied for public assistance ineligible to pursue legal residency status or citizenship.³⁹⁷ The rule discouraged immigrants from applying for Medicaid and the CHIP by interpreting "public charge" to include immigrants who either had previously received or who might rely on some types of public assistance in the future.

On March 14, 2020, the U.S. Citizenship and Immigration Services (USCIS) announced that it would not count the use of free COVID-19 testing services when determining if immigrants would potentially rely on public benefits in the future. However, likely many immigrants, including those who were direct care workers, chose not to take advantage of available testing, either because they were unaware of the March 14

clarification or because they were uncertain that USCIS would implement it.³⁹⁸ Responding to advocates' concerns about the devastating impact of the public charge rule on immigrant communities during the pandemic, the Biden Administration, on Tuesday, March 10, 2021, halted implementation of the policy following the reinstatement of a federal court order blocking it. The Department of Homeland Security would no longer consider receipt of Medicaid (except for Medicaid-supported institutionalization), public housing, or SNAP benefits as disqualifying factors in a public charge determination. The Department of Homeland Security also stated that it would not consider vaccination for the coronavirus or COVID-19 treatment in public charge determinations.³⁹⁹

Even though FFCRA and the CARES Act explicitly required that COVID-19 testing be free in most cases, the laws also required that testing be medically necessary. Guidance from CMS said that free testing was required "when medically appropriate for the individual, as determined by the individual's attending healthcare provider in accordance with accepted standards of current medical practice."⁴⁰⁰ Relying on this guidance, some health insurance plans applied cost sharing or denied COVID-19 testing claims for members who were asymptomatic when they were tested unless they knew or suspected they had been exposed to someone who was positive for the coronavirus.⁴⁰¹ Where testing was offered, this interpretation placed the payment burden on the individual, undoubtedly making it difficult for even those direct care workers who had insurance to navigate the cost obstacles.⁴⁰² Federal guidance issued by the Biden Administration early in 2021 clarified that health insurers must cover testing without any

cost to the individual being tested except when testing was a requirement in employee return-to-work programs.⁴⁰³

Reports in 2021 indicated that testing demand had dropped off even as testing availability was widespread in most areas. This suggested that testing barriers related to cost and availability had eased, making it somewhat easier for direct care workers to be tested later in the pandemic.⁴⁰⁴ Even so, the structural barriers related to testing and treatment for COVID-19 that some direct care workers encountered reveal the complex effects of historical racism.⁴⁰⁵

PPE, including gowns, masks, and gloves, was scarce for many months during 2020. Direct care workers interviewed for a study in New York reported receiving conflicting information on COVID-19 safety protocols and varied amounts of PPE from their home care agencies. They also reported relying on nonagency sources for news, PPE, and other supplies.⁴⁰⁶ DC workers, along with other health workers, reported being forced to use trash bags as gowns, reuse face masks for weeks, and sometimes go totally without gloves.⁴⁰⁷ The CARES Act appropriated considerable federal funding to hospitals and other healthcare entities, which they could use for PPE. Still, the law did not allocate such funding to nursing homes and other LTCFs.⁴⁰⁸ The Health Management Associates–Kaiser Family Foundation study confirmed that in a few states, making PPE available for workers in institutional settings was a high priority, thus leaving community-

based workers with fewer options for obtaining these supplies.⁴⁰⁹ The CARES Act also expressly provided funds for PPE to protect home health workers providing care for veterans from contracting or spreading the coronavirus.⁴¹⁰

A year and several months into the pandemic, most hospitals had access to PPE in bulk. Specific items, such as surgical masks, could be relatively easily purchased in stores. However, a few reports suggested that PPE supplies were still not readily and consistently available to small entities such as healthcare clinics, homeless shelters, home health agencies, and individual direct care workers. Even some nursing homes were still experiencing occasional shortages: One in 10 nursing homes reported not having a week's PPE

supply on hand during the four weeks ending March 7, 2021.⁴¹¹ This disparity in access to PPE was still evident as COVID-19 infections increased in some states during the spring of 2021.⁴¹²

DC workers, along with other health workers, reported being forced to use trash bags as gowns, reuse face masks for weeks, and sometimes go totally without gloves.

COVID-19 Vaccination

As word that COVID-19 vaccinations would likely be available in early 2021, people with disabilities, older people, home care workers (direct care workers providing care for people in their homes and community settings), and family caregivers worried that they might not be included in federal and state vaccine allocation policies. Disproportionate rates of COVID-19 infection and death among nursing home residents and staff were well known, and CDC and state and local public health leaders responded by identifying nursing home workers and residents as top priority populations for vaccination. However,

home care workers who worked for multiple clients faced a risk of COVID-19 infection similar to nursing home staff, yet federal and state officials did not include these direct care workers in recommended early vaccination eligibility. Public health officials based these decisions on the need to set priority populations because vaccine availability was limited, and public health data showing populations at greatest risk of COVID-19 infection should receive the first available shots. Little data was available about COVID-19 infection, illness, and death among home care workers, family caregivers, people with disabilities, and older people living in community settings. Therefore, these vulnerable groups were unnoticed and ignored by public health officials in many states' early vaccine allocation protocols, as further detailed in chapter 1.

Also emerging as a concern was how structural racism, especially in healthcare, would affect how Black, Indigenous, and other communities of color, including direct care workers who were members of these communities, would gain access to the vaccine and be interested in being vaccinated. Researchers have noted that the long-standing effects of historical racism underpin inequalities in the processes for vaccine distribution. Disparities in access to computers and other digital technologies, for example, made it difficult or impossible for some people to access the array of vaccine scheduling websites. While internet websites were intended to make access to vaccine appointments equitable, relying on them had the effect of widening access disparities for some marginalized communities. The long history of racism in science and healthcare also caused some people from communities of color to express a wait-and-see

attitude about the safety and efficacy of the COVID-19 vaccines.⁴¹³

In December 2020, the same month that the U.S. Food and Drug Administration (FDA) approved two COVID-19 vaccinations for emergency use, the CDC's Advisory Committee on Immunization Practices (ACIP) recommended priorities for demographic populations who would receive the vaccine first in light of limited supply. The CDC placed healthcare personnel and residents of long-term care facilities (LTCF) in Phase 1(a), the highest priority tier to receive the vaccine based on their risk of exposure to the virus and the high rate of COVID-19 deaths in nursing homes.⁴¹⁴ The CDC included home healthcare workers and people who deliver services for older people and people with disabilities, among many healthcare job classifications, in Phase 1(a) based on a comprehensive list of essential workers initially created by the US Department of Homeland Security.⁴¹⁵ However, ACIP's December 3 advisory defines essential healthcare workers for purposes of inclusion in Phase 1(a) at that time as, ". . . all paid and unpaid persons serving in *healthcare settings* who have the potential for direct or indirect exposure to patients or infectious materials." ACIP also explicitly noted that residents of LTCFs required personal care, thus DC workers who provided such services in these facilities were considered eligible healthcare personnel and included in Phase 1(a). Although the CDC was aware of the diverse workforce employed in the healthcare field, ACIP's early vaccination guidance was expressly aimed at healthcare personnel who worked in settings where healthcare was delivered.⁴¹⁶ The strong emphasis on vaccinating these workers first led many states to craft vaccine allocation

policies that excluded DC workers who delivered personal care services in the homes of people with disabilities or in other community settings rather than healthcare settings. Moreover, people with disabilities under age 65 living in the community who required DC worker assistance to live independently were not specifically ranked within any of the four primary phases even though many were at high risk of coronavirus infection, serious COVID-19 illness, and even death. Disability advocates recommended that younger people with disabilities in the community be included in a high priority category, but most states did not mention disability in their initial vaccine allocation plans.⁴¹⁷

Some states and locales modified the federal vaccine guidance to include direct care workers who provide home care in a higher Phase 1 tier. For example, California initially placed home care workers in Phase 1b, Tier 2. Vaccination of these workers began in some counties in February 2021. However, this did little to protect people with disabilities in HCBS since it was unclear at the time whether vaccination precluded the capacity to infect others.⁴¹⁹

Massachusetts planned to start vaccinating all home care workers in February 2021. The state defined home care worker as “a clinical or non-clinical healthcare or home care worker doing in-person consumer or patient-facing care when the work is performed in the home of the patient/healthcare consumer.” Personal care attendants, home health, hospice, home care agency staff performing visits in the home, and an array of others who might have contact with an individual in their home were included.⁴²² Even as some states included home care workers in their earliest vaccine phases, others did not, such as Louisiana. Moreover, officials in some locales were confused about direct care worker eligibility for the vaccine. For instance, some Florida vaccination sites initially turned away home care workers, thinking they were not yet eligible for the shots.⁴²³ Widespread media reports revealed that multiple vaccination websites were overwhelmed and hard to navigate, and the few available appointment slots were often filled. Rural direct care workers reported minimal availability, and they often had to travel long distances to get to a vaccine distribution site. Workers with limited English proficiency did not necessarily have access to technology or linguistically appropriate information about making a vaccine appointment

The Advisory Committee on Immunization Practices’ Updated Interim Recommendation for Allocation of COVID-19 Vaccine—United States December 2020⁴¹⁸

Phase	Groups Recommended to Receive COVID-19 Vaccine
1a	Healthcare personnel
	Long-term care facility residents
1b	Frontline essential workers
	Persons aged ≥75 years
1c	Persons aged 65–74 years
	Persons aged 16–64 years with high-risk medical conditions
	Essential workers not recommended for vaccination in Phase 1b
2	All persons aged ≥16 years not previously recommended for vaccination

Guidelines to California’s Health Departments Allocation of COVID-19 Vaccine During Phase 1⁴²⁰

PHASE 1a	<ul style="list-style-type: none"> ▪ Persons at risk of exposure to SARS-CoV-2 through their work in any role in direct healthcare or long-term care settings. <ul style="list-style-type: none"> • This population includes persons at direct risk of exposure in their nonclinical roles, such as, but not limited to, environmental services, patient transport, or interpretation. ▪ Residents of skilled nursing facilities, assisted living facilities, and similar long-term care settings for older or medically vulnerable individuals.
1b Tier 1	<ul style="list-style-type: none"> ▪ Acute care, psychiatric, and correctional facility hospitals ▪ Skilled nursing facilities, assisted living facilities, and similar settings for older or medically vulnerable individuals <ul style="list-style-type: none"> • Also, in concordance with ACIP, residents in these settings ▪ Paramedics, EMTs, and others providing emergency medical services ▪ Dialysis centers
Tier 2	<ul style="list-style-type: none"> ▪ Intermediate care facilities for persons who need noncontinuous nursing supervision and supportive care ▪ <i>Home healthcare and in-home supportive services</i> ▪ Community health workers, including promotoras⁴²¹ ▪ Public health field staff ▪ Primary Care clinics, including Federally Qualified Health Centers, Rural Health Centers, correctional facility clinics, and urgent care clinics
Tier 3	<ul style="list-style-type: none"> ▪ Specialty clinics ▪ Laboratory workers ▪ Dental and other oral health clinics

or navigating the multiple complex vaccine websites. Often, alternative methods to make an appointment, such as a telephone line, were overwhelmed with long wait times, could not record messages, or were not working. Other direct care workers were concerned about the cost of the vaccine and the possible need to reveal their immigration status in order to receive shots, problems similar to those

they faced being tested for the coronavirus. Even if they could make an appointment and surmount other hurdles, some workers simply could not take time off from work to travel to a vaccination site.⁴²⁴

As vaccine eligibility eased and availability of vaccines increased, CDC stated that everyone 16 years of age and older was eligible to get a COVID-19 vaccine as of April 19, 2021. On

May 10, 2021, the FDA approved emergency use authorization for the Pfizer-BioNTech COVID-19 vaccine for adolescents age 12 through 15 years.⁴²⁵ Even with increased vaccine availability, communities of color hit hardest by the pandemic were not always receiving an equitable share.

Federal vaccination data indicated that communities with the highest level of disadvantage and health vulnerabilities, based

on the Social Vulnerability Index,⁴²⁶ were being vaccinated at a lower rate than communities with fewer disadvantages and vulnerabilities.⁴²⁷

Moreover, decades of research confirmed that race and ethnicity status are factors that predict unequal access to healthcare and health disparities outcomes. The cumulative effect of these multiple, generational inequities disproportionately affected Black, Indigenous, and other communities of color, including direct care workers who are members of these communities. Such

systemic inequities inevitably contributed to poor healthcare experiences and distrust of medical professionals, establishing the basis for concern about the COVID-19 vaccine's

safety and effectiveness.⁴²⁸ These influences were reflected in vaccination figures: By early March 2021, only about a quarter of home care workers had been vaccinated, compared with approximately two-thirds of hospital workers and half of nursing home workers.⁴²⁹

Enhanced Employment Wages and Benefits

Federal COVID-19 relief legislation contained provisions that very likely benefitted many direct care workers, their families, and family caregivers, while other provisions specifically

worked against direct

care workers. The

FFCRA,⁴³⁰ the first of the COVID-19 relief

packages, signed into

law on March 18, 2020,

included assistance to

states for payment of unemployment insurance claims. Emergency paid sick leave was also included, but nursing homes and home health agencies were among various health providers and educational organizations that could exempt their direct care workers from eligibility if they chose to do so. Tax credits for paid sick and paid family and medical leave were also made available for employers of a specific size, including home care agencies and nursing facilities. Congress intended these credits to

encourage employers

to pay sick, family, and

medical leave.⁴³¹ While

FFCRA provided sick

leave and paid family and

medical leave, gaps in

the legislation excluded

some direct care workers

from eligibility for the

enhanced benefit. For instance, FFCRA excluded independent contractors from eligibility for emergency family medical leave. Therefore, home care workers employed as independent contractors were ineligible for this temporary benefit. FFCRA also exempted businesses

Even with increased vaccine availability, communities of color hit hardest by the pandemic were not always receiving an equitable share.

By early March 2021, only about a quarter of home care workers had been vaccinated, compared with approximately two-thirds of hospital workers and half of nursing home workers.

with fewer than 50 employees from providing emergency family medical leave, thus limiting eligibility for home care workers employed by some smaller home healthcare agencies.⁴³²

Some states responded to these gaps. For instance, California sought federal approval under FFCRA to increase sick leave for Medicaid home care workers. This request enabled workers in California's In-Home Supportive Services (IHSS) program who were employed by people with disabilities and who met specific eligibility requirements to receive the new federal COVID-19 sick leave. IHSS provides in-home assistance to eligible people with disabilities to enable them to live in the community.⁴³³ Because FFCRA expired at the end of 2020, California passed a measure in March 2021 that provided for supplemental paid sick leave for specified IHSS and other personal care service providers who were unable to work or telework due to certain reasons related to COVID-19. The measure made sick leave available retroactively to January 1, 2021.⁴³⁴

Many direct care workers and family caregivers who lost or left their jobs during the pandemic depended on income support provided by unemployment insurance. The CARES Act included a 6.2 percent increase in federal Medicaid matching funds available to states to ensure continued insurance coverage for beneficiaries. It also focused on expanding unemployment insurance by providing an additional, federally financed \$600 benefit, referred to as Federal Pandemic Unemployment Compensation, that supplemented weekly unemployment insurance benefits, expanded benefit eligibility, and provided weeks of additional federally financed benefits.⁴³⁵ Later in the year, on December 27, 2020, Congress

passed the Consolidated Appropriations Act extending Federal Pandemic Unemployment Compensation through March 2021.⁴³⁶ The Act added a \$300 additional benefit to all recipients, extended benefits for people who had been unemployed long-term and for low-wage and self-employed workers who were not eligible for regular unemployment.⁴³⁷ Another new law, the Coronavirus Response and Relief Supplemental Appropriations Act⁴³⁸ re-instituted some enhanced unemployment insurance benefits, covering January 1, 2021, through March 14, 2021. However, the law did not extend COVID-19-related paid sick leave or increase funding for Medicaid, long-term services and supports, and home and community-based services.⁴³⁹

The CARES Act also provided a recovery rebate for the 2020 tax year of \$1,200 for an individual return (\$2,400 for a joint return) with an additional \$500 per qualified dependent child. Income limited eligibility for these rebates, but they nonetheless likely benefitted direct care workers and some family caregivers.

During the spring of 2020, Congressional interest was building to provide federal funding for hazard pay for the nation's essential workers, including the direct care workforce. However, that interest never culminated in legislation, so individual employers had to decide whether they would provide this form of compensation for their workers. Research suggested that most chose not to do so. However, some states took advantage of CARES Act funding to allocate temporary hazard pay for some public and private sector essential workers, including direct care workers in some cases. For instance, Pennsylvania established a grant program that afforded about 40,000 workers who earned

less than \$20 per hour a \$3 per hour raise for 10 weeks. The program only helped a fraction of those who qualified. So, with equity in mind, the state emphasized assisting those with the greatest financial need. Direct care workers, including home health aides, personal care aides, and nursing home workers, benefitted most from the program. With \$120 million from the CARES Act, Michigan temporarily paid Medicaid-funded direct care workers an additional \$2 per hour.⁴⁴⁰

Virginia made \$1,500 one-time payments to over 43,500 home healthcare workers who provided support for Medicaid beneficiaries.⁴⁴¹

Comprehensive data is lacking on how many direct care workers

received COVID-19 wage

compensation; however,

one study reported that

70 percent of direct

support professionals

who work with people

with intellectual and

developmental disabilities

did not receive COVID-19

wage augmentation or

bonus pay, suggesting

that many other direct care workers were likely

left out of these benefits.⁴⁴²

In September 2020, CMS announced the availability of up to \$165 million in supplemental funding for 33 states that had been operating Money Follows the Person demonstration programs. Money Follows the Person, officially slated to end in 2018, had been extended several times temporarily. Its funding helped people with disabilities move from nursing homes to their own homes or other community settings. Among many options, states could use the new funding for direct care worker recruitment,

education, training, technical assistance, and quality improvement activities. States could also elect to include training people with disabilities to become direct service workers. Eligible states could submit supplemental budget requests under this funding opportunity on a rolling basis through June 30, 2021.⁴⁴³

Congress enacted the American Rescue Plan Act of 2021 (ARPA),⁴⁴⁴ a \$1.9 trillion response to the pandemic, on March 11, 2021. ARPA included \$350 billion for state and local governments and \$12.7 billion to allow more low-income people with disabilities and older people to receive care at home instead of nursing homes. It included a

one-year, 10 percentage point boost in the federal contribution for Medicaid HCBS to states.

According to CMS, funds could be used for a variety of purposes, provided they supplemented and did not supplant existing state funds used for HCBS. Of importance to the direct

care workforce, funds could support caregiver training and education and create financial incentives to expand the number, retention rates, and skills of the direct care workforce. States could provide hazard pay, overtime pay, and shift differential pay for home health workers and direct support professionals, including those who worked with people with intellectual and developmental disabilities. Funds could also be used to increase rates for home health and other HCBS agencies or individuals who employed direct support professionals, with the expectation that they would increase pay rates for workers.⁴⁴⁵

70 percent of direct support professionals who work with people with intellectual and developmental disabilities did not receive COVID-19 wage augmentation or bonus pay, suggesting that many other direct care workers were likely left out of these benefits.

California unveiled a preliminary ARPA HCBS spending plan in early May 2021.⁴⁴⁶ Following a short public comment period and additional discussion with lawmakers, HHS submitted a final, revised plan to CMS on July 12, 2021. The plan included expanding existing IHSS worker training to support people with complex care needs and supporting and incentivizing career pathways.⁴⁴⁷

ARPA also provided several other types of assistance for direct care workers, e.g., tax cuts and immediate cash relief for low- and middle-income families, renter assistance, help for homeowners to avoid foreclosure, extended unemployment benefits, and an additional \$300 per week federal increase in unemployment benefits. This provision prevented direct care workers and family caregivers who left their jobs to care for family members or who were laid off, or who contracted COVID-19, from losing their unemployment insurance benefits.⁴⁴⁸ ARPA also allocated \$145 million for the National Family Caregiver Support Program, which provided grants to states and territories to fund various supports that helped family and informal caregivers care for older adults in their homes for as long as possible.⁴⁴⁹

Medicaid and Medicare

As the pandemic spread, states soon recognized its effect on people with disabilities and older people who required Medicaid-funded HCBS, direct care workers, family caregivers,

and others who provided these services. As infection engulfed congregate care settings, affecting residents and workers alike, some direct care workers and family caregivers fell ill or stayed home to care for family members or avoid becoming ill themselves. Others continued working in homes, community settings, and nursing homes for the usual low wages and without hazard pay, even at the risk of becoming ill, especially when PPE was scarce. Recognizing the emergency, some states and the federal government used various Medicaid emergency waiver authorizations to respond to participant and workforce challenges,

including severe staff shortages, historically low direct care worker wages, and inadequate benefits, that had been brought to the forefront by the pandemic.

