



## **Strengthening the HCBS Ecosystem**

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**Responding to Dangers of Congregate Settings during COVID-19**



**National Council on Disability**

November 16, 2022

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

***Strengthening the HCBS Ecosystem: Responding to Dangers of Congregate Settings  
during COVID-19***

National Council on Disability, November 16, 2022  
Celebrating 38 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

November 16, 2022

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

The pandemic has shone a light on our nation's insufficient investment in Home and Community Based Services (HCBS). These critical services are a life-line for millions of people with disabilities who desire to live independently in their respective communities. The lack of investment in HCBS was a significant contributor to the needless deaths of people with intellectual and developmental disabilities (IDD) living in congregate settings during the pandemic. On behalf of the National Council on Disability (NCD), I submit the report, *Strengthening the HCBS Ecosystem: Responding to Dangers of Congregate Settings during COVID-19*.

Building on NCD's report *Deinstitutionalization: Unfinished Business* (2012) and the *2021 Progress Report: The Impacts of COVID-19 on People with Disabilities*, this report describes significant barriers to an effective, adequate system of HCBS, and provides recommendations that will be responsive to the nation's present and growing need for community-based living.

COVID-19 was the number one cause of death for people with IDD during 2020, with a disproportionate death toll of those residing in congregate settings such as group homes and nursing homes. These settings were hotbeds for transmittal of the coronavirus, and though people with IDD in such settings were highly susceptible to infection and death from the virus, they were largely unable to transition out of these settings. Tragically, disabled residents who were hospitalized after contracting the virus were commonly returned to these settings to shelter in place, rather than be transferred to home or low census community-living options where social distancing and other Center for Disease Control and Prevention recommended health protocols could have been implemented. The shelter in place decision was a stark contrast to the quick transfer of other populations in institutional settings, such as prisoners and residents of homeless shelters who were transferred to low census settings with positive results in containing the spread of the virus. Because of the ensuing death toll, the shelter in place strategy for people with disabilities has been referred to as "dying in place." The unnecessary deaths are a potent reminder that institutionalization is detrimental and failed model.

The integration mandate of the Americans with Disabilities Act and the Supreme Court's decision in *Olmstead v. L.C.* are the bases for moving people with disabilities, who can and want to live in the community, out of institutionalized settings. However, this report points out continued barriers that restrict the ability to do so. In the year preceding the pandemic, HCBS transitions under Money Follows the Person dropped 46% and the transitions that took place were largely not people with IDD. State HCBS programs, a major avenue for moving people out of institutionalized settings, have long waiting

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lists. Wait times can span years and are partially fueled by persistent barriers, such as the nationwide, prolonged shortage of direct care workers which was exacerbated by the pandemic. Direct care workers are a critical part of HCBS because they provide the services that people with disabilities need in order to live in the community. The dearth of this crucial workforce slowed or prevented transfers to the community and put people in the community at risk of institutionalization. The report also describes the persistent barrier of a national lack of affordable, accessible, housing. Public Housing Authorities are utilizing vouchers from HUD to transition people out of institutions, but demand for affordable housing far outpaces supply. Wait lists for low-income housing are often years long and the amount of units designed for wheelchair users or those with sensory impairments is inadequate to meet the nation's needs. A recent report estimates that there is a shortage of 3.4 million affordable rental units, which pales in comparison to the shortage of affordable and accessible rental homes.

In addition to the Federal integration mandate, it is well established that living in one's home with supports is safer than living in an institutionalized setting, costs less, and is the desire of most individuals. But data from the Centers for Medicare and Medicaid Services show that in 2018 there were almost 600,000 people with IDD living in institutionalized settings who were on HCBS waiting lists to transition to the community. A 2021 report raises this number to over 800,000. The latest census data also increases the urgency for action, as age is a predictor of disability: by 2030, more than one in five people in the U.S. will be sixty-five or older, and by 2035, the number of people over eighty-five will nearly double. As with group homes, nursing homes were deadly places to reside during the pandemic and as the population grows older it becomes more imperative that older individuals with disabilities can remain in their homes with necessary supports.

The U.S. has come a long way in its efforts on deinstitutionalization, but still has much to do. COVID-19 showed the danger of continued reliance on the institutionalization model, and the hundreds of thousands deaths beg for immediate, concrete actions to address the barriers to an adequate and robust HCBS system now, before the next public health emergency.

We welcome the opportunity to discuss the issues raised in this report and to support your Administration in implementing the recommendations to improve the lives of people with disabilities.

Respectfully submitted,



Andrés J. Gallegos, J.D.  
Chairman

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(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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# Acknowledgments and Dedication

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## Acknowledgments

The National Council on Disability expresses its appreciation to Dr. Kara Ayers, Ph.D., Assistant Professor and Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities for her research and drafting of this report.

## Dedication

This report, focused on home and community based services, is dedicated to the late Lois Curtis. The lawsuit she filed – *L.C. v. Olmstead* – led to a landmark Supreme Court decision benefitting people with disabilities. *L.C. v. Olmstead* made living in one's own community a reality for so many people who had been relegated to institutions to live out their lives. When fully integrated and supported in our communities, people with disabilities have a better opportunity to live fulfilled lives.



## Executive Summary

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COVID-19 has laid bare what has been the reality for so many in our country, who over generations have been minoritized and marginalized and medically underserved, and the pandemic took advantage of the legacy of intentional policies that have structurally disadvantaged communities over time.<sup>1</sup>

—COVID-19 Biden/Harris White House  
Health Equity Task Force member

**A**s of June 30, 2022, COVID-19 