For instance, CMS approved various state requests for Medicaid “Appendix K” and Section 1135 emergency

wavers, including raising direct care workforce wages and increasing benefits. CMS approved 34 states to pay spouses and parents of minor children as Medicaid providers through various waivers, and 33 states gained permission to add family members as eligible providers for adults with disabilities.⁴⁵⁰ CMS approved these waivers as mitigation strategies to limit exposure to COVID-19 in the family home and to provide support for individuals who returned from congregate settings to family homes to avoid the risk of transmission. They also responded to the existing direct care workforce and family

CMS approved 34 states to pay spouses and parents of minor children as Medicaid providers through various waivers, and 33 states gained permission to add family members as eligible providers for adults with disabilities.

caregiver challenges that had been intensified by COVID-19.⁴⁵¹

Thirty-three states also received CMS approval to modify Medicaid HCBS provider payment rates. For instance, Michigan and Wisconsin received Medicaid Section 1115 waivers allowing them to pay higher pay rates for direct care workers providing HCBS to maintain worker capacity. Delaware, Hawaii, Massachusetts, North Carolina, Rhode Island, and Washington were granted Section 1115 waivers to enable retainer payments to certain habilitation and direct care workers to maintain capacity during the COVID-19 emergency. In California, an approved 1915(c) waiver extended emergency paid sick leave for direct care workers unable to work during COVID-19. California allocated money to hire social workers and pay overtime when clients and Medicaid-funded direct care workers needed their services.⁴⁵²

Recent changes to the Medicare program, including some that responded to the pandemic, also affected older people with disabilities and their family caregivers. The CARES Act permitted nonphysicians such as nurses and physician assistants to approve Medicare home healthcare services, streamlining the approval process and reducing the burden on family caregivers who often had to coordinate skilled long-term care services through a physician.

The 2018 Chronic Care Act, contained in the Bipartisan Budget Act of 2018, another federal law that benefited family caregivers and people with disabilities during the pandemic, expanded Medicare supplemental benefits and allowed health plans to provide services that were

not primarily health-related.⁴⁵³ For instance, supplemental services could include medical transportation for nonemergencies, caregiver support including respite and in-home services, and bathroom safety devices. By 2021, 95 plans offered support for caregivers of enrollees.⁴⁵⁴ While the availability of these benefits varied widely regionally and by health insurance plan, some family caregivers and Medicare beneficiaries nevertheless likely benefited during the pandemic.⁴⁵⁵

ARPA and other pandemic relief laws partially responded to the economic and other hardships the direct care workforce experienced before and during the pandemic. States' actions to achieve flexibility within the complex Medicaid program, the main source of funding for HCBS, also

foretold a possible future when direct care workers could gain recognition, wages, and benefits commensurate with their critical roles. Changes in

Medicare before and during the pandemic also provided some modest help to family caregivers and increased access to a few new services for beneficiaries in specific geographic health insurance markets.

These stopgap measures provided some short-term help for a struggling direct care workforce and family caregivers. However, because they were a temporary response to a public health crisis, they did not establish a permanent pathway to reversing the inequities that direct care workers and family caregivers experienced every day. Even so, these measures spurred an overdue conversation about the critical, yet undervalued and underrecognized role direct care workers and family caregivers played

Thirty-three states also received CMS approval to modify Medicaid HCBS provider payment rates.

in the lives of people with disabilities and older people. This heightened awareness, driven by a worldwide public health emergency, presented advocates and policymakers with a unique opportunity to create permanent reforms built on state and federal emergency Covid-19 policies.

Federal Policy Proposals

Two federal policy proposals, the Better Care Better Jobs Act, as initially outlined in the American Jobs Plan,⁴⁵⁶ and the HCBS Access Act⁴⁵⁷ aimed to increase funding and reduce waiting lists for Medicaid HCBS services and invest in the nation's caregiving infrastructure. These proposals represented decades of advocacy by people with disabilities and older people, allies, organizations of home care workers, unions, researchers, and policy leaders.⁴⁵⁸ They were brought to the forefront because the coronavirus pandemic revealed deficiencies in HCBS and deep inequities in the treatment and status of direct care workers and family caregivers. If these proposals are enacted, people with disabilities and older adults would have greater access to Medicaid HCBS and direct care workers could experience improvement in wages, benefits, and collective bargaining opportunities. Family caregivers could also gain access to additional assistance and supports.

Building on the \$12.7 billion short-term funding included in the American Rescue Plan, the Biden Administration sought an additional \$400 billion investment in the nation's caregiving infrastructure. The Better Care Better Jobs Act,⁴⁵⁹ introduced in the Senate on June 24,

2021, if enacted, would strengthen and expand access to Medicaid HCBS, promote adequate wages and benefits for direct care workers, and ensure opportunities to organize or join a union. The Better Care Better Jobs Act would support quality and accountability and would facilitate state planning. It would also help states build innovative workforce programs and connect workers with people with disabilities and older people. The proposed legislation would permanently authorize protections against impoverishment for people whose spouses receive Medicaid HCBS and make permanent the Money Follows the Person program.⁴⁶⁰

The HCBS Access Act,⁴⁶¹ a federal legislative discussion draft introduced in March 2021, would amend Title XIX of the Social Security

[T]he coronavirus pandemic revealed deficiencies in HCBS and deep inequities in the treatment and status of direct care workers and family caregivers.

Act to make coverage of HCBS mandatory rather than optional under the Medicaid program. This proposal advances a long-standing recommendation from disability advocates to

reverse the institutional bias in the Medicaid program in favor of HCBS.

Another Biden Administration proposal, the American Families Plan, directly addressed issues that affect direct care workers throughout the country and emphasized reforms that responded to the effects of the pandemic. If enacted, the American Families Plan would extend key tax cuts and child tax credits in the American Rescue Plan, create a national paid family and medical leave program, and reform unemployment. It would also improve healthcare affordability, ensure that childcare is affordable, and provide two years of free community college.

The U.S. Citizenship Act of 2021,⁴⁶² another Biden Administration proposal, would provide an earned pathway to citizenship for the U.S. undocumented population. The bill was introduced on February 18, 2021. While it is beyond the scope of this chapter to report fully on immigration proposals, the U.S. Citizenship Act, if enacted, would directly bear on some immigrant members of the direct care workforce and provide remedies to some of the starkest problems they faced before and during the pandemic. Immigrants make up a substantial part of the direct care workforce and fill a crucial role in meeting the growing national need for direct care workers. Barriers to legal residency and citizenship have forced some of these workers into the shadows, even as they provide critical services that enable people with disabilities and older people to remain in their homes and community-based settings. Expediting immediate routes to lawful immigrant status would help expand the direct care workforce to meet the growing need, provide important long-term economic benefits, and create career advancement opportunities for these workers.⁴⁶³

Social Insurance

The National Academy of Social Insurance (NASI) has proposed Universal Family Care (UFC), a social insurance program model that states could consider for early childcare and education (ECCE), paid family and medical leave (PFML), and long-term services and supports (LTSS). NASI argues

that large-scale social forces inspire the need for social insurance that would respond to race, ethnicity, gender, and disability inequalities that social institutions have created over decades. The UFC model envisions that all workers would contribute to a single care insurance fund that would pay out ECCE, PFML, and LTSS benefits when these needs arise. The fund would provide these benefits through a single, integrated access point for families. Program designs would be based on state priorities, such as funding sources, eligibility requirements, who is covered, and adequacy of benefits. Federal programs, including Social Security and state

programs including for LTSS and PFML, have successfully used this social insurance model and serve as examples of how programs can be successfully structured.⁴⁶⁴

The impact of the coronavirus pandemic on direct care workers illustrates the appeal

of social insurance by revealing structural inequalities that have affected direct care workers disproportionately and pointing out the inadequacies of the current social safety net in times of crisis. The pandemic has brought to the forefront the urgency of increasing wages for the direct care workforce as a means of acknowledging the critical work they do, retaining them in the workforce, attracting people to the field, and meeting their basic economic needs. At the same time, policy advocates have expressed concern that providing direct care workers with a living wage over the long term will be difficult

The pandemic has brought to the forefront the urgency of increasing wages for the direct care workforce as a means of acknowledging the critical work they do, retaining them in the workforce, attracting people to the field, and meeting their basic economic needs.

if the primary funding source is Medicaid, which must compete with other public programs for general tax revenue.

Over many years, federal policymakers proposed public insurance plans in response to the need to find ways to pay for the nation's growing demand for LTSS/HCBS. The Community Living Assistance Services and Supports (CLASS) program was passed as part of the Affordable Care Act,⁴⁶⁵ but later was repealed, in 2013, because it was considered financially unstable.⁴⁶⁶ Since then, at least four states—California, Maine, Michigan, and Minnesota—have explored models for making LTSS available beyond Medicaid.⁴⁶⁷ Washington has passed legislation establishing a Long-Term Care Trust that would provide a daily benefit of \$100 beginning in 2025, after a 10-year vesting period. The lifetime benefit was capped at \$36,500 and would be available to individuals who require help with three or more ADLs. Revenue came from a small tax (.58 percent) on each person's earnings.⁴⁶⁸ Hawaii enacted the Kūpuna Care Program in 2008, making limited LTSS available to non-Medicaid-eligible residents 60 or older so they can continue living at home or in the community.⁴⁶⁹

These state policies mark a trend that recognizes the current system of support for people with disabilities and older people is unsustainable, leaving gaps in service for people who do not meet income eligibility requirements for Medicaid. Moreover, it does not provide adequate pathways to achieve pay equity, provide a living wage, or expand career opportunities for direct care workers. The social insurance model offers an alternative to Medicaid-funded LTSS/HCBS that could bolster and stabilize wages for the direct care workforce, spur improvements in training and job performance, and foster economic stability.

Summary of Findings

- Improvements in wages and employment benefits, including healthcare insurance, have long been identified as fundamental reforms required to reduce direct care worker shortages, boost job opportunity and satisfaction, and increase financial security for this diverse and underrecognized workforce. In addition to low wages and limited benefits, few career development and advancement opportunities spurred high job turnover in a workforce made up disproportionately of women and people of color. Moreover, some direct care workers faced additional insecurities based on their immigration status. The coronavirus pandemic laid bare these deficiencies.
- DC workers who are members of racial, ethnic, and immigrant groups faced disproportionate health and economic risks during the pandemic. Long-standing health and healthcare inequities left them more likely to experience severe COVID-19 illness if they become infected. Yet, they often were overlooked and were not provided with adequate coronavirus testing or PPE and supplies. Such systemic inequities contributed to distrust of medical professionals and established the basis for concern about the COVID-19 vaccine's safety and effectiveness. Moreover, the direct care workforce lacked employee benefits such as paid medical and family leave that could help them avoid a financial crisis if they contracted the virus, lost their jobs, chose to isolate to protect themselves or their families, or left their jobs to care for their own family members.

would support family caregivers and fully acknowledge the value and worth of direct care workers by reducing some of the most pervasive barriers to their recruitment, retention, and promotion.

- Even as the Biden Administration proposals held promise for improving wages, benefits, and employment opportunities for direct care workers, policy advocates worried that providing direct care workers with a living wage and benefits over the long term would be difficult if the primary funding source was Medicaid. Social insurance program models

that include HCBS, such as Universal Family Care, offered payment alternatives and responded to race, ethnicity, gender, and disability inequalities that social institutions had created over decades.

Recommendations

To ensure the United States will have the necessary DC workforce that will be needed to support people with disabilities safely in the community in the event of a future pandemic or similar national health crisis or emergency, NCD recommends the following actions.

Recommendations for Congress

Congress should:

- Enact the Better Care Better Jobs Act, the American Families Plan, the U.S. Citizenship Act of 2021, and the HCBS Access Act. Enact federal legislation based on the principle of Universal Family Care, a social insurance program model for early childcare and education, paid family and medical leave, and long-term services and supports as envisioned by the National Academy of Social Insurance. Built on the models of Social Security and Medicare, Universal Family Care is an integrated approach to care policy that recognizes long-standing social inequities based on race, ethnicity, and disability. Ensure that future and proposed legislation, such as the Better Care Better Jobs Act, which builds on the ARPA's expanded funding for Medicaid home and community-based services, includes funding to improve direct service workforce wages and benefits and increase recruitment and retention. This funding should include a mechanism to ensure that workers' wages and benefits are adequate for the present and adjusted as necessary in the future to ensure a stable workforce that is paid a living wage. It should also require as a condition of receiving such funding that states either provide directly or require that home healthcare agencies, CCFs, and other service providers provide paid family and medical leave for their direct care workers. States should also be required to ensure that direct care workers have access to adequate, affordable healthcare insurance either as an employer or union-sponsored benefit, through the Health Insurance Marketplace, or by other means.

(continued)

Recommendations for Congress: *continued*

Provide federal tax credits for employers offering a minimum number of weeks of paid leave to family caregivers as an incentive to make such leave available. Tax credits should also be offered to offset out-of-pocket expenses related to caregiving, such as housing costs, home modifications, respite, medical costs and other expenses incurred from providing care.

Recommendations for Federal Agencies

- **HHS and CMS** should require State Medicaid waiver requests to include assurances that the direct care workforce will receive fair and living wages and benefits, including paid family and medical leave, if waiver funds are used for direct care workforce compensation.
- **HHS, DOL, and BLS** should collaborate to update the occupational codes assigned to direct care workers to reflect more accurately the wide range of jobs they perform and to better include those workers who do not fit squarely into current classifications.
- **FEMA, HHS, and ACL** should collaborate to develop specific distribution networks with state and local departments of public health and community-based organizations that are in direct contact with direct care workers and family caregivers (e.g., Aging and Disability Resource Centers, Independent Living Centers, grantees of the National Family Caregiver Support Program [NFCSP], veterans' organizations) that can assist with distribution of PPE and other resources and supplies during natural or public health emergencies, with an emphasis on reaching individual home care workers who do not work for a home health agency, in nursing homes, or other residential facilities and therefore do not have ready access to resources or collective purchasing power.

Recommendations for States and State Medicaid Agencies

- **States and State Medicaid agencies** should implement permanent policies that encourage and facilitate paid family caregiving and invest in support services for such caregivers.

Chapter 4: Education and COVID-19

Students with Disabilities Before and After the Pandemic

Under ordinary circumstances, students with disabilities—about 14 percent of students from kindergarten to 12th grade, and more than 7 million children—face multiple and substantial barriers to education. In 2018, NCD reported that the longstanding federal underfunding of the Individuals with Disabilities Education Act (IDEA) was adversely affecting the ability of students with disabilities to receive Free and Appropriate Public Education (FAPE), causing delays and denials of services, and triggering unfair social resentment and discrimination.⁴⁷⁰ NCD also found a nationwide shortage of qualified special education teachers and related service providers.⁴⁷¹

In this funding context, districts often fail to comply fully with the IDEA, and instead make decisions that ration and deny services and supports to meet the unique needs of students with disabilities.⁴⁷² Students with disabilities then suffer the consequences. Students with disabilities have lower test scores and are less likely to graduate high school.⁴⁷³ Just over 67 percent of students with disabilities graduate

high school, compared to about 85 percent of all students.⁴⁷⁴ Students with disabilities are more likely to be chronically absent.⁴⁷⁵ The “academic achievement gap” between students with and without disabilities has remained roughly unchanged over the last decade.⁴⁷⁶

Students with disabilities also have higher rates of discipline, including suspensions and referrals to law enforcement. Students with disabilities represent 12 percent of students enrolled, but are 26 percent of students

Just over 67 percent of students with disabilities graduate high school, compared to about 85 percent of all students.

receiving an out-of-school suspension, and 25 percent of students referred to law enforcement.⁴⁷⁷

Students with disabilities are much more likely than students without disabilities to be restrained and secluded at school,⁴⁷⁸ a dangerous and ineffective practice that has caused serious injuries and deaths.⁴⁷⁹ Rates of discipline and handcuffings at school are even higher and more disproportionate for Black students with disabilities.⁴⁸⁰

Discipline often causes exclusion from the classroom and lost instruction⁴⁸¹ and can advance the “school to prison pipeline.”⁴⁸² Up to 85 percent of youth in juvenile detention facilities have disabilities that make them

eligible for special education services, and a disproportionate number of percentages of these detained youth are youth of color.⁴⁸³

Many students with disabilities are multiply marginalized, which creates additional barriers to equal educational opportunity. Students with disabilities are more likely to be low-income.⁴⁸⁴ They are disproportionately

Black.⁴⁸⁵ They may be in the foster care system, or juvenile justice systems, or both. About 32 percent of children in foster care are children with disabilities,⁴⁸⁶ and, as noted, up to 85 percent of children in juvenile detention have disabilities. Children with disabilities may be homeless;⁴⁸⁷ they may be English language learners.⁴⁸⁸ Many experience intersectional discrimination based on multiple statuses, such as disability, sex, race, ethnicity, sexual orientation, gender identity, and size. These additional statuses and traumas exacerbate the vulnerabilities of those who are already struggling with academics, behavior, planning, speech, motor skills, and other areas essential to long-term success.

The COVID-19 pandemic worsened the educational experience for many students with disabilities.⁴⁸⁹ The shift from an in-person model of learning to fully remote education as the sole option for education exacerbated the exclusion of students with disabilities.⁴⁹⁰ Barriers to education were worse for students with disabilities in low-income households who did not have access to reliable high-speed internet and appropriate computers, or to adults with expertise in this technology.⁴⁹¹

During the pandemic, families with students with disabilities experienced the failure of school districts to provide notices, meetings,

assessments, plans, and services, and to comply with the procedural and substantive requirements of the IDEA and Section 504 of the Rehabilitation Act. A GAO study that interviewed researchers, representatives from

national organizations, and officials from four school districts, and reviewed the learning plans from 15 school districts, supported much of the anecdotal evidence of the pandemic's impacts on education for students with disabilities. It found that some students with disabilities did not receive all of the services and supports contained in their IEPs or Section 504 plans during shelter in place,⁴⁹² and many school districts shortened their school day for all students, making it difficult to find time to provide the specialized instruction and related services detailed in students' IEPs.⁴⁹³

The onset of the pandemic and remote learning for K-12 students triggered the abrupt cessation, often for months, of essential services and supports that are typically provided to students with disabilities in person or on school campuses, such as occupational therapy, speech and language therapy, behavioral and mental health supports, small group instruction, and one-on-one aides.⁴⁹⁴ Students with disabilities no longer had access to Braille or tactile learning tools. Officials from the school districts studied by the GAO reported that it was particularly difficult to deliver these "related services" that would ordinarily include hands-on instruction or

Many students with disabilities are multiply marginalized, which creates additional barriers to equal educational opportunity. Students with disabilities are more likely to be low-income. They are disproportionately Black.

equipment not available in families' homes.⁴⁹⁵ While some school districts implemented small in-person cohorts for children with disabilities or provided an in-person (at-home) aide for students who could not access a free and appropriate public education (FAPE) without in-person services, many school districts refused to do so.⁴⁹⁶ Even students with disabilities who were provided with an in-person setting on school campuses were often still receiving their instruction through a computer screen. In-person staff

wore masks and maintained distance, making any communication difficult for many students with disabilities, particularly those with hearing loss. Many K-12 students with disabilities were denied FAPE for months and even more than one year (the length of the pandemic). Many students with disabilities who rely upon in-person supports experienced substantial regression in their behaviors and educational goals.⁴⁹⁷

Many students with disabilities, including not only K-12 students but also students with disabilities at colleges and universities, struggled to engage and participate in their education once all learning moved to a virtual environment.⁴⁹⁸

Some schools failed to ensure that their remote educational programs and materials were accessible to students with disabilities, including

students who are Deaf or Hard of Hearing, students who have low vision or are blind, students with learning or attention disabilities, and students with psychiatric disabilities.⁴⁹⁹ A survey of more than 30,000 students at nine universities found that college students with disabilities were less likely during the pandemic to feel that they “belonged” at their

schools, or that their institution supported them, compared to students without disabilities.⁵⁰⁰

These students with disabilities were also more likely to be experiencing food and housing

insecurity.⁵⁰¹ As the pandemic continued, disability resource professionals—staff who ensure access and reasonable accommodations at colleges and universities—faced budget cuts, in some cases triggering layoffs.⁵⁰²

Some students with disabilities flourished in the remote classroom or experienced unexpected benefits. Some students with disabilities that affect their social and emotional

The onset of the pandemic and remote learning for K-12 students triggered the abrupt cessation, often for months, of essential services and supports that are typically provided to students with disabilities in person or on school campuses, such as occupational therapy, speech and language therapy, behavioral and mental health supports, small group instruction, and one-on-one aides.

A survey of more than 30,000 students at nine universities found that college students with disabilities were less likely during the pandemic to feel that they “belonged” at their schools, or that their institution supported them, compared to students without disabilities.

functioning experienced decreased social anxiety in the virtual learning environment and were able to participate more freely.⁵⁰³ Some students with disabilities had fewer challenging behaviors while learning from home because they faced fewer transitions in location and activity. Remote education also benefited some students with disabilities who rely on attendants, because it made it easier for these individuals to go off-camera when they needed to engage in personal care.

As a result of the pandemic and the gaps in the federal response to COVID, many K-12 students with disabilities experienced an extended exclusion from FAPE, and now need compensatory education to recover and regain skills they have lost. Students with disabilities at all levels including K-12 and postsecondary experienced barriers in remote educational programs and activities, including discrimination and denials of effective communication and reasonable accommodations.

The Heavy Impact of the Pandemic on Low-Income Families with Children with Disabilities

Children with disabilities disproportionately live in low-income households.⁵⁰⁴ These children, often children of color with disabilities, experienced particularly severe barriers to education during the pandemic. Many low-income parents lost their jobs or had work hours decreased after COVID-19 hit, and they struggled to feed their families.⁵⁰⁵ Among low-income families, families of Black, Hispanic/Latino, and Native American children were more likely to experience income loss and food insecurity.⁵⁰⁶ Parents who retained employment often had to work in person,⁵⁰⁷ preventing them from providing their children

with at-home supports for remote learning. Many low-income families did not have reliable internet, appropriate computers, or an area free of distraction for distance learning.⁵⁰⁸

A survey of 1,000 low-income families in Tulsa, Oklahoma, found that opportunities for learning shrank dramatically with the shift to remote instruction, especially for children with disabilities.⁵⁰⁹ Low-income parents of children with disabilities were more likely than other low-income parents to report problems with distance learning (83 percent versus 63 percent).⁵¹⁰ And almost half of low-income parents of children with and without disabilities reported that their children experienced increased emotional and behavioral problems during the pandemic.⁵¹¹

Broadband Technology, Computer Equipment, and Related Supports

When the pandemic hit, many students with disabilities were unable to access remote education due to technology barriers, including poor internet connections, outdated equipment, and difficulties with accessing and navigating online platforms.⁵¹² Some parents of students with and without disabilities were reported to child welfare agencies when their children did not participate in remote education and were found truant, even though in many cases the absences were related to technology, disabilities, lack of supports, the competing demands of the pandemic, or combinations of these factors.⁵¹³

Many students with disabilities, including children with learning, attention, and behavioral disabilities, struggled to focus and learn through a computer screen.⁵¹⁴ The consequences for students with disabilities, and particularly



students of color with disabilities, were at times dire. Grace, a 15-year-old Black girl in Michigan with Attention Deficit Hyperactivity Disorder (ADHD), spent 78 days in juvenile detention when her probation was revoked for her not completing her online work.⁵¹⁵ She reported feeling unmotivated and overwhelmed by online learning and got easily distracted without live instruction or structure.

Access to equipment and connectivity slowly improved as the pandemic continued, but barriers persisted.⁵¹⁶ And the primary response to the “digital divide” was for school districts to distribute tablets and hotspots. While this was an essential intervention, it did not represent a permanent solution. Tablets do not have the same level of functionality as laptops, and

hotspots—which can be slow and unreliable—are not a substitute for high-speed connection to the internet.⁵¹⁷

Reasonable Accommodations, Supports, and Accessibility in Remote Education

Many students with disabilities have disability-related barriers to learning in a remote environment. During the pandemic, some K-12 students with disabilities needed in-person supports such as one-on-one aides to prompt and sustain their attention to on-screen lessons. While in some cases this was the student’s parent or family member, some families were unable to perform this role for a variety of reasons, including competing

employment necessary to maintain basic human needs such as food and housing.⁵¹⁸ Some families needed in-person supports from outside the family, but these were denied by school districts.⁵¹⁹

Some students with disabilities experienced disability-related conduct during remote sessions; sometimes these students were removed from the digital “room” without appropriate procedures or documentation for the removal.⁵²⁰ Some students with disabilities could not participate with their camera turned on, including because of disruptive anxiety or other disability-related conditions, or due to aspects of their home environments. Despite such equity concerns, an October 2020 survey found that most K-12 teachers, principals, and district leaders required cameras to be turned on during remote sessions, and imposed consequences—including losing points and being marked absent—if students turned them off.⁵²¹ And as described above, some students with disabilities were reported as “truant” when they did not log in to class, including when this occurred because of disability-related barriers in accessing the virtual classroom.

Students with disabilities faced barriers when education moved online, because the digital platforms and related digital documents were not accessible. Students who are blind need audio description, sound options for verification, adjustments to increase font size, type, and color, magnification that does not destroy the integrity of the text or page, and compatibility with assistive technology such as screen readers.⁵²²

Students who use screen readers or Braille translation devices such as BrailleNote need accessible documents, but often did not receive them.⁵²³

Students who are Deaf or Hard of Hearing, and students with other disabilities, need accurate real-time captioning. Students with disabilities often need transcripts of remote sessions, including transcripts that can be converted into other formats such as large print or Braille. The availability of captions and transcripts for all students advances the principles of universal design.⁵²⁴

During the pandemic, many colleges and schools relied on automatic captioning to convert speech into text for students who need captions in class.⁵²⁵ While automatic captioning has improved, it does not offer many functions critical to the classroom setting such as proper grammar and punctuation markers, identification of multiple speakers and changes in speakers, and accurate captioning of technical vocabulary, jargon, and proper nouns. Automatic captioning does not allow for clarification or corrections.⁵²⁶ In many educational settings, students needed a professional captioner.

Students who are Deaf and who communicate using sign language need sign language interpreters integrated into the video platform. To see and understand the interpreter, Deaf students need to be able to view the speaker and the interpreter on the computer screen in larger boxes, and to reduce the size of the other video participants. These features were not available during much of the pandemic.⁵²⁷

Students with disabilities faced barriers when education moved online, because the digital platforms and related digital documents were not accessible.

Students with various disabilities may have needed other adjustments to remote educational platforms. Examples include having participants speak one at a time, ensuring that participants not speaking are on “mute,” and having instructors on video, with proper lighting and their faces clearly visible in the frame, to facilitate lip reading or perception of other visual cues.⁵²⁸

In-Person Services and Supports

During the pandemic, K-12 students with disabilities were particularly harmed by the cessation of virtually all services and supports that are typically provided to students with disabilities in person. Many students went months without essential services and supports such as occupational therapy, speech and language therapy, behavioral and mental health supports, small group instruction, and one-on-one aides. A review by GAO of the COVID-19 distance learning plans of 15 school districts found that none included details on how the specialized instruction or related services specified in students’ IEPs would be provided.⁵²⁹

For some students with disabilities, access to a free and appropriate public education and to equal employment opportunity thereafter is only possible with in-person instruction and/or supports. Many school districts across the country established and maintained in-person instruction for small cohorts of students with disabilities who could not learn in a remote environment. Some provided at-home aides for

students with disabilities who needed support. However, other school districts refused to provide any in-person instruction or supports for months or for as long as one year during the pandemic.⁵³⁰ Many parents did not have the specialized training, or the time, to fill these roles. The result for many students with disabilities was substantial regression.⁵³¹

Children with disabilities also experienced mental health crises during shelter in place, exacerbated by the lack of in-person mental health and behavioral health services. According to the CMS, between March and May 2020, children on Medicaid received 44 percent fewer outpatient mental health services—including

therapy and in-home support—compared to the same time period in 2019.⁵³² It is challenging to provide effective therapy in the remote environment to children with mental health disabilities. Many children do not have a private space with appropriate

technology (including broadband internet) to speak confidentially with a therapist. Children with mental health disabilities may struggle with attention, behavioral regulation, and dissociation, making it more difficult for clinicians to therapeutically engage through a video screen.⁵³³ Children with disabilities experienced significantly more mental health problems such as fear and anxiety than other children.⁵³⁴

With fewer effective outpatient options, children with disabilities increasingly ended up in emergency rooms, psychiatric hospitals, and residential treatment, and even jail.⁵³⁵ Across

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the country, journalists profiled the devastating impact of the pandemic on families of children with significant disabilities who needed in-person supports. For example, in Philadelphia, Aaron and Syrita Powers parent three children with disabilities, a 12-year-old girl with autism, a 10-year-old nonverbal girl with intellectual disability, and an eight-year-old nonverbal girl with autism. Before the pandemic, the three children attended school every day, and were supported in their educational goals by therapies, tutoring, and paraprofessionals. The oldest child attended an afterschool program.⁵³⁶ That all changed abruptly when schools closed in March 2020. Because of a lack of technology available to students, online teacher-led instruction did not begin until May 2020. Even when online school began, it was not effective for the two younger children due to their disabilities. Some therapies were offered by the district, but only remotely, which did not work for the younger children. And the oldest child was distracted from her online education by the needs of her siblings. With the demands of parenting during the pandemic, Aaron and Syrita skipped doctors' appointments for their own disabilities (kidney disease and fibromyalgia).⁵³⁷

All three children regressed substantially during the pandemic, when they did not attend in-person school for more than one year. The two younger children lost their toilet training, and their educational goals—holding a pencil, writing some words, sitting down, and following instructions—deteriorated. The oldest child lost ground in math and social skills and began carrying and speaking

with a stuffed animal. Even after one month of in-person instruction beginning in April 2021, there was no change in the youngest child's regression.⁵³⁸

Outside of Atlanta, 17-year-old Lindsay who has autism experienced a mental health crisis when schools closed. Without the routine of in-person school and the support of in-person therapies, Lindsay began walking out of the house and wandering several times a week. Her mother, a nurse, would try to call the mental health crisis line to seek a crisis team, but would often be put on hold for 40 or 50 minutes. After an incident in which Lindsay walked into a Family Dollar retail store in a t-shirt and underwear to get Doritos, she ended up tackled and handcuffed

by police, and spent most of a night in jail until her mother was able to post bail.⁵³⁹

In Los Angeles, Luis Martinez, an 11-year-old nonverbal fifth grader with autism, rarely missed a day of school

before the pandemic, and enjoyed seeing his friends and teachers. But after ten months of remote education, Luis stopped looking at his tablet or making any attempt to interact with his peers online. He began acting out nearly every day, scratching and biting himself and members of his family out of frustration.⁵⁴⁰

In Whittier, California, six-year-old Mateo has Phelan-McDermid syndrome, a rare genetic condition causing developmental delays and limited fine motor skills. He has difficulty walking and is nonverbal, and usually uses a device to communicate. During the in-person portion of the school year, he made progress working with his teacher and speech, occupational, and physical

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therapists. After the pandemic hit, his progress stalled. His speech therapy, which was previously three times a week for half an hour each time, was cut to once a week for about 15 minutes. He stopped learning new vocabulary, tasks, or modes of communication.⁵⁴¹

On May 6, 2021, a parent testified about his experiences during the pandemic with his nine-year-old son with autism and ADHD, and his nine-year-old daughter with cerebral palsy and intellectual disability, before the U.S. House of Representatives Subcommittee on Early Childhood, Elementary, and Secondary Education.⁵⁴² He described how his children regressed and deteriorated with no in-person services, and his son ended up suicidal and hospitalized. Because his daughter cannot engage in learning over an iPad, his wife had to quit her job to stay home to provide schooling. When schools opened part-time in March 2021, his son was a whole year behind in reading. So far, the school has only offered this child 30 minutes of extra support per week.

These are just a handful of accounts of the experiences of thousands of families of children with disabilities. These stories and others attest to how the effects of the pandemic will be long lasting for families of children with disabilities who need in-person education and supports to learn and thrive in the community.

Sustained access to compensatory education will be critical for students with disabilities who needed in-person supports and services, but who did not get them during the pandemic.

The Pandemic's Impact on Native American Students with Disabilities

Native American students with disabilities served through the Bureau of Indian Education (BIE)

received few educational services during the pandemic, effectively losing more than one year of education. Throughout the pandemic, BIE failed to issue comprehensive distance learning guidance to BIE schools, despite a need for such guidance.⁵⁴³ Instead, in August 2020, BIE issued a reopening guide for the 2020–2021 school year focused on in-person school, even though COVID-19 infection rates were high in rural Native communities, and nearly all schools were closing or planning for distance learning for the fall of 2020.⁵⁴⁴

The BIE and other Interior offices provided over 7,000 hotspots to students to improve home internet access, but they did not order laptops for most students until September 2020. Most BIE schools received laptops from late October 2020 to early January 2021, and some laptops still had not been delivered as of late March 2021. Once laptops were delivered, schools faced challenges configuring them, leading to further delays in distributing them to students. By the end of December 2020, more than 80 percent of the laptops had not been delivered by schools to students. As a result, most BIE students who received laptops did not get them until several months after the school year began.⁵⁴⁵

While these failures in pandemic response affected all students, BIE students with disabilities also did not receive the services and supports required by IDEA. The National Indian Education Association (NIEA) found that 21 percent of BIE schools closed during COVID-19 and did not provide any services to their students, including students with disabilities. Thirty-four percent of BIE schools sent home learning packets for their students to work on during school closures, and 30 percent sent students technology devices to use at home.⁵⁴⁶

The relatively high percentage of BIE schools using learning packets correlates to the substantially lower level of connectivity in Native American communities. According to a survey by the NIEA, 40 percent of students who attended BIE schools reported that they had no access to internet services during school closures. Another 34 percent reported that they used a cell phone for their internet service. Only about 21 percent of BIE students had access to broadband internet.⁵⁴⁷ The American Community Survey

also found that fewer than half of households in many BIE school communities had access to broadband internet prior to the pandemic, and that connectivity is particularly limited on the Navajo Nation Reservation, the site of more than one-third of BIE schools.⁵⁴⁸ Internet access

was higher for Native American students who were in public school, but still much lower than for non-Native students, with 16 percent reporting no access to the internet during school closures and 22 percent accessing the internet through a cell phone.⁵⁴⁹

During the pandemic, Native American households had fewer resources to pay for internet or cell phone data during the pandemic. Families were struggling to secure food, as

sources of revenue were closed, and children were not eating any meals at school.⁵⁵⁰ Moreover, providing hotspots and laptops could not resolve barriers to connectivity. Native American families

in remote tribal areas may not have electric service at all and must depend on generators to power all appliances that require electricity, including laptops and hotspots.⁵⁵¹ Moreover, hotspots do not function in rural areas without cell coverage.⁵⁵²

Educators who attempted to serve Native students with

disabilities in these challenging environments reported using a variety of approaches. Some examples included: sending text messages to family members with ideas for gross and fine motor activities that could be done at home; having the speech pathologist, occupational

therapist, and physical therapist provide consultation to the family through phone calls, and then sending parents hard copies of suggested activities to do at home with their children; sending special education and general education packets to the student's

home, or delivering these packets by school bus; making materials available for pickup or delivering equipment such as walkers, communication devices, and assistive technology; and conducting

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IEPs by phone. Where families and children had connectivity, special education teachers and related service providers conducted short classes or sessions online, and IEPs could be conducted by videoconference. In some cases, parents declined special educational services or requested that teachers and service providers stop calling them, which may have been due to concerns about increased use of the family's cell phone minutes.⁵⁵³

The efforts of some dedicated educators did not change the fact that for over a year many Native American students with disabilities received none of the services in their IEPs. Moreover, the failure of BIE to provide or ensure necessary IDEA services and supports predates the pandemic. In an analysis of BIE school documentation from late 2017 and early 2018, the GAO found that the BIE either did not provide or did not document 38 percent of special education and related service time for students with disabilities.⁵⁵⁴ The agency also failed to comply with an obligation to verify that IDEA services were provided at all BIE schools each year, and instead only checked services at one-third of schools.⁵⁵⁵ The BIE failed to provide required technical assistance to 14 schools that were determined to be at high risk of not complying with IDEA, and provided required monitoring reports late.⁵⁵⁶ The BIE acknowledged that its field staff were not qualified to support schools on their IDEA obligations.⁵⁵⁷

Summary of Findings

- The federal, state, and local response to COVID-19 left behind many K-12 and postsecondary students with disabilities.
- During the shelter-in-place period, many K-12 students with disabilities did not receive

FAPE over an extended period of time and went months without essential services and supports that are usually provided in person. Many students with disabilities did not learn and experienced regression in their behavioral and educational goals.

- Children with disabilities in low-income households, and particularly children of color with disabilities in low-income households, experienced particularly severe barriers to remote education during the pandemic.
- Many students with disabilities were unable to access remote education due to technology barriers, including lack of access to broadband internet and appropriate equipment.
- While some students with disabilities flourished in the remote learning environment, many students with disabilities struggled to focus and learn through a computer screen. Punitive responses to students with disabilities who did not attend or engage in remote education were counterproductive and had particularly dire consequences for students of color with disabilities.
- At all levels including K-12 and postsecondary, students who are Deaf, Hard of Hearing, blind, or with other disabilities faced access barriers in digital platforms and related digital documents.
- Without access to effective mental health supports, including in-person supports, some children with disabilities experienced mental health crises during the COVID-19 pandemic, ending up in emergency rooms, psychiatric hospitals, residential treatment, and even jail.

- Native American students with disabilities served through the BIE received few educational services during the pandemic, effectively losing more than one year of education.
- Many students with disabilities now require compensatory education to allow them to recover and regain skills lost during the COVID-19 pandemic, or to learn them for the first time.

Without better guidance, planning, and investment before the next national public

health crisis or other emergency, students with disabilities will again experience the denial of FAPE and equal education opportunity.

Recommendations

To ensure the United States is prepared to continue providing special education services and supports needed by students with disabilities to maintain educational benefit during a future pandemic or similar national health crisis, NCD recommends the following actions:

Recommendations for Congress

Congress should:

- Ensure that new or amended legislative proposals.
- Include funds dedicated to compensatory education for students with disabilities who were denied necessary educational services and supports during the pandemic and who have experienced disruption and regression in their behavioral and educational goals. Priority should be given to compensatory education for children with disabilities living in low-income families, children with disabilities who needed—but did not receive—in-person instruction and supports, and Native American children with disabilities.
- Include funds dedicated to making high-speed broadband internet available to and affordable for everyone, and particularly for low-income families, homeless families, and families in rural and other areas where high-speed internet access is not consistently available. Federal recovery efforts must continue to expand connectivity in Native American communities, with a focus on BIE school communities and American Indian reservations. Funds should be allocated soon to ensure that every student has an appropriate laptop or tablet for remote education so that education is not interrupted by another emergency.
- Include funds dedicated to the U.S. Departments of Education and Justice, and to state departments of education, for prompt and effective complaint processing, including free voluntary mediation, for complaints of denial of FAPE and disability discrimination in education during the COVID-19 pandemic.

Recommendations for Federal Agencies

U.S. Department of Education (ED) should:

- Direct school districts to provide compensatory education to students with disabilities to allow them to recover and regain skills. The right to and need for compensatory education should be presumed for children with disabilities who did not receive necessary instruction and supports during the COVID-19 pandemic. Given the extended crisis and national emergency caused by the pandemic, the extent and duration of gaps in educational services, and the known impacts on children with disabilities, families should have a right to “opt in” to compensatory education without any requirement of an extensive individualized factual showing. Sustained access to compensatory education will be critical for many students with disabilities because they were virtually excluded from all education for more than one year.
- Direct school districts to structure compensatory education to provide families with the option to receive additional educational services over several years following the pandemic. Such services should extend past age 22 if the student needs them to make up for the education lost.
- Direct school districts to assess and support access to computer technology for students with disabilities as part of the IEP or Section 504 plan, and should clarify that computer equipment, broadband internet, and computer training are appropriate IEP services.
- Direct school districts to provide in-person services and supports as necessary for students with disabilities to access FAPE and to prevent regression, mental health crises, institutionalization, and family separation, even during a pandemic or public health emergency.
- Affirm that removals from a digital classroom are subject to the same procedures and documentation requirements that apply to removals from a regular classroom. ED should direct schools not to remove students with disabilities from remote sessions for purported misconduct without considering reasonable accommodations and supports. These principles should be established and made known to parents in the event of a future public health emergency.
- Prioritize resolution of complaints of denial of FAPE and disability discrimination that occurred during the COVID-19 pandemic, including through the use of free voluntary mediation.

(continued)

Recommendations for Federal Agencies: *continued*

ED and DOJ should:

- Issue joint guidance to school districts and child welfare agencies directing them to intervene in a problem-solving rather than punitive manner to address student truancy from remote education caused by disabilities, lack of technology, or lack of supports.
- Issue a joint guidance document outlining the elements of accessible remote education for students with disabilities. The guidance should review accessibility requirements for digital platforms and digital documents and emphasize the necessity of designing remote education to be fully accessible to students who are Deaf, Hard of Hearing, and/or blind, or who have other disabilities. The guidance should review necessary auxiliary aids and services such as real-time captioning, accessible transcripts, sign language interpreting, and alternative formats. The guidance should specify the educational contexts in which automatic captioning is not appropriate and detail the features necessary to properly integrate sign language interpreters into a video platform.

Federal Communications Commission (FCC) should:

- Take affirmative steps to make high-speed broadband internet available to and affordable for everyone, including Native Americans and people with disabilities living in rural areas. The FCC's Lifeline program should be expanded to provide high-speed broadband internet to low-income households for \$10.00 a month.

Congress should task GAO with:

- Continuing to audit the performance of the BIE during and after the pandemic, including for children with disabilities.

ED and U.S. Department of the Interior should:

- Cooperatively develop, and have the BIE implement, a plan for bringing BIE schools into compliance with the IDEA and Section 504 and delivering compensatory education for Native American children with disabilities who were impacted by the pandemic.

Recommendations for States and State Agencies

State Education Agencies should:

- Direct school districts to provide compensatory education to students with disabilities to allow them to recover and regain skills. The right to and need for compensatory education should be presumed for children with disabilities who did not receive necessary instruction and supports during the COVID-19 pandemic. School districts should offer flexible options for receiving compensatory education over several years following the pandemic.
- Direct school districts to provide in-person services and supports necessary for students with disabilities who require them to receive FAPE and to prevent regression, mental health crises, institutionalization, and family separation, even during a pandemic or public health emergency.
- Direct school districts that student removals from a digital classroom are subject to the same procedures and documentation requirements that apply to removals from an in-person classroom.
- Prioritize resolution of complaints of denial of FAPE and disability discrimination that occurred during the COVID-19 pandemic, including through the use of free voluntary mediation.
- Work with appropriate federal and state agencies to develop and implement plans for ensuring timely and effective delivery of special education services to Native American children in geographic areas where those children can attend public schools or BIE schools.

Chapter 5: Employment and COVID-19

Employment of People with Disabilities Before and After the Pandemic

The passage of the ADA more than 30 years ago advanced a vision for people with disabilities that included among its core principles economic self-sufficiency and full participation in the mainstream economy. The ADA instituted new requirements for how employers were required to evaluate the capabilities of people with disabilities, and spurred the development of accommodations, services, and supports for individuals with significant support needs to succeed in many work environments. Since its enactment, barriers to employment have been lifted for millions, and many individuals with disabilities have been able to secure employment.⁵⁵⁸

At the same time, a large proportion of people with disabilities remain “persistently locked out of employment,”⁵⁵⁹ and people with disabilities disproportionately live in poverty.⁵⁶⁰ Prior to the COVID-19 pandemic, nearly two-thirds of working-age Americans with disabilities were left out of the labor market altogether.⁵⁶¹

Fewer than one-third of working-age people with disabilities had a job, compared to nearly three quarters of working-age people without disabilities.⁵⁶² This employment gap of 40 or more points has remained steady for years.⁵⁶³ Federal investments in vocational services, and tax credits for employers that hire and retain people with disabilities,⁵⁶⁴ have not been adequate to significantly alter employment and labor participation rates for people with disabilities.

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Many people with disabilities excluded from the labor market are in a “poverty trap”; they rely on federal public assistance programs, and cannot work without losing essential healthcare.⁵⁶⁵

For example, people with disabilities who need Medicaid to pay for necessary services like personal care attendants face an abrupt loss of this life-sustaining coverage should their earnings exceed certain modest caps.⁵⁶⁶ Congressional efforts to reduce the barriers to work imposed by the SSA programs have resulted in complex exemptions that have achieved only very small positive effects.⁵⁶⁷ Individuals with disabilities who rely upon SSI receive a benefit amount below the federal

poverty level, and more than two-fifths of SSI beneficiaries live below the poverty line.⁵⁶⁸

The unemployment rate for persons with a disability, at 12.6 percent in 2020, increased by 5.3 percentage points from 2019. Their jobless rate continued to be much higher than the rate for those without a disability. (Unemployed persons are those who did not have a job, were available for work, and were actively looking for a job in the four weeks preceding the survey.)⁵⁶⁹ The 2019 unemployment rate for persons without a disability increased by 4.4 percentage points to 7.9 percent in 2020. In 2020, 17.9 percent of persons with a disability were employed, down from 19.3 percent in 2019.⁵⁷⁰ In contrast, 61.8 percent of people without a disability were employed in 2020, down from 66.3 percent in the prior year. In 2020,

persons with a disability were more likely to work in service occupations than those with no disability (18.0 percent, compared with 15.4 percent). Workers with

a disability were also more likely than those with no disability to work in production, transportation, and material moving occupations (14.9 percent, compared with 12.2 percent). Persons with a disability were less likely to work in management, professional, and related occupations than those without a disability (36.1 percent, compared with 43.3 percent),⁵⁷¹ a fact that closely related to their ability to telework—as the ability to telework was far greater in these occupations.

These significant problems of exclusion and unemployment for people with disabilities have persisted throughout a time period that has otherwise been characterized by a rapid pace of innovation and disruptive changes in the

American workplace—including greater flexibilities, technology, and diversity—and the recovery from the Great Recession to the lowest overall unemployment rate in decades.⁵⁷² Emerging employment opportunities in an increasingly digital world have not translated into more jobs for people with disabilities. The fastest growing and most dynamic technology-based industries have the poorest representation of people with disabilities.⁵⁷³

The sustained failure to fund and implement the IDEA exacerbates and contributes to the employment gap experienced by people with disabilities. Young people with disabilities are twice as likely as their peers without disabilities to have no high school diploma, leaving them unqualified for many jobs.⁵⁷⁴ Only 16.1 percent of

people with disabilities earn a bachelor’s degree or more, compared to 39.2 percent of people without disabilities.⁵⁷⁵

These failures in education translate into exclusion from

employment for young adults with disabilities. In 2019, before the onset of the pandemic, 40.2 percent of young people with disabilities ages 20–24 years were employed, as compared to 73.4 percent of their peers without disabilities.⁵⁷⁶ One year out of school, only 17 percent of youth with intellectual and developmental disabilities and 12 percent of youth with multiple disabilities were employed.⁵⁷⁷ Many of these youth are made to participate in school transition programs where they are trained to perform manual tasks. These youth are often referred to sheltered workshops directly from school, where they earn far less than the minimum wage under section 14(c) of the Fair Labor Standards Act.⁵⁷⁸

The fastest growing and most dynamic technology-based industries have the poorest representation of people with disabilities.

The onset of the COVID-19 pandemic triggered a massive decline in employment, and the initial hit had a disproportionate impact on people with disabilities. By the end of April 2020, nearly 1 million people with disabilities lost their jobs, representing about 20 percent of working people with disabilities. By comparison, 14 percent of people without disabilities lost their jobs.⁵⁷⁹

School closures forced by the pandemic also had a disproportionate impact on young people with disabilities, who were depending upon transition and other IDEA services to prepare to leave school and enter the workforce. These services are typically provided in person to students with disabilities. With school days shortened and instruction moved to remote platforms, school districts struggled to deliver required IDEA services.⁵⁸⁰ Many states and districts failed to plan for or provide postsecondary preemployment transition services during the COVID-19 pandemic.⁵⁸¹ Although the U.S. Department of Education stated that state departments of rehabilitation must continue to make “good faith and reasonable efforts” during the pandemic to provide preemployment transition services to students with disabilities,⁵⁸² deadlines were extended and in practice such services were interrupted and delayed.⁵⁸³

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Against this backdrop of historic barriers, and the disproportionate impact of the pandemic, individual people with disabilities worked, teleworked, looked for work, lost their jobs, and navigated unemployment benefits. Many workers

with disabilities have medical statuses putting them at risk for severe outcomes from COVID-19 infection and struggled to balance their own safety with their need to go to work and earn a wage. Households including people with disabilities

faced the multiple challenges of managing COVID-19 safety protocols, employment, job loss, caregiving, and remote K-12 learning.

“Reasonable accommodations” under the ADA helped some workers but not others. Gaps in civil rights protections became apparent. Some workers at sheltered workshops were

denied unemployment benefits. And the extended duration of the pandemic pushed some workers with disabilities—and particularly older workers with disabilities—out of the labor market altogether.

Unemployment and Other Income and Job Supports

As discussed above, people with disabilities who rely upon SSI and/or SSDI frequently cannot work because their earnings would threaten their access to the essential healthcare coverage that is

provided through these assistance programs—a “poverty trap.” The COVID-19 relief packages have included three economic incentive payments totaling a maximum of \$3,200 per individual. These incentive payments were available to beneficiaries of SSI and SSDI without the need for complicated paperwork and without jeopardizing their benefits. For individuals receiving the maximum federal SSI benefit of \$783 per month, the three economic incentive payments raised their income by nearly 35 percent and posed no threat to their healthcare coverage. The simplicity of this approach should be the standard for a reimagining of the “working while disabled” programs of the SSA, which are complex and have had only very small positive effects of bringing people with disabilities into employment.⁵⁸⁴

For people with disabilities facing unemployment during the pandemic, federal relief has been necessary but inadequate. The Paycheck Protection Program helped employers keep some people employed, particularly in the service industries in which many people with disabilities work. But many businesses closed and could not retain employees. It is difficult to know how many jobs were saved,⁵⁸⁵ and there is no way to know how many were held by people with disabilities.

People with disabilities who lost their jobs due to the pandemic could apply for unemployment, and people who quit because they have medical conditions making them vulnerable to severe effects from COVID-19, or because of a household member with such

a medical condition, were generally able to access unemployment benefits.⁵⁸⁶ Many people with disabilities have medical conditions that made them more vulnerable to severe or life-threatening outcomes from COVID-19.⁵⁸⁷ Access to unemployment benefits for people with disabilities vulnerable to COVID-19, and for their household members, was critical to the safety and economic stability of people with disabilities.

In response to the overall loss of employment due to the pandemic, the federal government, which ordinarily pays a share of state unemployment benefits, boosted the weekly amounts available

to many beneficiaries, by \$600 for about four months, and by \$300 for longer, but provided no supplement at all during a gap in the fall and winter of 2020. Without the federal supplements, the unemployment benefit amounts varied greatly from state to state, and at best were modest (one-third to

[The] incentive payments were available to beneficiaries of SSI and SSDI without the need for complicated paperwork and without jeopardizing their benefits. . . . The simplicity of this approach should be the standard for a reimagining of the “working while disabled” programs of the SSA . . .

half of the individuals’ earnings, with a cap). This was particularly true for people with disabilities because the amount of unemployment benefits is based upon the amount of the person’s prior earnings, which is generally lower for people with disabilities.⁵⁸⁸ Federal pandemic support also included access to unemployment benefits for self-employed, gig, freelance, and part-time workers. This was critical to many workers with disabilities, who are more likely than workers without disabilities to work for themselves or to work part-time.⁵⁸⁹

In many states, there were huge backlogs before people received unemployment benefits.

Some people waited weeks to get their application processed. The waits were even longer for people who had to appeal the denial of benefits. It was virtually impossible for claimants to reach a benefits worker by phone to resolve issues such as delayed payments or website problems.⁵⁹⁰ Many people were deterred from filing or pursuing these claims due to these problems.⁵⁹¹ While there are no formal studies yet, it is likely that those deterred from accessing the benefits owed to them included large numbers of people with disabilities, including people with cognitive, intellectual, developmental, and attention disabilities, who faced disability-related barriers in accessing state unemployment benefit systems.⁵⁹²

Technology, Telework, and Remote Work

The pandemic created an unprecedented expansion in telework in certain sectors.⁵⁹³ Up to half of American workers teleworked during the pandemic, and remote workdays doubled.⁵⁹⁴ The expansion of telework had disparate effectiveness, positive and negative, on employees with disabilities.

The ability of employees with and without disabilities to telework was closely related to education level, which had a disproportionate impact on people with disabilities. Very few people with no education beyond high school were able

to telework during the pandemic.⁵⁹⁵ Those who switched to telework reported higher income and education and better health than those who did not change their typical in-person work.⁵⁹⁶ Data

shows that people with disabilities are less likely than people without disabilities to graduate from high school⁵⁹⁷ or to achieve a bachelor's degree.⁵⁹⁸

The switch to telework was of great benefit to

many people with disabilities who, prior to the pandemic, had advocated for more telework.⁵⁹⁹ Telework offered workers with disabilities more flexibility, and improved the ability to avoid barriers to working such as inadequate accessible public transportation.⁶⁰⁰ Many people with disabilities flourished in a digital environment, in some cases more so than in person. Among people with and without disabilities, more than half of those

telecommuting during the pandemic said that, given a choice, they would want to keep working from home even after the pandemic.⁶⁰¹ Many said that telework provided greater flexibility, and made it easier to balance

work and family responsibilities.⁶⁰²

Expanded telework and remote work also offer the hope of increased job opportunity for the disproportionate number of people with disabilities who live in rural areas.⁶⁰³ Rates of employment are lower in rural areas for both people with and without disabilities, but the differences are more pronounced for people with disabilities.⁶⁰⁴ Computers and

Telework offered workers with disabilities more flexibility, and improved the ability to avoid barriers to working such as inadequate accessible public transportation.

Among people with and without disabilities, more than half of those telecommuting during the pandemic said that, given a choice, they would want to keep working from home even after the pandemic.

high-speed internet must be viewed as necessary utilities for people with disabilities, particularly in rural areas.⁶⁰⁵ While the large majority of working-age people with disabilities have broadband internet, a computer, and a smart phone,⁶⁰⁶ people with disabilities experience a “digital divide” and are less likely than people without disabilities to have these technologies.⁶⁰⁷

Some employees with disabilities were not able to telework, including those with jobs that are not well suited for telework, those who are not allowed by their employers to telework, those for whom telework is not accessible, and those who have been laid off or whose jobs have been eliminated.⁶⁰⁸ Some supports, such as job coaching for people with intellectual disabilities, moved to digital platforms, which worked for some but not all people with disabilities in supported employment.⁶⁰⁹

Some employees with disabilities faced barriers to participating in employment-related meetings on Zoom or other digital platforms. These include some workers with medical conditions such as migraines who experience triggered or worsening symptoms when they look at a computer for too long or when they use digital meeting platforms,⁶¹⁰ or employees with sensory disabilities, such as people who are Deaf, Hard of Hearing, blind, or low vision, who experienced barriers in using digital platforms. In many cases, accessibility can be feasibly provided in the platform by employers.⁶¹¹

In 2018, the federal government employed about 269,000 people with disabilities.⁶¹² About 40,000 of them had “Targeted Disabilities,” defined as severe disabilities that are associated with high rates of unemployment and underemployment.⁶¹³ Most federal workers who telecommuted during the pandemic, and who responded to an anonymous online survey, said that their productivity either

increased or stayed the same since the pandemic began.⁶¹⁴ Most said that they think that their agencies will have greater support for remote work even after the pandemic is over.⁶¹⁵ On June 10, 2021, the U.S. Office of Personnel Management together with the General Services Administration issued a guidance document to federal agencies on personnel policies for reentry that includes guidance on telework.⁶¹⁶ The document states that the federal government’s nationwide operating status remains at “open with maximum telework flexibilities” for workers eligible for telework,⁶¹⁷ and emphasizes the value of tools such as telework, remote work, and flexible work schedules to advance federal agency goals effectively and efficiently:

OPM/GSA Guidance on Telework

Agency leaders can leverage issues such as telework, remote work, and flexible work schedules as tools in their broader strategies for talent recruitment and retention, and for advancing diversity, equity, inclusion, and accessibility in the Federal workforce. . . . As shown during the pandemic, agencies can, where appropriate, deploy personnel policies such as telework, remote work, and flexible work schedules effectively and efficiently as strategic management tools for attracting, retaining, and engaging talent to advance agency missions, including in the context of changes in workplaces nationwide as a result of the pandemic and in response to long-term workforce trends.⁶¹⁸



The document urges all agencies “to consider telework as part of overall strategic workforce planning,” and “to think of remote work as another option in their overall strategic workforce planning to assist them in competing for top talent.”⁶¹⁹ The document states that decisions about telework should be based on job functions and other mission-related priorities, “rather than mere managerial preference.”⁶²⁰ Workers with disabilities have a greater opportunity to succeed when the flexibility of telework is incorporated into the ordinary policies and practices of the employer, which may now be the case for the federal government.

Reasonable Accommodations and Leaves of Absence

Telework

Prior to the COVID-19 pandemic, telework was used by relatively few employees—about 7

percent of private sector workers and 4 percent of state and local workers.⁶²¹ But when the pandemic hit, many employers had no choice but to switch to a largely remote work environment for all workers, with and without disabilities.⁶²² Over the months of the pandemic, working from home became the “new normal” for many workers, with up to half of the workforce telecommuting.⁶²³ As a result of this experience, there is renewed interest in and acceptance of teleworking, which offers cost savings and a recruitment edge for employers and flexibility for workers, including individuals with disabilities.⁶²⁴ Employees with disabilities may benefit from the expansion of telework, which has resulted from economically common needs and experiences during the pandemic.⁶²⁵

EEOC has long recognized telework as a form of reasonable accommodation under the Americans with Disabilities Act.⁶²⁶ A qualified

employee with a disability may be entitled to telework as an accommodation when they need the arrangement to perform the essential functions of the job and/or to enjoy equal employment opportunity.⁶²⁷ Telework can help remove a range of disability-related work barriers, including difficulties commuting to and from work, accessibility barriers or environmental issues at the worksite, and the need for regular access to private spaces or the bathroom to attend to disability treatment or symptoms.⁶²⁸ During the pandemic, telework was an essential reasonable accommodation for workers with disabilities who were at increased risk for severe illness or death from acquiring COVID-19. These disabilities included diabetes, HIV, cancer, stroke, Down syndrome, lung, heart, and liver diseases, and additional disabilities.⁶²⁹

At the same time, telework was not always easily granted by all employees everywhere. Disability Rights Texas, in testimony submitted to an April 2021 EEOC hearing, reported that it received dozens of employment-related intakes in Texas during the pandemic.⁶³⁰ More than 60 percent involved an employer rejecting a telework accommodation. In some cases, the workers were permitted partial telework, but were refused a full-time remote assignment.⁶³¹ Most of the intakes were from employees with a high-risk health condition or disability, but in some cases telework was needed by individuals who had a mental health condition that was exacerbated by the pandemic.⁶³²

These telework cases reflected a broad range of jobs. The most common setting was in the school context, both public and private, including teachers, professors, coaches, administrators, counselors, instructional aides, and support personnel. But many other parts of

the economy were also represented, including real property management, real estate, state and local employees, mental health and addiction counselors, social workers, call center employees, and technical writers.⁶³³ Some employers required a certain date by which the person with a disability would stop teleworking and start working on site. But before vaccine appointments became widely available, there was no way to provide such a date.⁶³⁴

Where telework was refused as a reasonable accommodation during the pandemic, the employee with a disability was left with bad choices: requesting unpaid leave, quitting, or returning to work and risking acquiring the virus. Workers with disabilities who went on unpaid leave lost their usual income, and were more likely to lose their jobs altogether, particularly as the pandemic went on. There is also indication that women with disabilities and particularly women of color with disabilities were hit particularly hard by employers' refusal to grant telework. Many women with "high-risk" disabilities were insufficiently accommodated in entry-level jobs and also had greater caregiving responsibilities. Now these workers must explain a significant gap in their employment history as they seek new employment.⁶³⁵ During fiscal year 2020, which included seven months of the pandemic, the EEOC saw a small uptick in the frequency of claims of disability discrimination (from 24,238 to 24,324), while a number of other types of claims decreased.⁶³⁶

In 2020, the District Court for Massachusetts granted a preliminary injunction to allow the plaintiff, an assistance manager for a mental health provider, to continue to telework. The plaintiff had moderate asthma that imposed a

greater risk of serious illness if they contracted COVID-19. The employee tried to return to the office but was not given PPE and was exposed to other people not wearing masks. The plaintiff returned to teleworking without the accommodation being approved and understood that they would be fired as a result; the lawsuit followed.⁶³⁷ After the court granted the injunction, the case settled.⁶³⁸ Many employees with disabilities do not have a lawyer to represent them in court.⁶³⁹

Some employers who allowed telework during the pandemic ended the practice once vaccines became available and directed employees to return to the workplace.⁶⁴⁰ But some workers with disabilities still needed telework as a reasonable accommodation, either because of the continued effects of the pandemic, or for other disability-related reasons. The EEOC has stated that the fact that an employer has permitted telecommuting for a period of time during the pandemic does not mean that it is a required reasonable accommodation.⁶⁴¹

If, because of the experience during the pandemic, more employers offer flexible hours, remote work, and telework into the future, this could greatly expand employment opportunities for workers with disabilities.⁶⁴² Telework can allow individuals with disabilities to work even if they have disability-based limitations to travel such as not driving due to disability, and despite ongoing access barriers in the transportation system.⁶⁴³ Increased availability of remote work could also improve job opportunity for the disproportionate number of people with disabilities who live in rural areas and who experience lower rates of unemployment.⁶⁴⁴ The success of the federal government in maintaining its efficiency and productivity during

the 18 months that most federal employees teleworked should guide public policy with respect to telework.

Leaves of Absence

For people with disabilities who were vulnerable to severe outcomes from COVID-19 infection, accessing sufficient job-protected unpaid leave during the pandemic was difficult. While the Family and Medical Leave Act was helpful, it grants only 12 weeks of job-protected leave and is available only to a small portion of the workforce—those employees who work for large employers and who have one year’s tenure and sufficient hours.

The ADA may provide additional job-protected leave, but the case law is mixed. While some ADA case law is protective, other ADA cases hold that indefinite or lengthy leaves are not required as reasonable accommodations. For example, in *Hwang v. Kansas State University*, a professor with cancer requested an extension of leave beyond six months because there was a flu epidemic on campus and her immune system was compromised. She was fired. In 2014, the court of appeals for the Tenth Circuit ruled that her termination was not disability discrimination.⁶⁴⁵ During the pandemic, leaves of absence sufficient to reach the end of the pandemic or the rollout of vaccines were typically both indefinite and lengthy.

Accommodations for People with COVID-19–Vulnerable Household Members

The pandemic revealed a substantial gap in civil rights protections: Many employees needed reasonable accommodations such as telework, not because of their own vulnerability, but because

they were household members and caregivers of people with disabilities who were vulnerable to severe effects from COVID-19 infection. There is no civil rights law that adequately protects this group of workers. According to EEOC guidance, employees without disabilities are not entitled to reasonable accommodations needed to protect a vulnerable household member or care recipient.⁶⁴⁶

Some of these household members and caretakers took unpaid leave. Some went to work and took the risk that they would spread the virus to the vulnerable person. Some quit. For those who took unpaid leave, leave was often not guaranteed or job-protected. As noted above, most employees are not covered by the Family and Medical Leave Act, and even those who are covered are only entitled to up to 12 weeks of unpaid leave.

Masks and Other COVID-19 Safety Protocols at Work

CDC recommended cloth masks or other face coverings and social distancing for individuals older than two years during the pandemic, including people who were not medically at risk.⁶⁴⁷ During the pandemic, as a matter of basic workplace safety for all employees, employers should have monitored and enforced compliance with COVID-19 protocols such as masks and social distancing.

In addition, compliance with COVID-19 protocols was a form of reasonable

accommodation that was needed by some employees with disabilities during the pandemic. These included people who had conditions that made them vulnerable to severe effects from COVID-19 such that they could not safely work without masks and social distancing in place, as well as people who had anxiety disabilities or other conditions that made them extremely

fearful of the coronavirus. Where requested by an employee with a disability as a reasonable accommodation, employers should have enforced safety protocols such as masks and social distancing.

Unfortunately, COVID-19 protocols including masks were resisted in some workplaces, sometimes because they have been

harmfully politicized. In these environments, employees with disabilities had difficulties resolving their accommodation needs without facing harassment and hostility.⁶⁴⁸

At the same time, employers must also provide reasonable accommodations to employees who cannot wear masks or cannot wear them consistently or for long periods of time, due to their disabilities. Examples may include individuals with developmental or intellectual disabilities, including autistic people, who cannot tolerate masks, and people with mobility impairments who cannot independently put on or take off a mask. During a pandemic, under the ADA, employers must provide reasonable accommodations to all employees with disabilities, including employees

Many employees needed reasonable accommodations such as telework, not because of their own vulnerability, but because they were household members and caregivers of people with disabilities who were vulnerable to severe effects from COVID-19 infection. There is no civil rights law that adequately protects this group of workers.

with disabilities who have needs that appear to conflict (such as an employee with a disability who needed safety protocols in place due to their preexisting condition that made them vulnerable to severe effects from COVID-19, and a fellow employee with a disability who was not able to consistently wear a mask due to their developmental disability). This requires creativity and flexibility to reach safe and inclusive outcomes.⁶⁴⁹

Older Workers with Disabilities

Older workers with disabilities who have lost their jobs due to the pandemic face a high risk that they will never rejoin the workforce.⁶⁵⁰ Many of these workers have been or will be forced into early retirement, with the serious financial and other losses that accompany this change in status.⁶⁵¹

During and after the Great Recession, it took older workers longer to find work.⁶⁵² Older workers are more likely to suffer long-lasting negative consequences due to recessions, including job loss, pay cuts, loss of healthcare, poverty, and decreased longevity or life expectancy.⁶⁵³ The COVID-19 pandemic and resulting recession hit older people, especially older women, even harder than past recessions.⁶⁵⁴ Workers over age 55 experienced higher unemployment from the pandemic than midcareer workers and returned to work more slowly.⁶⁵⁵ Older workers who are Black, female, or lack a college degree experienced even higher rates of job loss.⁶⁵⁶

Even if a prior workplace reopens after being closed due to the pandemic, older employees with disabilities may not be called back to work with the others.⁶⁵⁷ This kind of discrimination is extremely difficult to demonstrate or remedy. Research shows that age discrimination in hiring increases during recessions, contributing to longer periods of unemployment for older workers.⁶⁵⁸ Age

discrimination is also a significant barrier for older workers who look for temporary jobs to delay retirement.⁶⁵⁹

Some older workers with disabilities may have worked somewhere for a very long time before the pandemic, with reasonable

accommodations and job supports in place (whether formal or informal).⁶⁶⁰ Once these tailored positions were lost due to the pandemic, they were extremely hard to recreate later. These workers may not be very knowledgeable about how to go about getting a job in the current reality. They may not be proficient at using computers and application portals to apply for jobs.

Older people also experience more severe aftereffects of COVID-19 infection. New or more severe disabilities are primary reasons that older workers with disabilities leave the labor force.⁶⁶¹ Workers with new disabilities may have less ability to successfully advocate for reasonable accommodations at work, compared to individuals with long-standing, chronic disabilities who may better understand their rights.⁶⁶² Robust and explicit accommodation programs can help keep older workers with disabilities on the job.⁶⁶³

Workers over age 55 experienced higher unemployment from the pandemic than midcareer workers and returned to work more slowly. Older workers who are Black, female, or lack a college degree experienced even higher rates of job loss.

People with Disabilities Earning Subminimum Wage at Sheltered Workshops

Since 1938, Section 14(c) has allowed employees with disabilities to be paid less than the minimum wage under special certificates used to operate sheltered workshops. Some employees with disabilities earn as little as cents per hour.⁶⁶⁴ Section 14(c) creates a federally sanctioned segregated jobs system for people with disabilities, and is contrary to the civil rights principles of the ADA and its integration mandate.⁶⁶⁵ NCD has long recommended that Congress phase out Section 14(c) of the Fair Labor Standards

Act as a policy relic from the 1930s, when discrimination was inevitable because service systems were based on a charity model, rather than empowerment and self-determination.⁶⁶⁶

NCD favors instead investment into training programs and competitive, integrated employment, including supported employment. The U.S. Commission on Civil Rights recently made the same recommendation.⁶⁶⁷ The Transformation to Competitive Integrated Employment Act (H.R. 2373) would provide states and employers with resources to transition workers with disabilities into fully integrated and competitive jobs while phasing out the subminimum wage for individuals with disabilities.⁶⁶⁸

The onset of the pandemic caused many sheltered workshops to close. These congregate

workplaces posed substantial health risks to workers with intellectual and developmental disabilities, who are at increased risk of severe illness and death from COVID-19.⁶⁶⁹ Many people with disabilities who worked in sheltered workshops under Section 14(c) of the Fair Labor Standards Act found that they were not eligible for unemployment when their work stopped due to the pandemic. This was because they were classified as “trainees” or recipients of services rather than as employees, and their employer-provider did not pay into the state unemployment system.⁶⁷⁰ These workers found themselves overlooked and disregarded while nondisabled

workers were able to access unemployment benefits.

Many of these segregated programs have reopened or are slowly reopening.⁶⁷¹ The ongoing recovery effort provides an opportunity for a substantial federal investment into

developing integrated employment opportunities as alternatives to sheltered workshops.

Summary of Findings

- Before the onset of the COVID-19 pandemic, nearly two-thirds of working-age Americans with disabilities were left out of the labor market altogether, caught in a “poverty trap” created by federal public assistance programs. People with disabilities who were working or looking for work experienced an unemployment rate more than twice that of people without disabilities.

Many people with disabilities who worked in sheltered workshops under Section 14(c) of the Fair Labor Standards Act found that they were not eligible for unemployment when their work stopped due to the pandemic.

- The onset of the COVID-19 pandemic triggered a massive decline in employment, and the initial losses were borne disproportionately by people with disabilities, with nearly 1 million people with disabilities—about one in five—losing their jobs.
- Young people with disabilities, who were already disproportionately excluded from the workforce, did not receive mandated IDEA services during the COVID-19 pandemic, including preemployment transition services.
- The expansion of telework during the pandemic was of great benefit to many people with disabilities. It offered workers with disabilities more flexibility, and reduced barriers to working such as those associated with transportation.
- While in many cases accessibility can be feasibly provided by employers in digital platforms such as Zoom, some employees with disabilities faced barriers to participating in remote employment-related meetings.
- Some employees with disabilities were not able to telework during the pandemic, including those with jobs that were not well suited for telework, those who were not allowed by their employers to telework, those for whom telework is not accessible, and those who have been laid off or whose jobs have been eliminated.
- Telework has long been recognized by the EEOC as a reasonable accommodation under the ADA. Telework can help remove disability-related work barriers, including difficulties commuting, accessibility barriers at the worksite, and the need for regular access to private spaces to attend to disability treatment or symptoms.
- During the pandemic, telework was an essential reasonable accommodation for workers with disabilities who were at increased risk for severe illness or death from acquiring COVID-19. When telework was refused as a reasonable accommodation, these employees with disabilities were left with bad choices: quit, request unpaid leave, or return to work and risk acquiring the virus.
- For people with disabilities who were vulnerable to severe outcomes from coronavirus infection, accessing sufficient job-protected unpaid leave during the pandemic was difficult because the leaves needed were long and often indefinite.
- The pandemic revealed a substantial gap in civil rights protections: no federal civil rights law protected employees who needed a reasonable accommodation such as telework, not because of their own disability, but because they were household members and caregivers of people with disabilities who were vulnerable to severe effects from acquiring COVID-19.
- The availability of benefits from the COVID-19 relief packages was critically important to the safety and economic stability of people with disabilities. These benefits included three EIPs that were made available to beneficiaries of SSI and SSDI without jeopardizing their benefits. These benefits included extended unemployment insurance, including for self-employed and

part-time workers, with federal supplements of \$300 or \$600 during most weeks of the pandemic. The unemployment benefits were valuable to people with disabilities, who are more likely to have lower earnings, meaning that their unemployment benefit amounts were lower, and who are more likely to work for themselves or to work part-time.

- State unemployment insurance claims systems experienced huge backlogs, and it is likely that those deterred from accessing the benefits owed to them included large numbers of people with disabilities.
- The federal government maintained its efficiency and productivity during the 18 months that most federal employees teleworked. If implemented, the June 2021 guidance issued by the U.S. Office of Personnel Management and the General Services Administration will afford workers with disabilities a greater opportunity to succeed by incorporating the flexibility of telework into the ordinary employment policies and practices of the federal government.
- If, because of experiences during the pandemic, more employers offer flexible hours, remote work, and telework into the future, this could greatly expand employment opportunities for workers with disabilities. Telework can allow individuals with disabilities to work even if they have barriers to commuting, such as not driving due to disability, or inaccessible public transportation. Increased availability of remote work could also improve job opportunity for the disproportionate number of people with disabilities who live in rural areas and who experience lower rates of unemployment.

- Section 14(c) to the Fair Labor Standards Act creates a federally sanctioned segregated jobs system for people with disabilities and is contrary to the civil rights principles of the ADA and its integration mandate. The onset of the pandemic caused many sheltered workshops to close. These congregate workplaces posed substantial health risks to workers with intellectual and developmental disabilities, who are at increased risk of severe illness and death from COVID-19.
- Many people with disabilities who worked in sheltered workshops under Section 14(c) of the Fair Labor Standards Act found that they were not eligible for unemployment when their work stopped due to the pandemic.
- Many of these segregated programs have reopened or are slowly reopening. The ongoing recovery effort provides an opportunity for a substantial federal investment into developing integrated employment opportunities as alternatives to sheltered workshops.
- Older workers with disabilities who have lost their jobs due to the pandemic face a high risk that they will never rejoin the workforce. Many of these workers have been or will be forced into early retirement, with the serious financial and other losses that accompany this change in status.

Recommendations

To ensure the United States is prepared for a future pandemic or similar national health crisis, NCD recommends the following actions based on our findings about the impact of COVID-19 on workers with disabilities and working-aged people with disabilities:

Recommendations for Congress

Congress should:

- Task GAO with examining the gaps in employment protections that occurred during the COVID-19 pandemic, including for people with disabilities who were vulnerable to severe outcomes from COVID-19, and for people who have COVID-19–vulnerable household members, or who are caregivers to COVID-19–vulnerable individuals. This examination should consider whether existing laws and federal policies will provide adequate protections to these workers during future pandemics, or whether new laws or federal policies are needed.
- Pass legislation to decouple eligibility for Medicaid and Medicare from eligibility for cash benefits. The legislation should allow people with disabilities covered by Medicaid and/or Medicare through the SSI and SSDI programs to work and to retain their existing healthcare coverage permanently, without cost to the individual and without any complex paperwork.
- Pass legislation to allow people with disabilities receiving Social Security Administration benefits to work without fear of losing necessary income and supports, such as the Work Without Worry Act (S. 2108) which would allow adults with disabilities who receive the Disabled Adult Child benefit to work without jeopardizing their benefits. Congress should also raise the benefit amount for SSI to above the federal poverty line.
- In the event of a future national disaster or public health emergency, pass legislation immediately to provide dedicated unemployment and relief funds to stabilize households, including those of part-time workers, self-employed individuals, and gig workers, who are disproportionately people with disabilities, working families with children with disabilities, individuals with caregiving obligations, and people with disabilities receiving SSI and SSDI benefits.
- Enact the Transformation to Competitive Integrated Employment Act (TCIEA), which would phase out and repeal 14(c) from the Fair Labor Standards Act and would invest in alternative service models prioritizing competitive integrated employment.
- Adequately fund vocational rehabilitation by increasing authorization for preemployment transition services, training programs, and integrated competitive employment, including supported employment, for individuals with disabilities.
- Enhance tax credits for employers who hire and retain employees with disabilities by enacting the Disability Employment Incentive Act.

(continued)

Recommendations for Congress: *continued*

- Authorize and fund a federal exchange for state unemployment benefits, to be overseen by the U.S. Department of Labor, that is accessible to and usable by everyone eligible for unemployment benefits, including people with disabilities. Require states that are unable to provide an accessible and usable system for state unemployment benefits to join the federal exchange.

Recommendations for Federal Agencies

EEOC should:

- Work to strengthen legal protections for workers with disabilities who seek telework, leaves of absence, and safety policy modifications as reasonable accommodations. EEOC should offer guidance to employers in accommodating employees with needs that appear to conflict.
- Consider amending Section 501 regulations to include a sub-goal for older people with disabilities, and/or to require reporting on older workers with disabilities.

EEOC and DOL should:

- Prioritize enforcement of the Americans with Disabilities Act and Sections 501 and 503 of the Rehabilitation Act to ensure that workers with disabilities receive reasonable accommodations needed to secure or maintain employment, including accommodations needed due to the pandemic.

Office of Personnel Management (OPM) should:

- Maintain maximum telework flexibility for all federal agencies on a permanent basis and ensure that federal employees with disabilities receive necessary, reasonable accommodations in their technology while working remotely and retain flexibility to work from their designated federal office as needed or desired.

DOL and OPM should:

- Issue joint guidance on effective telework tools and highlight the benefit of telework for many people with disabilities. The guidance should describe the need for accessibility in remote work platforms and allow agencies to use the platforms that are most accessible based on employee needs.

Recommendations for Federal Agencies: *continued*

Federal Communications Commission (FCC) should:

- Take affirmative steps now to ensure that high-speed broadband internet is available to and affordable for everyone. The FCC's Lifeline program should be expanded to provide high-speed broadband internet to low-income households for \$10.00 a month.

Department of Labor should:

- Audit state systems of unemployment benefits, and issue notices of correction to agencies that failed to maintain functional and accessible systems for applying for and maintaining benefits during the COVID-19 crisis, so that such agencies will be better prepared for any similar public emergency. The Department should require states to join a federal exchange if they cannot offer eligible workers such a system.

Office of Federal Contract Compliance Programs (OFCCP) should:

- Consider amending Section 503 regulations to include a sub-goal for older people with disabilities, and/or to require reporting on older workers with disabilities.

Recommendations for States and State Agencies

Fair Employment Practices (FEP) Agencies should:

- Review any gaps in state employment law protections that occurred during the COVID-19 pandemic, including for people with disabilities who were vulnerable to severe outcomes from COVID-19, and for people who have COVID-19–vulnerable household members, or who are caregivers to COVID-19–vulnerable individuals. State FEP agencies should report on their findings to state legislatures.

Chapter 6: Effective Communication

Overview of Effective Communication Before and During the Pandemic

The COVID-19 pandemic has uniquely impacted Deaf and Hard of Hearing communities, people who are blind, and people who cannot rely on speech to be heard and understood. Today, there are over 37.5 million people with difficulty hearing, and an additional 5 million people who cannot rely on speech to communicate, in the United States.⁶⁷² Prior to the pandemic, they faced communication barriers across healthcare, education, employment, and government contexts. The provision of disability-related accommodations and proper auxiliary aids and services by public entities, employers, and public accommodations—as required by the ADA,⁶⁷³ Section 504 of the Rehabilitation Act,⁶⁷⁴ and Section 1557 of the Affordable Care Act⁶⁷⁵—was inconsistent and often a barrier to equal access.

Widespread mask use and social distancing protocol, as well as increased reliance on virtual forums of communication, among other pandemic-era policies, created new challenges for people with hearing, vision, speech, and/or intellectual or developmental disabilities to interact with their communities and equally access health care, education, and employment.

With the pandemic, disparities in effective communication deepened. Widespread mask use and social distancing protocol, as well as increased reliance on virtual forums of communication, among other pandemic-era policies, created new challenges for people with hearing, vision, speech, and/or intellectual or developmental disabilities to interact with their communities and equally access healthcare, education, and employment. These

new communication barriers also hindered the dissemination of public health information critical to slowing the spread of COVID-19 and exacerbated the difficulties that people with disabilities already faced in accessing essential services. When, as during the pandemic, written and oral communications related to the provision of medical care and public

health precautions are of the utmost importance, it is critical that public entities, employers, and places of public accommodation ensure that their

communications are fully accessible to people with disabilities.

Healthcare Setting

The failure to provide proper accommodations to people with communication disabilities in healthcare settings can have life-threatening consequences. During the COVID-19 pandemic, which disproportionately caused serious illness and death among people with disabilities,⁶⁷⁶ it was crucial for patients and family members with disabilities to have the auxiliary aids and services that they need to be able to effectively communicate in healthcare settings. The failure of a hospital, doctor's office, or medical provider to provide accurate, real-time communication in accessible formats can lead to a misunderstanding of a patient's symptoms, inappropriate diagnosis, and/or delayed or improper medical treatment.⁶⁷⁷ While the entire country feared contracting COVID-19, millions of people with disabilities experienced the additional anxiety of being unable to learn about, communicate, and express decisions regarding their medical circumstances.⁶⁷⁸

Face Masks and Physical Distancing

COVID-19 is transmitted through exposure to respiratory fluids carrying infectious virus. Exposure occurs in three principal ways: (1) inhalation of very fine respiratory droplets and aerosol particles, (2) deposition of respiratory droplets and particles on exposed mucous membranes in the mouth, nose, or eye by direct splashes and sprays, and (3) touching mucous membranes with hands that have been soiled either directly by virus-containing respiratory fluids or indirectly by touching surfaces with virus on them. To prevent infection and spread

of the virus, including those who were disabled and those medically at risk, the CDC recommended maintaining a physical distance of at least six feet from other individuals, practicing hand hygiene and environmental cleaning. By April 3, 2020, CDC recommended the universal use of face coverings.⁶⁷⁹ Following this guidance, healthcare entities, as well as many government entities, businesses, and employers, mandated the use of face masks. These measures have been a double-edged sword for disability communities. These requirements are important to protecting high-risk individuals from contracting COVID-19, such as people with lung disease, asthma, heart conditions, diabetes, kidney disease, or conditions that deem a person immunocompromised.⁶⁸⁰ At the same time, however, the common use of opaque masks created new challenges for people who are Deaf and others with disabilities that impact their hearing or speech.

People who are Deaf and Hard of Hearing have varying degrees of hearing loss and rely on a variety of auxiliary aids and services in the healthcare setting, such as sign language interpreters, assistive technologies, and/or amplification of sound. Everyone has different needs and preferences, but auditory cues and visual cues such as mouth and lip movements and facial expressions can play an important role in effective communication for many of these individuals.⁶⁸¹

The use of face masks can muffle sound, making it more difficult for people with hearing loss to understand speech and higher pitched voices.⁶⁸² It can also take away an individual's ability to lip read and contextualize communications through the observation of facial expressions.⁶⁸³ People with hearing loss have

reported “widespread difficulty” in understanding healthcare providers who are wearing face masks during the COVID-19 pandemic.⁶⁸⁴ For example, one participant in a recent study, who had significant but not complete hearing loss, reported that they “attended a clinic appointment . . . [and] struggle[d] to understand what was said [] by the consultant wearing [a] facemask.”⁶⁸⁵ Others report having to ask healthcare workers to repeat themselves and speak more loudly because of the barriers created by the face mask.⁶⁸⁶

Physical distancing can also create heightened communication challenges. Distance causes speech to sound quieter and makes it more difficult to see visual cues, especially when an individual also has vision loss.⁶⁸⁷ It can also be more difficult for individuals to focus their attention on a speaker from a distance, because other sounds and movements in the environment can distract or overshadow the communication.⁶⁸⁸ The change in nature of face-to-face interactions caused by the pandemic “hinder[ed] speech understanding” among people with hearing loss and/or intellectual or developmental disabilities.⁶⁸⁹

Several solutions were suggested to lessen the communication difficulties created by face mask use and social distancing in the healthcare setting. First, the use of adaptable, clear masks has been widely endorsed as an alternative that accommodates people who lip read.⁶⁹⁰ In one study, the sentiment that key healthcare workers should be supplied with a transparent face

mask was “widely shared.”⁶⁹¹ However, while some clear masks were approved by the FDA, they were not N95-rated and therefore were inappropriate in certain healthcare settings, such as when a provider is interacting with COVID-19 patients.⁶⁹² Additionally, they do not alleviate communication barriers created by muffled sound and certainly cannot be a substitute for an ASL interpreter, when that is the patient’s primary language.

Alternative accommodations must also be considered. Depending on the needs and preferences of the individual, the use of a sign language interpreter; assistive technology

such as video-remote interpreting (VRI), transcription services, Communication Access Realtime Translation (CART), and assistive listening devices; low-tech solutions such as communication boards; or moving an appointment to

In addition to the challenges that face mask mandates create in the receipt of information from health care professionals, they also can create barriers for people with disabilities to provide information to their health care providers.

an accessible telemedicine forum may be appropriate. While each of these accommodations have their own complications related to the COVID-19 pandemic (as further discussed in the following subsections), it is essential that healthcare providers and administrators continue to listen to the needs of people with communication disabilities and devise effective solutions to ensure that they can learn and communicate about their health conditions.

In addition to the challenges that face mask mandates create in the *receipt* of information from healthcare professionals, they also can create barriers for people with disabilities

to *provide* information to their healthcare providers. There are individuals who, by virtue of their disability, cannot wear a mask either at all or for an extended period of time.⁶⁹³ Examples include individuals with developmental or intellectual disabilities who cannot tolerate masks, people with mobility impairments who cannot independently put on or take off a mask, people who use ventilators to support breathing, people with seizure disorders who may be in danger if they experience a seizure while wearing a mask, people with lung diseases or breathing difficulties, and people who experience panic attacks while wearing masks.⁶⁹⁴

In-Person Interpretation

Prior to the COVID-19 pandemic, in-person interpretation in the hospital setting was the highest standard of care for people who communicate through sign language. Healthcare experiences can be fast-paced and dynamic. Especially in emergency situations, there are often multiple healthcare providers (doctors, nurses, technicians, etc.) in a room at once, performing several tasks, and attempting to communicate multiple pieces of information, all while the patient is potentially in a supine or prone position and in pain. In such situations, it is critical that the auxiliary aids or services provided to an individual with a communication disability be built for this dynamic environment. Digital interpretation services,

such as VRI, have limited effectiveness in crisis care situations and are inferior to an in-person interpreter, who can observe the whole scene and move around the room as needed to facilitate communication.

However, at the onset of the pandemic, sign language interpreters expressed concern for their lives and safety, given the increased chance of contracting COVID-19 in the hospital setting.⁶⁹⁵ Likewise, patients expressed concern that interpreters could spread COVID-19 to the people who use their services, other patients

in the facility, and hospital staff. These safety concerns were amplified by nationwide shortages in PPE.⁶⁹⁶ The economic crisis caused by the pandemic also significantly reduced the number of sign language interpreters available to provide services to people with disabilities.⁶⁹⁷ Many interpreters lost their jobs as funding

To protect all parties involved, while still providing the in-person interpretation services that are necessary in many critical healthcare circumstances, interpreters need adequate safety gear. Likewise, healthcare entities must be provided the resources they need . . . , including funding to ensure the availability of qualified interpreters and other augmentative communication tools.

for interpreter services decreased and public and private health insurers failed to cover interpretation and disability accommodation services.⁶⁹⁸

In order to balance the competing need for in-person interpretation services in hospital settings with the safety concerns of potential COVID-19 exposure from the use of such a service, interpreters must have access to PPE. Just like any other individual who is working in a hospital, a sign language interpreter is essential staff. To protect all parties involved, while still

providing the in-person interpretation services that are necessary in many critical healthcare circumstances, interpreters need adequate safety gear. Likewise, healthcare entities must be provided the resources they need to effectively communicate with patients or family members with a communication disability, including funding to ensure the availability of qualified interpreters and other augmentative communication tools.

Assistive Technology

As an alternative to in-person interpretation, healthcare entities increased reliance on assistive technologies such as VRI, transcription services, or Communication Access Realtime Translation (CART), and communication boards during the COVID-19 pandemic. These communication tools have the advantage of bypassing the need for another individual—a potential vector for COVID-19—to be in the room. However, as explained in the previous section, the use of remote interpretation and other auxiliary aids is not always appropriate, especially in critical care settings. In situations where an in-person interpreter is not required, however, they can provide an effective tool to facilitate effective communication—when used properly and when certain technological performance standards are met.

For example, VRI is a videoconferencing technology for accessing an offsite interpreter to provide real-time sign language or oral interpretation services for conversations between hearing people and the Deaf or Hard of Hearing.⁶⁹⁹ To be effective, VRI must be used over a dedicated high-speed, wide-bandwidth internet connection; the screen must be large enough to display the interpreter’s entire upper body; the audio must be clear; and facility staff must

be trained in its set-up and proper operation.⁷⁰⁰ Provided that the situation does not require an in-person interpreter and the individual with hearing loss prefers VRI over an in-person interpreter, then properly used VRI can be an effective solution to communication in healthcare settings, while also reducing potential exposure to the COVID-19 virus.⁷⁰¹

Alternatively, some people with hearing loss may prefer to use remote real-time transcription services like CART to communicate with their healthcare providers,⁷⁰² or low-tech communication methods, such as supplemental communication boards.⁷⁰³

Telemedicine

In an effort to slow the spread of the COVID-19 virus, healthcare entities have rapidly adopted telephone and video visits (collectively “telemedicine”) as an alternative to traditional in-person care. Prior to the pandemic, telemedicine was widely unavailable due to a preference for seeing patients in person and potential Health Insurance Portability and Accountability Act of 1996 (HIPAA) concerns related to the perceived lack of security of telecommunications. Where available, if a person with a disability faced barriers accessing the platform or communicating with healthcare providers, then they could revert to in-person care. For this reason, some argue that the focus of communication access has concentrated almost exclusively on how to adapt the in-person healthcare environment to accommodate the needs of people with disabilities; while telemedicine, up until the pandemic, was largely an afterthought.⁷⁰⁴ COVID-19 has swiftly changed that.

For some people with disabilities, particularly those who are immunocompromised and/or have mobility disabilities, telemedicine was a welcome

addition to healthcare systems. It created a safer and more affordable method of receiving healthcare when physical presence is not necessary—reducing potential exposure to communicable diseases like COVID-19, lowering transportation costs and hardships, and lowering the cost of care.⁷⁰⁵ On the other hand, however, it has created a host of new communication barriers for people with hearing loss, vision loss, and/or intellectual or developmental disabilities.⁷⁰⁶

Most HIPAA-compliant telemedicine platforms do not have built-in accessibility features to facilitate communications with patients with disabilities.⁷⁰⁷ Features such as live captioning and three-way video visits (which allow an interpreter to join the meeting and facilitate communication) are not yet commonplace.⁷⁰⁸ This means that telemedicine visits can be useless to the Deaf or Hard of Hearing, who may be able to see but not communicate with their healthcare providers. While a telephone visit—when coupled with a relay service operator such as Text Telephone (TTY)—may be a more viable option, quality of care is questionable when the only means of communication is through text, especially when visits are further constrained by time limits.

Most HIPAA-compliant telemedicine platforms do not have built-in accessibility features to facilitate communications with patients with disabilities.

[D]ue to the inflexibility, lack of exemptions, . . . regarding these [no visitor] policies, they also had the unintended consequence of blocking people with disabilities from accessing the direct care workers/direct support professionals and family members they needed . . . to effectively communicate . . . to health care providers, . . . and make informed medical decisions.

Likewise, telemedicine platforms and the patient education materials posted on them are often not accessible to people with vision loss.⁷⁰⁹ Websites, software programs, and electronic documents are often not designed

and formatted to be accessible with a screen reader. Compliance with World Wide Web Consortium's (W3C) Web Content Accessibility Guidelines (WCAG) is not widespread.⁷¹⁰

To remedy the communication barriers in telemedicine, the digital interfaces must be customized to accommodate the needs of people with disabilities. This includes ensuring that three-way video visits are supported by the platform and the interface is visually accessible.

No-Visitor Policies

During the course of the COVID-19 pandemic, some hospitals have enacted no-visitor policies.⁷¹¹ These policies were aimed at decreasing the number of people in hospital settings, thus curbing the spread of COVID-19 among patients and hospital staff alike. However, due to the inflexibility, lack of

exemptions, and lack of forethought regarding these policies, they also had the unintended consequence of blocking people with disabilities from accessing the direct care workers/direct

support professionals and family members they needed by their side in order to effectively communicate their symptoms and needs to healthcare providers, accurately understand information provided by those staff members, and make informed medical decisions.⁷¹²

A person with a disability's daily direct care workers and family members know the individual, their conditions, and their needs better than anyone else. Blocking a support person from accompanying an individual during a hospital visit can decrease the quality of their care and put their lives at risk. As an example, consider the experience of Cindy (name changed for privacy reasons) and her adult son, who has an intellectual disability that impacts his ability to perform self-care. In Fall 2020, Cindy's son experienced a medical emergency and needed to be transported to the hospital. Cindy, as the support person for her son, accompanied him to the emergency room. Cindy has the greatest perspective on and knowledge of her son's needs. She knows, for example, when he needs respiratory suction and how to properly administer it. She also knows how to communicate with her son better than anyone else. When she visited the hospital in Fall 2020, the staff members refused to allow her to be by her son's side. Despite bringing supporting documentation with her to the emergency room and citing relevant laws and State policy, the hospital refused to let her attend to her son for an hour and a half. Cindy feared for her son's life the entire time.

Situations like what Cindy and her son experienced are unacceptable. Many people with disabilities rely on direct care workers or family members in order to effectively communicate with their providers. Exceptions to no-visitor

policies must be made when it is necessary to effectuate the communication rights of people with disabilities. HHS OCR agrees with this position.⁷¹³ As discussed in detail in Chapter 1, HHS OCR asserted in a series of resolutions with healthcare entities that no-visitor policies that fail to make exemptions for support persons of people with disabilities violate the ADA, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act, and can result in a denial of effective communication within the meaning of those laws.⁷¹⁴

While the law is clear, federal and state entities must remind hospitals and healthcare facilities of their obligations to provide reasonable accommodation and policy modifications when needed by people with disabilities, including providing exceptions to general "no-visitor" policies during the pandemic when a patient needs a support person for disability-related reasons such as effective communication. These reminders must be clear that effective communication needs are one of the disability-related reasons that a support person may be needed, and for which an exception must be granted.

Congregate Care Settings

The COVID-19 pandemic also impacted the communication methods of people with disabilities who are in CCFs. By virtue of the danger of the COVID-19 virus spreading quickly through CCFs, in-person communication with individuals outside of the facility was sharply curtailed. Outside of staff members, very few individuals were able to connect with residents. This includes close family members, whose physical presence could place their loved one and other residents at risk of contracting COVID-19.

As a replacement for in-person interaction, CCFs increasingly relied on technology to provide residents with social interaction and healthcare. Technologies such as smartphones and tablets, which allow for video conferencing and telemedicine, became commonplace. Such technologies also created opportunities for social workers and other providers to assist residents in touring potential housing, assessing site accessibility and safety, picking out furniture, and engaging in other activities that ease transitions out of the CCF.

With the increased use of communication technologies, however, also came new barriers for some people with disabilities. An individual may not have the capacity to communicate via video screen if, for example, screen use triggers migraines; instead they may need telephone or in-person communication. Likewise, the communication platform being used may not be accessible for people with hearing or vision loss, as was discussed in greater detail in the previous section.

As in the healthcare context, in order to improve communication in CCFs, accessibility in virtual communication technologies must be prioritized. WCAG 2.1 standards should be adopted, and individuals living in CCFs should be given the assistance they need in learning and using new communication technologies.

Education Setting

Students with disabilities, as well as their parents and educators, were intimately affected by the social distancing policies enacted during the

COVID-19 pandemic. While constantly evolving, the K-12 education system has incorporated remote learning modalities in a way never envisioned prior to the pandemic.

Remote Learning

At the beginning of the COVID-19 pandemic, many K-12 schools shifted from an in-person model of learning to a fully remote education system. Many still remained remote in 2021. The rise of remote education was a double-edged sword for the communication needs of students with disabilities: It has benefitted some students, but it has severely disadvantaged others.

For some disabled students, the remote learning modality allowed them to interact with

their teachers and fellow students in a manner not previously possible. For example, the use of video conferencing provided them with greater exposure to the

world and connectivity with their classmates as they could, quite literally, see into each other's homes. An act as simple as sharing one's pets with each other over a video platform can provide a valuable social interaction to some students with disabilities who may not otherwise be able to experience such close interaction with other students. Learning from home can also benefit some disabled students who have attendants, because remote learning makes it easier for these individuals to go off-camera when they need to engage in personal care. This can reduce stigma associated with the presence of the attendant and decrease any generalized classroom disruption. Further, particularly

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for students with disabilities that affect their social and emotional functioning, the degree of separation created by the virtual learning environment can decrease their social anxiety and actually encourage greater communication in the classroom.⁷¹⁵

For other students with disabilities, however, the COVID-19 pandemic had a devastating impact on classroom communications.⁷¹⁶ For many students, remote learning cut off access to education attendants, physical therapists, occupational therapists, and speech therapists. Parents do not have the specialized training, or, often, the time, to fill these roles. Many disabled students no longer had access to Braille or tactile learning tools that they may have relied on in the physical classroom. These problems were only amplified by the lack of proper accessibility in

remote learning platforms. Video platforms are not always compatible with assistive technology, and sign language is difficult through video. Technological inadequacies can severely hinder educational accommodations.

Because of these concerns, it is critical that schools and teachers using remote learning make assistive technologies and services available for students, including real-time captioning of video lectures, video interpreter services, and other assistive technologies that a student who is Deaf or Hard of Hearing may need.⁷¹⁷ Teachers should also ensure that they are on video, with proper lighting and their faces clearly visible in the frame, to facilitate lip reading and perception of other visual cues. If a student has a disability that affects their concentration or they easily become overstimulated, then teachers should ensure that

everyone except the speaker is on mute.⁷¹⁸ The needs and preferences of each student with a disability will be different. What is most important is that the school, teacher, and parents are on the same page about the needs of the students and, if necessary, their IEP is updated to reflect any new communication needs in the remote learning environment.

Modified In-Person Instruction

When schools reopened, teachers and administrators modified the physical learning environment to account for safety precautions. In particular, the use of masks and physical distancing changed the nature of in-person instruction and affected students with hearing loss and other disabilities that cause them to rely on visual cues to effectively communicate.

Masks can muffle sound, hide lip movements, and hide facial expressions; while increased physical distance from the teacher decreases the volume of communications. These new challenges made in-person learning even more difficult for students with communication disabilities. Depending on the needs of the student, measures such as wearing clear masks, amplifying the teacher's voice, and following communication best practices (such as directly facing a student while talking, speaking slower and louder, and providing extra written resources that bolster verbal instruction) are helpful.⁷¹⁹ All students who are commonly

expected to participate in classroom discussions should receive some basic instructions on how to effectively communicate with all their classmates in a modified in-person, hybrid learning context, or simulcast context. IEPs should also be updated, as needed.

Hybrid Learning Models

Some schools used a hybrid learning environment involving both in-person and remote instruction. This mixed approach can be confusing and anxiety-producing for students, especially for students with intellectual or developmental disabilities or with learning disabilities, who benefit from regular routines.

If a student is a part of a hybrid model, then it is important for the school and parents to foster as much consistency as possible. For example, if a student uses an ASL interpreter in person,

then that interpreter should also be available to help with remote instruction as well.⁷²⁰ It is also important that the student have regular check-ins to determine whether the new way of learning is working for them and how it can be modified to better meet their needs. Like

all learning models, IEPs should be modified as needed.

Government Activities

The most important aspect of slowing the spread of COVID-19 was to empower people with accurate information about the virus, its transmission, and vaccines.⁷²¹ If facts about mask

Masks can muffle sound, hide lip movements, and hide facial expressions; while increased physical distance from the teacher decreases the volume of communications. These new challenges made in-person learning even more difficult for students with communication disabilities.



use, physical distancing, and other protective practices were not available to everyone then we could not expect to slow the spread of the virus or decrease infection rates and the development of dangerous variants.⁷²² Likewise, if accurate information about the efficacy and side effects of vaccines, or the availability of economic stimulus support related to COVID-19, was not made accessible to all individuals, then we could not expect equity in vaccination and economic support.

Traditionally, the role of disseminating public health information has been tasked to federal, state, and local governments. All federal programs and agencies, and all entities receiving federal financial assistance, are subject to disability rights laws that require information to be made available in alternative formats such

as large print, electronic format, and Braille.⁷²³ Likewise, all federal websites and the content posted on them must be fully accessible.⁷²⁴ This includes all documents, videos, charts, graphs, or infographics that are made public.⁷²⁵

Despite clear legal requirements, people with disabilities were overlooked on multiple governmental levels during the COVID-19 pandemic. Not only did state public health departments and local municipalities fail to make critical information accessible to people with communication disabilities,⁷²⁶ but so too did the federal government. For example, while the pandemic was still in its infancy—arguably at its most critical stage in relation to stopping or at least slowing the spread of the deadly COVID-19 virus—the Trump administration’s White House consistently failed to provide sign language



interpreters during its COVID-19 briefings.⁷²⁷ This left millions of U.S. residents who communicate using ASL, a language distinct from English,⁷²⁸ without access to critical, up-to-date information related to the pandemic.⁷²⁹ It took a lawsuit from the National Association of the Deaf in order to change this injustice. In September 2020, six months into the known pandemic, a federal court ordered the White House to provide live ASL interpreters for all COVID-19–related briefings.⁷³⁰ The decision made clear: “With their lives at risk due to the pandemic, it is important to provide the information in ASL so that Deaf and Hard of Hearing people have access to this information.”⁷³¹

Federal, state, and local governments must ensure that their programs and activities during the pandemic, and communications related to the

pandemic, are fully accessible for people with disabilities. In the middle of this national crisis, it is essential that people with disabilities have access to the same information that any other individual does.⁷³²

All information shared by governmental entities must be accessible to people with disabilities, and this includes persons who may have limited English proficiency and require information in another language. Video briefings from the federal government must provide sign language interpretation and live captions, to ensure that individuals with hearing loss can have equal access. All written materials must be provided in formats accessible to people with visual impairments, including the availability of large print, Braille, and electronic copies of documents. All forms related to COVID-19 care

and vaccination must be accessible and fillable. Additionally, all information disseminated on federal websites must be accessible for people with vision and/or hearing impairments. The failure to ensure accessibility in these contexts is not only a violation of the law but puts the lives of a population that is already particularly vulnerable to COVID-19 at even more risk.

Summary of Findings

- The widespread use of opaque face masks served as a communication barrier to people with disabilities who rely on lip-reading and facial cues for effective communication.
- There was a months-long nationwide shortage of PPE, and sign language interpreters in healthcare settings did not have sufficient access to it, hindering the safe use of their services.
- Telemedicine platforms were initially inaccessible to people with communications disabilities, with many platforms not supporting three-way video visits with interpreters or screen-reader accessibility.

- Hospital protocols, such as mask mandates and no-visitor policies, failed to account for the needs of people with communication disabilities at the onset of the pandemic.
- Remote and hybrid learning modalities failed to provide proper communication accommodations to students with disabilities at the beginning of the pandemic, rendering the school environment inaccessible for many children with disabilities.
- Local, state, and federal government entities did not disseminate information related to the COVID-19 pandemic, its transmission, and vaccines in fully accessible formats.

Recommendations

To ensure that the United States is prepared to support effective communication for people with disabilities as fully as possible in a future pandemic or similar national health crisis, NCD recommends the following actions based on our findings about the impact of COVID-19 on people with disabilities:

Recommendations for Congress

- Congress should increase funding to healthcare entities and providers during public health emergencies specifically aimed at ensuring effective communication services and PPE for in-person interpreters.

Recommendations for Federal Agencies

- **HHS OCR and DOJ** should direct hospitals and other healthcare entities to include in their nondiscrimination notices and staff training the recognition of policy modifications as part of a patient’s right to effective communication, in addition to the provision of auxiliary aids and services when needed by patients with disabilities to receive effective care. Concrete examples should be provided, such as giving exceptions to face mask mandates when an individual cannot wear a mask by reason of their disability and to general “no-visitor” policies when needed for disability-related communication needs.
- **HHS** should release guidance outlining appropriate exemptions to face mask mandates and encouraging the use of adaptable face masks.
- **HHS OCR** should enforce the WCAG 2.1 standards in the telemedicine.
- **ED** should direct schools to assess and provide necessary reasonable accommodations and supports, including auxiliary aids and services such as captioning, sign language interpreting, and audio description, to students with disabilities during in-person, remote, and hybrid learning.
- **All federal entities involved in public health, emergency management, and the provision of public announcements or briefings of broad public importance:**
Disseminate information related to any pandemic or public health emergency in accessible formats, including information about the nature of the emergency, mitigating actions that individuals should take, available federal and state assistance and support, and available medical treatments, This includes providing sign language interpretation and/or captions during live and pre-recorded video briefings; making all written materials available in alternative formats; and making all online materials accessible.

Recommendations for Other Entities

- **State Hospital Associations:** Work with state departments of public health and disability advocacy groups to develop guidance and best practices for ensuring effective communication in hospitals and associated urgent care clinics during public emergencies, including:
 - The provision of clear, adaptable masks to hospital staff, to be used when an N-95 mask is not required;
 - The provision of qualified in-person interpretation when a person with a disability requests it, with PPE made readily available to interpreters;
 - Fully accessible telemedicine platforms to ensure effective communication for people with communication disabilities, including ensuring that their interface supports three-way video visits with interpreters and that the platform and its content are screen-reader accessible, consistent with the WCAG 2.1 standards.

Chapter 7: Addressing the Impact of COVID-19 on Mental Health and Suicide

Introduction

The pandemic has had a tremendous adverse impact on the nation's mental health. The economic impact of job losses resulting from the pandemic, the social isolation caused by remote work, closed businesses, stay-at-home orders, and physical distancing, the burnout experienced by healthcare workers, and the difficulty of obtaining needed accommodations in school and at work all contribute to increased rates of mental health disabilities, substance use disorders, and suicide. Rates of anxiety and depression have risen significantly, particularly for healthcare workers and other essential workers. Crisis hotlines have experienced high call volumes and surveys show rising rates of individuals contemplating suicide, particularly people of color, unpaid caregivers, and essential workers.

At the same time, the pandemic has created severe limitations on the availability of mental health services. Behavioral health services in public systems were already strained before COVID-19, and the pandemic has tremendously

hampered service delivery due to the impact on provider staffing and the need to shift service delivery mechanisms and find new flexibilities. The pandemic has presented opportunities for service improvements, however, including changes to policies to facilitate telehealth

The social isolation caused by protective measures to combat COVID-19—including physical distancing, quarantining, and a dramatic reduction in social activities—has resulted in isolation, loneliness, and depression.

services that may enable greater numbers of people to access services. Moreover, the pandemic presents opportunities to revisit our approach to suicide prevention, which is ineffective and focuses primarily on

hospitalization, placing people at risk of COVID-19 transmission.

The Pandemic Has Had a Dramatic Effect on the Nation's Mental Health

The pandemic's impact on the mental health of adults and children across the United States has been well documented. The social isolation caused by protective measures to combat COVID-19—including physical distancing, quarantining, and a dramatic reduction in social activities—has resulted in isolation, loneliness, and depression. Literature and studies showing

that these results of the pandemic have negatively affected the mental health of adults and children abound.⁷³³ Surveys consistently show high percentages of adults and children experiencing anxiety and depression as a result of this situation, as well as an increase in suicidal thoughts.⁷³⁴ Surveys conducted in June 2020 found that symptoms of anxiety disorder and depression increased considerably in the United States during April through June compared with the same period in 2019, with anxiety symptoms three times as high and depression symptoms four times as high.⁷³⁵ About twice as many people reported serious consideration of suicide within the previous 30 days than did adults in the United States during 2018.⁷³⁶

These trends have continued throughout the pandemic. In January 2021, CDC's National Health Interview Survey and Census Bureau Household Pulse data showed that 41 percent of adults reported symptoms of anxiety and/or depressive disorder that month—a figure that had changed little since the spring of 2020—compared to 11 percent between January and June of 2019.⁷³⁷

The negative impact on mental health has not only amplified the impact of preexisting mental health disabilities but also resulted in individuals developing mental health disabilities that they did not have before the pandemic. Indeed, many people with psychiatric disabilities had already experienced loneliness and social isolation prior to the pandemic, and that isolation was further magnified as a result of the pandemic's public

health measures.⁷³⁸ For people with chronic illness, already high rates of concurrent mental health disabilities may have been heightened further because of their vulnerability to severe effects of COVID-19.⁷³⁹ Older adults are also at particular risk, as many “have experienced an acute, severe sense of social isolation and loneliness with potentially serious mental and physical health consequences.”⁷⁴⁰ Further, having COVID-19 itself may have led to mental health disabilities for some people; one study found that 18 percent of people with and without a past psychiatric diagnosis were later diagnosed with a mental health disability after having

been diagnosed with COVID-19.⁷⁴¹

The pandemic's mental health impact has been felt with particular force in communities of color, which have experienced disproportionately high rates of COVID-19 cases and deaths. Black and Latinx adults have more

commonly reported symptoms of anxiety and/or depressive disorder during the pandemic than White adults. Further, Black and Latinx adults were less likely to receive needed mental health services than others prior to the pandemic.⁷⁴²

In addition, the impact of the pandemic on veterans' mental health is significant. Veterans already face isolation and a sense of social disconnectedness due to the challenges of explaining past traumatic experiences to those who have not served in the military. Ordinarily, between 17 and 18 veterans die by suicide each day in the United States.⁷⁴³ According

In January 2021, CDC's . . . data showed that 41 percent of adults reported symptoms of anxiety and/or depressive disorder that month—a figure that had changed little since the spring of 2020—compared to 11 percent between January and June of 2019.

to the Wounded Warriors Project, a national veteran services organization, “lack of social connection (loneliness) along with co-occurring mental health conditions (PTSD, depression, suicidal ideation) exacerbates and magnifies the burden warriors experience during adverse events like COVID-19.”⁷⁴⁴ The Project reported that at the time of its 2020 survey, “60% of warriors were experiencing moderate to severe depression symptoms, 56% were experiencing PTSD symptoms, 66% reported loneliness, and 30% reported recent suicidal ideations.”⁷⁴⁵

The mental health impact on children from prolonged periods of time outside of school, without physical interaction with peers, remains to be seen; but grave concerns have been raised about the impact of this situation in the short and long term. As one stakeholder convening

participant observed, “this pandemic is a perfect storm of those suicide risk factors, including social stressors, . . . loss, adverse life events, life transition, physical illness, feeling trapped and isolated,” and COVID-19 increases the presence as well as the severity of all of these risk factors.⁷⁴⁶

Mental Health Impact on Healthcare Workers and Other Essential Workers

Frontline healthcare workers and other essential workers have been particularly impacted by the pandemic. Essential workers had the highest rates of adverse mental health outcomes compared to all other employment groups surveyed by CDC.⁷⁴⁷ Research has shown that frontline healthcare workers are generally at higher risk of negative mental health outcomes



during pandemics.⁷⁴⁸ During the COVID-19 pandemic, caregivers working in LTCFs and those providing unpaid care to family members or other loved ones have faced particular mental health risks due to the stressors of high coronavirus infection risks and burnout.⁷⁴⁹ Staffing challenges due to COVID-related illness, exposure, or childcare or other family responsibilities during the pandemic have also exacerbated stresses on healthcare workers.

Approximately one third of U.S. adults reported being essential workers required to work outside their homes during the pandemic.⁷⁵⁰ These workers are disproportionately Black and low-income.⁷⁵¹ Women of color are particularly overrepresented.⁷⁵² More than 90 percent of workers in the bottom 25th income percentile cannot work from home.⁷⁵³ In the healthcare industry, more than 6.5 million healthcare support workers earn less than the U.S. median wage, and many do not receive basic benefits such as paid sick leave or personal leave.⁷⁵⁴

A significant proportion (30 percent) of adult workers reported symptoms of anxiety or depression in a June 2020 survey, but essential workers reported such symptoms at even higher rates (42 percent). Twenty-two percent of essential workers also reported suicidal thoughts, compared with 8 percent of nonessential workers.⁷⁵⁵ Nearly three in ten essential workers said that their mental health has worsened, and 75 percent said they could have used more emotional support than they received.⁷⁵⁶ Thirty-one percent of unpaid caregivers for adults “seriously considered suicide” during the past 30 days.⁷⁵⁷ Moreover,

multiple studies have found that frontline healthcare workers with preexisting mental health conditions “were more likely to exhibit severe mental health outcomes during outbreaks.”⁷⁵⁸

This level of distress suggests that many of these workers experience psychiatric disabilities, whether or not they had such disabilities before the pandemic. Indeed, 25 percent of essential workers reported being diagnosed with a mental health disorder since the start of the pandemic.⁷⁵⁹ Essential workers were more than twice as likely as those who are not to have received treatment from a mental health professional (34 percent vs. 12 percent) and to have been diagnosed with a mental health disorder since the coronavirus pandemic started (25 percent vs. 9 percent).⁷⁶⁰

... 25 percent of essential workers reported being diagnosed with a mental health disorder since the start of the pandemic.

The mental health impact on healthcare workers in particular has manifested itself not only in the anxiety, depression, and loneliness that many

have experienced during the pandemic, but also in trauma-related disorders. Frontline healthcare workers have experienced sickness and death on a daily basis during the pandemic, and have repeatedly been placed at risk for infection, often without adequate staffing and resources.⁷⁶¹ Thirty-five percent of healthcare workers have experienced trauma-related symptoms.⁷⁶² These symptoms were particularly common in women, nurses, frontline workers, and workers who experienced physical symptoms of COVID-19.⁷⁶³

Recommendations to address these issues have included both clinical approaches, such as expanding the mental health workforce to expand the availability of services, and nonclinical approaches including making available peer

support services (provided by individuals with lived experience with psychiatric disability to help individuals develop skills in managing illness and recovery, in self-advocacy, and in identifying and using natural supports) and workplace supports such as employee assistance programs.⁷⁶⁴ Peer support is a highly effective intervention that has been used for many decades and recognized by the CMS as an evidence-based service.⁷⁶⁵ It has also been a widely used and successful intervention for veterans with mental health disabilities including PTSD.⁷⁶⁶

Other recommendations have included employers providing flexibility and support to essential workers, including making reasonable accommodations, removing nonessential tasks, ensuring essential workers have access to PPE and to needed transportation, recognizing the phenomenon of burnout, and helping employees prioritize critical tasks.⁷⁶⁷ Diversifying the mental health workforce has also been recommended, given the disproportionate representation of Black Americans and other people of color among the essential workers impacted by the pandemic.⁷⁶⁸

Mental Health Impact Resulting from Remote Work and from Increased Job Loss and Unemployment

The isolation and stress of remote work also seem to have had a significant impact on individuals' mental health. The closure of many schools, daycares, and public spaces has meant that many people who have been able to work from home during the pandemic are facing new stresses, additional responsibilities at home, and diminished

work-life balance.⁷⁶⁹ Surveys found that nearly half of adults working from home during the pandemic experienced stress, anxiety, or depression; for many, these experiences began or worsened after they started working from home.⁷⁷⁰

Further, the increased job loss and unemployment associated with the COVID-19 pandemic has contributed to the development of mental health and substance use disabilities.⁷⁷¹ During April 2020, the U.S. unemployment rate peaked at 14.8 percent, the highest since data collection began in 1948.⁷⁷² Unemployment rates have been higher for workers without a college degree and for racial and ethnic minorities during the pandemic.⁷⁷³ People of color have historically experienced higher unemployment rates than

white people in the United States, but the disparities in unemployment rates spiked during April 2020 and unemployment rates for people of color remained high

through the end of 2020, even though the overall unemployment rate fell.⁷⁷⁴ Estimates of how many Americans lost employment due to the pandemic range from 13 million to 36 million, depending on the methodology used.⁷⁷⁵

Half or more of those who became unemployed during the COVID-19 pandemic have developed behavioral health conditions.⁷⁷⁶ Research has consistently found that rises in unemployment are directly associated with increases in suicide.⁷⁷⁷ The Meadows Mental Health Policy Institute estimated that a COVID recession on par with the 2007–2009 recession, which brought a 5 percent increase in unemployment, would result in the loss of approximately 4,000 additional Americans to

Half or more of those who became unemployed during the COVID-19 pandemic have developed behavioral health conditions.

suicide.⁷⁷⁸ Individuals who are most at risk of having adverse mental health impacts are those for whom unemployment is an immediate threat to their survival.⁷⁷⁹

Moreover, during and after a major recession, individuals who have developed behavioral health conditions have an especially difficult time becoming re-employed.⁷⁸⁰ In addition, research has shown that people with behavioral health conditions are disproportionately likely to contract COVID-19 and die from it. Thus, as one set of prominent mental health experts observed, “COVID-10 infection and behavioral health conditions influence each other in a bidirectional relationship.”⁷⁸¹

It is no surprise that the job loss and unemployment caused by the pandemic have had such a significant adverse effect on mental health. Not only is unemployment associated with negative mental health effects, but conversely, work is associated with improved mental health outcomes. Work is not only a means to economic security: “[E]mployment is itself an effective behavioral health intervention” and “part of the [mental health] recovery process itself.”⁷⁸²

Accordingly, one key measure that has been recommended as a strategy to address the mental health effects of the pandemic is making evidence-based supported employment services available to individuals who have developed behavioral health conditions as a result of the pandemic. The experts recommending this strategy pointed out that the rate at which the Individual Placement and Support model of supported employment for people with psychiatric disabilities succeeded in getting people competitively employed during the fourth quarter of 2020, when the pandemic was at its height, was 42 percent—just as high as it has averaged over the past decade.⁷⁸³

The success of these services even during the pandemic reflects that individual placement and support (IPS) teams continued to provide services remotely throughout the pandemic and developed expertise in providing all phases of supported employment with minimal face-to-face contact.⁷⁸⁴ Since the behavioral health disabilities developed by individuals unemployed due to the pandemic are less severe than those experienced by individuals who have traditionally received IPS, these unemployed individuals may be helped with lower levels of service than IPS usually requires.⁷⁸⁵

Mental Health Impact on Children and Youth

The pandemic has particularly affected the mental health of children and youth due to the isolation, stresses, and difficulties associated with remote learning. A November 2020 report from CDC showed a dramatic increase in mental health emergencies among children and youth.⁷⁸⁶ Beginning in March 2020 and continuing through the end of the reporting period in October 2020, the proportion of mental health–related emergency department visits increased sharply, with increases of 24 percent among children aged 5–11 years and 31 percent among adolescents aged 12–17 years compared with the same period in 2019.⁷⁸⁷ While CDC cautions that this data has limitations, including that the percentage of children’s mental health emergency department visits may appear proportionally inflated due to the sharp declines in emergency department use for other issues such as asthma and musculoskeletal injuries in 2020, it is still troubling.⁷⁸⁸ Most emergency departments do not have adequate capacity to treat pediatric mental health concerns.⁷⁸⁹

In addition to the loneliness and social isolation experienced by children and youth who spent

months isolated from their peers and school communities, one cause of increased mental health concerns may be the reduced access to the mental health services that many children receive through their school or in their communities, leading to increased reliance on emergency department services for routine treatment as well as crisis services.⁷⁹⁰ Between March and May 2020, children on Medicaid received 44 percent fewer outpatient mental health services, such as therapy and in-home support, compared to the same time period in 2019.⁷⁹¹

Story of Student Mental Health Crisis

Crisis services were impacted. One story of a 17-year-old girl with autism who experienced mental health crises when her school closed is particularly poignant. The girl continued to get up early and wait for the school bus and began wandering when the bus did not show up. Her mother began calling a mental health crisis line and was routinely put on hold for 40 or 50 minutes. Out of frustration, the mother called the police for help. When the police showed up the girl became agitated and hit her mother in the back, leading police to arrest her and take her to jail. The mother pleaded with the police instead to drive the girl home so that she could take her medication, but the police indicated that they were unable to do that and the only places they could transport her were the jail or the hospital. The girl spent most of the night in jail until her mother posted bail.⁷⁹²

Additionally, with many children having been away from school and disconnected from adults who might ordinarily identify signs of abuse or neglect, the potential for children to be exposed to trauma as abuse or neglect goes unaddressed is high.⁷⁹³ Such adverse childhood experiences are strongly correlated with the development of mental health disabilities.⁷⁹⁴

A survey of college students conducted by Active Minds, a mental health organization with chapters on hundreds of college campuses, found that 80 percent of college students reported that COVID-19 has negatively affected their mental health, and one in five reported that their mental health has significantly worsened during the pandemic.⁷⁹⁵ Another survey found that college students' mental health needs had changed during the pandemic, and many did not feel supported by their schools.⁷⁹⁶

Barriers to conducting mental health counseling and other services through telehealth have generally been removed, although some challenges may impede the effectiveness of telehealth to deliver these services, including the availability of adequate technology and the ability to ensure that students and staff can use that technology.⁷⁹⁷ For example, the above-referenced 44 percent decrease in outpatient mental health services for children on Medicaid between March and May 2020 occurred despite the increased use of telehealth services.⁷⁹⁸ In addition, for some students, telehealth visits simply may not substitute for in-person interactions, and academic-focused mental health services may be more challenging to deliver through telehealth technology.

At the same time, the use of telehealth actually presented an opportunity to expand availability of mental health services to a greater

number of children and youth who could benefit from them, given the reductions in time needed for providers or clients to travel to in-person appointments. Hybrid in-person and virtual approaches, where providers serve some children through virtual appointments and others in person, could be an important part of that expansion and may help reach children who need additional support or do not have regular access to the internet.⁷⁹⁹

The Pandemic Has Limited Access to Mental Health Services at a Time When They Are Most Needed

While the COVID-19 pandemic created greater need for mental health services, at the same time it has significantly impaired the availability of mental health services. The National Governors Association reported that capacity and operations of the behavioral health system are increasingly strained due to the negative impact of illness and job loss on the direct care workforce.⁸⁰⁰ Most behavioral health community service

providers suspended site-based services early in the pandemic. Providers struggled with staffing challenges, including for assertive community treatment (ACT), in-home services, and other services.⁸⁰¹ Some agencies enhanced rates and other incentives to maintain staffing. Ensuring access to PPE was also a challenge.⁸⁰²

As noted above, state and federal rules restricting billing for behavioral health telehealth services were largely lifted during the pandemic. Nonetheless, use of telehealth by behavioral health providers remained limited due to lack of staff training, internet connectivity issues, and insufficient funds for technology, as well as concerns about clinical efficacy and privacy concerns.⁸⁰³ In addition, some services require face to face interaction.⁸⁰⁴

Federal and state efforts to address these issues made some difference, though more remains to be done, particularly in light of the challenges that mental health service systems faced even before the pandemic. Some of the strategies that were used include:

Strategies to Address the Need for Mental Health Services

- Utilizing Medicaid flexibilities permitted due to the public health emergency.⁸⁰⁵ Florida, for example, waived prior authorization and limits on the frequency and duration of behavioral health services. North Carolina waived prior authorizations, limits on length of services, certain staff training requirements, supervision requirements, and face-to-face requirements for certain behavioral health services.⁸⁰⁶ Connecticut used an Appendix K waiver (these are discussed in the CCF chapter) to increase staff providing services for individuals with psychiatric disabilities coming out of nursing facilities.⁸⁰⁷ By November 17, 2020, 36 states temporarily increased provider payment rates and 39 were temporarily using retainer payments to address emergency issues through Appendix K.⁸⁰⁸
- Using Medicaid State Plan Amendments or other administrative actions to increase reimbursement rates for providers more permanently.⁸⁰⁹

Strategies to Address the Need for Mental Health Services: *continued*

- Taking advantage of CMS guidance allowing states to request authority for advance payments to providers. States and Medicaid managed care organizations used prospective payments and advanced cash flow to help providers during the pandemic. New Hampshire, for example, asked its managed care plans to reallocate 1.5 percent of the capitation dollars for provider rate enhancements for certain providers, and Washington has worked with its managed care organizations to direct advance payments, capitated contracts, and other funding strategies toward providers at the highest risk of closing.⁸¹⁰
- Using state resources and providing guidance and training to support community-based provider needs related to the pandemic. For example, Washington paid for Zoom licenses for providers to ensure access to telehealth services.⁸¹¹
- Taking advantage of new federal resources available through the COVID-19 relief legislation. These resources include a 10 percent increase in federal Medicaid reimbursement for HCBS, including a wide array of community mental health services, available through the American Rescue Plan (available for one year beginning April 1, 2021), an 85 percent federal match rate for mobile crisis services available through the American Rescue Plan (available for three years beginning April 1, 2022), new funding for Certified Community Behavioral Health Clinics available through the American Rescue Plan and prior COVID-19 relief legislation, and increased mental health and substance use disorder block grant funding through the various COVID relief packages.⁸¹²

As the National Governors Association observed, additional support for technical assistance, training, and general capacity building by community behavioral health providers is needed given that these providers were already under-resourced for years prior to the pandemic.⁸¹³

More Effective Suicide Prevention Strategies are Needed

As noted above, during the pandemic, the United States has seen significant increases in the percentage of individuals considering suicide. Participants in an NCD stakeholder convening

concerning the pandemic's impact on mental health and suicide universally identified problems with the way that suicide has been understood and the strategies being discussed to address and prevent suicide during the pandemic.

Participants noted that it was unsurprising that the pandemic had caused an increase in suicides, given all of the associated losses that it has caused, including loss of friends, family members and others, adverse life events, loss of jobs and housing, physical illness, a sense of feeling trapped and isolated, and life transitions.⁸¹⁴ One participant mentioned that the first suicide that her organization saw during

the pandemic was that of a transgender woman stuck in a hotel who took her life within hours after unsuccessfully asking someone for help with housing. That participant described how both the COVID-19 pandemic and the individuals' past experiences with coercive mental health treatment led to a sense of loss of power and control that, consistent with research findings, increases the likelihood of suicidal thoughts.⁸¹⁵ One survey found that for individuals who had been involuntarily confined in a psychiatric facility in the past or subjected to coercive mental health services, more than twice as many reported increased suicidal thoughts during the pandemic compared to individuals who had not been involuntarily hospitalized or subjected to force.⁸¹⁶

Participants observed that suicide should not be understood as a "mental health problem," and suicides during the pandemic have not been limited to individuals with preexisting mental health disabilities or individuals with newly developed mental health disabilities. They highlighted that efforts to focus on suicide itself as the problem to be stopped miss the root causes of suicide—the underlying stressors and problems that individuals who attempt suicide are trying to "solve" or escape.⁸¹⁷ Rather than focusing on clinical approaches that target suicide itself, participants urged a public health approach that focuses on the systemic needs and inequalities that cause people to be in distress—for example, measures that focus on ensuring

a living wage and measures that focus on preventing evictions.⁸¹⁸

Participants pointed out that the common strategies discussed for addressing suicide during the pandemic are problematic or ineffective and that suicide prevention efforts should focus on alternative strategies. First, a great deal of attention has been given to screening and identifying individuals who may be suicidal, including particularly through the use of crisis or suicide hotlines.⁸¹⁹ For example, the recommendation to call suicide or crisis hotlines features prominently in documents published by CDC, the National

Institute of Mental Health, and the National Governors Association concerning strategies to address the mental health impact of the pandemic.⁸²⁰ Due to the passage of legislation designating a national "988" crisis line that will use the National Suicide Prevention Line

Many individuals have come to avoid using these hotlines for assistance because of concerns about the requirement that hotlines contact law enforcement in certain circumstances and calls that have led to the frequent outcome of involuntary hospitalization.

for calls relating to both suicide and mental health crises generally, 988 has featured prominently in discussions of how to address mental health crises as we emerge from the pandemic.⁸²¹

Convening participants noted, however, that little attention has been paid to what happens when individuals call these hotlines.⁸²² Many individuals have come to avoid using these hotlines for assistance because of concerns about the requirement that hotlines contact law enforcement in certain circumstances and calls that have led to the frequent outcome of



involuntary hospitalization.⁸²³ A recent article chronicling the experiences of individuals who experienced unwanted police encounters and involuntary hospitalization as a result of calls to the National Suicide Prevention Line observed:

Driving much of this is growing awareness that calling 911 for issues of emotional distress can lead to deadly police interventions. Yet under-reported and under-investigated is the fact that calls to the National Suicide Prevention Lifeline (NSPL)—which prominently advertises itself as “confidential”—are often covertly traced. Callers get subjected to police interventions and forced psychiatric hospitalizations. Police shootings occur. Many callers describe their experiences

as terrifying and traumatizing and say the betrayal has made them feel more isolated than ever.⁸²⁴

Among the examples described in the article are:

- A veteran who called the NSPL during his lunch break at work when he was “feeling pretty down” but not actively suicidal. The man hung up after 10 minutes to return to work, and 20 minutes later police arrived, took his access badge, and escorted him to an ambulance that brought him to a veterans’ hospital. The man relayed that it was embarrassing and traumatizing because “[a]ll my coworkers and my

lead and supervisor, they saw me get taken away.” The man, who is Black, was particularly intimidated by the police encounter because growing up he was frequently subjected to random stop-and-frisks by police. He was detained in the hospital until a family member came to pick him up several hours later. He was required to get clearance from a doctor in order to return to work, and subsequently received an ambulance bill for \$1,000. He wonders whether the incident played a role in his being laid off several months later while individuals with less seniority were kept on.

- A student who called the NSPL because she had no health insurance, could not afford therapy, and “was just depressed and kind of wishing that I might just die” and “wanted to talk to another person and maybe be reassured a little.” When the call attendant urged her to go to a psychiatric hospital immediately and the student explained she had a class that was about to start, the call attendant threatened to send police and the student hung up. Fifteen minutes later, the police and an ambulance showed up, strapped the student to a stretcher, and took her to a hospital where she was forced to strip and sit in an empty room for 12 hours without explanation. When her 72-hour involuntary detention period expired, the student consented to a voluntary admission out of fear that going through a court proceeding for involuntary commitment could threaten her ability to obtain a law license. The student received a \$50,000 hospital bill at the end of her two-week stay.⁸²⁵

According to the NSPL, its call centers dispatch emergency services in only 2 percent of calls. But if its projection of up to 40 million annual 988 calls by 2027 is accurate, a 2 percent rate of dispatching police and ambulances could affect up to 800,000 callers each year.⁸²⁶ Thus, while crisis or suicide hotlines may help many people, they may create other problems including expanding law enforcement involvement with people with psychiatric disabilities.

Moreover, suicide hotlines rely on screening tools that research has consistently demonstrated have little effectiveness in predicting suicide. The lead author of a widely read meta-analysis of the past 50 years of research on assessing suicide risk stated:

Our analyses showed that science could only predict future suicidal thoughts and behaviors about as well as random guessing. In other words, a suicide expert who conducted an in-depth assessment of risk factors would predict a patient’s future suicidal thoughts and behaviors with the same degree of accuracy as someone with no knowledge of the patient who predicted based on a coin flip. This was extremely humbling—after decades of research, science had produced no meaningful advances in suicide prediction.⁸²⁷

Convening participants noted that little has changed in the interventions that we offer once someone has been identified as at risk of suicide; the primary intervention continues to be hospitalization, despite research demonstrating that hospitalization does not result in lower rates of suicide and despite the dangers to which

institutionalized people are exposed during the COVID-19 pandemic.⁸²⁸

Participants urged a demedicalized approach to suicide prevention that addresses the root causes of suicidality such as loss of jobs and housing, the need for culturally competent services to understand the different expressions of suicidality across cultures, expanded public and private coverage of suicidality treatments that focus on the underlying problems that are causing distress, including Collaborative Assessment and Management of Suicidality and Dialectical Behavioral Therapy for suicidality, and efforts to remove lethal means from individuals' environments.⁸²⁹ They also urged the expansion of peer-run peer support services and approaches such as the "Alternatives to Suicide" groups conducted by the Western Massachusetts Recovery Learning Community, which are run by suicide attempt survivors and prohibit calls to law enforcement.⁸³⁰

Participants noted the challenges in expanding peer support, including extremely low wages in many areas, the general limitation of private insurance coverage to services provided by licensed professionals, and the strictures of Medicaid reimbursement for peer support services, which requires peer support workers to be supervised by clinical professionals. Participants also discussed the challenges of clinician involvement because clinicians may face potential liability connected with licensure obligations if they do not warn others or act if a person may be at risk of suicide.⁸³¹ These concerns make it difficult for many individuals to speak freely to professionals about their distress, limiting the

effectiveness of treatment. One participant referenced a survey concerning "Alternatives to Suicide" groups in which over 90 percent of respondents indicated that the most useful thing about these groups is being able to talk openly to someone without the prospect of being subjected to force.⁸³²

Many of these recommendations have been echoed by the American Foundation for Suicide Prevention. Its chief medical officer has developed priorities for addressing suicide that include involving individuals with lived experience (including COVID-19-related lived experience) in decision-making related to policy, clinical practice, and research; expanding the use of peer specialists and peer educators; expanding access to evidence-based suicide risk-reducing treatments such as Cognitive Behavioral Therapy, Dialectical Behavioral Therapy, and Collaborative Assessment and Management of Suicidality; and reducing access to lethal means.⁸³³

Summary of Findings

The COVID-19 pandemic had a devastating impact on the mental health of Americans. Due to the social isolation caused by remote work, job loss, closed schools, stay-at-home orders, shuttered businesses, and physical distancing, many adults and children experienced new mental health disabilities or exacerbations of existing ones. The adverse mental health effects of the pandemic hit certain groups particularly hard, including frontline and other essential workers, children and youth, veterans, and those who lost jobs. Women and people of color also experienced high rates of mental health disabilities due to their disproportionate representation among essential workers. Rates

of anxiety and depression rose significantly, crisis hotlines saw high call volumes, and more people experienced suicidal thoughts.

At the same time that the pandemic caused increased mental health needs, it hamstrung the ability of mental health service systems to address those needs. Service providers experienced staffing shortages due to illness, exposure, and family or childcare responsibilities during the pandemic. Providers dramatically expanded their use of telehealth, but not everyone could access the technology needed for telehealth and not every service could be delivered remotely.

Expanded access to mental health services in public and private insurance is important to address the lasting impact of the pandemic even as it recedes. Peer support services and supported employment are particularly critical.

Policymakers should also take this opportunity to rethink suicide prevention strategies and expand approaches that focus on the root causes of suicide such as job loss and housing unaffordability, as well as expanding insurance coverage of clinical strategies that address these root causes rather than relying so heavily on hospitalization.

Recommendations

To address the dramatic impact of the pandemic on the mental health of adults and children in the United States, expanding access to mental health services is urgent. The services needed include clinical services but also nonclinical approaches, including expansion of peer support services, services and accommodations that support individuals with mental health disabilities in the workplace, and housing supports.

Recommendations for Congress

Congress should:

- Permanently authorize telehealth flexibilities that enable tele-mental health services while also ensuring that in-person services and hybrid in-person and virtual services are available options for those who need and want them. (This recommendation also applies to state lawmakers, as well as to private insurance regulators).⁸³⁴
- Promote effective suicide prevention efforts. Rather than promoting screening and identification of individuals who may be suicidal and involuntarily hospitalizing them, Congress should promote suicide prevention efforts focusing on approaches that address the underlying problems that cause people to consider suicide. These should include helping individuals secure housing, preventing evictions, and helping individuals secure and maintain employment. They should also include peer-run support services for individuals who are experiencing suicidal thoughts. (This recommendation also applies to state lawmakers, as well as to private insurance regulators).

Recommendations for Federal Agencies

- **SAMHSA and state mental health agencies** should robustly promote effective suicide prevention efforts focusing on approaches that address the underlying problems that cause people to consider suicide. These should include helping individuals connect with housing services and referring individuals to vocational rehabilitation or other employment programs for people with disabilities.
- **CMS** should:
 - Revisit Medicaid rules requiring that peer support services be delivered under the supervision of clinicians. While clinical input and consultation may be beneficial, it should not be a requirement for reimbursement of all peer support services.

Recommendations for States

States should:

- Take steps to expand the mental health workforce, and particularly the peer support workforce, including through using new HCBS dollars and mobile crisis dollars available through the American Rescue Plan and new block grant and Certified Community Behavioral Health Center (CCBHC) funds. States should ensure that their service systems include robust peer support services.
- Provide guidance, training and supplies to support community-based mental health provider needs related to new and increased operational needs raised during the pandemic, including paying for Zoom licenses to ensure access to tele-mental health services.
- Invest in peer-run services including peer crisis respite centers, peer “bridger” services that help individuals transitioning from institutional to community settings, and peer-run services for individuals experiencing suicidal thoughts.
- Expand supported employment services using the Individual Placement and Support (IPS) model. Peer specialists should be part of the IPS teams.
- Make efforts to diversify the mental health workforce so that it reflects the racial, ethnic, cultural, sexual orientation, and gender identity diversity of the communities it serves.

(continued)

Recommendations for States: *continued*

Peer support workers should not only have lived experience with mental health disabilities but also reflect the lived experiences of communities of color and particularly Black communities.

- Take advantage of federal Medicaid flexibilities permitted due to the public health emergency to suspend premiums and other cost sharing, suspend the need for prior authorizations for community mental health services, make advanced or supplemental payments to community mental health providers, increase payment rates for these services, allow early or extended refills of medication without prior authorization, and add benefits including peer support, supported employment, and housing-related services.
- Take advantage of CMS guidance allowing states to request authority for advance payments to providers in order to support community mental health providers at risk of closure.
- Reconcile the important suicide prevention measure of removing lethal means from individuals' environments with privacy and equity concerns. Removal efforts most commonly take the form of "extreme risk protection orders" that allow the removal of guns from individuals' homes when those individuals have engaged in conduct that indicates that continuing to possess a gun would be dangerous. Such laws should identify individuals based on conduct and not based on a disability diagnosis, treatment, or history.
- Review evidence on effective suicide prevention efforts. Rather than focusing on trying to screen and identify individuals who may be suicidal and involuntarily hospitalizing them, suicide prevention efforts should focus on approaches that address the underlying problems that cause people to consider suicide. These should include helping individuals secure housing, preventing evictions, and helping individuals secure and maintain employment. They should also include peer-run support services for individuals who are experiencing suicidal thoughts.

Appendix A: Convening Participants

November 10, 2020: Convening on Education, Employment, Mental Health, Suicide Prevention Policy*

Alexis DeLaCruz	Staff attorney with Native American Disability Law Center whose work includes litigating on behalf of Native American students with disabilities
Alissa Fernandez	Disability activist and mental health peer support specialist, founder of Peer Mental Health Alliance
Allison Nichol	Director of Legal Advocacy with the Epilepsy Foundation, former Deputy Chief of the Disability Rights Section in the federal Department of Justice
Brian East	Senior Attorney, Disability Rights Texas whose work includes litigating disability rights and employment litigation
Denise Marshall	Education specialist and Executive Director of the Council of Parent Attorneys and Advocates (COPAA)
Diane Berman	K-12 teacher who received an employment accommodation to teach remotely, inclusion trainer for college education students, parent of children with disabilities
Joel Boehner	Assistant Director of Exceptional Learners with South Bend Community School Corporation, former Executive Director of InSource, a Parent and Training Information Center in Indiana
Paula West-Hernandez	Project Manager for Region 2 at Team of Advocates for Special Kids (TASK)
Sera Davidow	Peer advocate and Director of Western Massachusetts Recovery Learning Community (RLC)
Susan Stefan	Attorney and advocate for people diagnosed with psychiatric disabilities, affiliated with Massachusetts Committee for Public Counsel Services

November 12, 2020: Healthcare Discrimination, Congregate Care Facilities, Direct Care Workforce

Alyssa M Burgart	Pediatric anesthesiologist and bioethicist, Clinical Associate Professor, Department of Anesthesiology, Perioperative & Pain Medicine, Stanford Center for Biomedical Ethics, Stanford University, Lucile Packard Children's Hospital
Anaya Robinson	Associate Director, Atlantis Community, Inc., Denver
Andres Gallegos	Disability Rights Attorney, Robbins, Salomon & Patt, LTD. and NCD Council Member

* Note that the topic of Effective Communication was raised and discussed in both convenings.

Devan Stahl	Assistant Professor of Bioethics, Baylor University
Elizabeth Pendo	Joseph J. Simeone Professor of Law, Saint Louis University School of Law
Gelila Selassie	Staff Attorney, Justice in Aging
Gloria Ramsey	Associate Dean for Diversity, Equity and Inclusion, Johns Hopkins School of Nursing
Hannah Karpilow	Personal Care Attendant, Hand in Hand member, SEIU 2015 member
Jennifer Steneberg	Attorney, Dale Law Firm, P.C., support person for sibling with disabilities
Joni Mahler	Educational Therapist, adult child of a parent living in a memory care facility
Kristina Bas Hamilton	Legislative Director, UDW/AFSCME Local 3930
Kristi Kirschner	Physiatrist, Clinical Professor, Departments of Medical Education; Neurology and Rehabilitation; and Academic Internal Medicine University of Illinois College of Medicine and Adjunct, Department of Disability and Human Development, College of Allied Health Sciences, University of Illinois, Chicago
Larry Grable	Executive Director, Service Center for Independent Life, California
Lindsay Imai Hong	California Director, Hand in Hand, The Domestic Employers Network
Lisa Iezzoni	Professor of Medicine, Harvard Medical School, Health Policy Research Center, Mongan Institute, Massachusetts General Hospital
Marty Knisley	Director, Technical Assistance Collaborative
Rick Rader	Internist and Medical Anthropologist, Director of the Morton J. Kent Habilitation Center, Orange Grove Center, NCD Council Member
Steven Barnett	Professor, Department of Family Medicine, University of Rochester School of Medicine & Dentistry and Director, Rochester Prevention Research Center: National Center for Deaf Health Research (RPRC/NCDHR)
Tara Lagu	Internist, Director, Center for Health Services and Outcomes, Northwestern University Institute of Public Health and Medicine
Tom Heinz	Executive Director, East Bay Innovations
Wendy Eisenbeisz	Parent, support person for adult son with disabilities

DREDF and Bazelon Representatives Present at Both Convenings

Brit Vanneman	David and Mickey Bazelon Fellow, Bazelon
Carly Myers	Staff Attorney, DREDF
Claudia Center	Legal Director, DREDF
Jennifer Mathis	Deputy Legal Director & Director of Policy & Legal Advocacy, Bazelon
Mary Lou Breslin	Senior Policy Advisor, DREDF
Silvia Yee	Senior Staff Attorney, DREDF
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Chapter Three: The Direct Care Workforce

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Chapter Six: Effective Communication

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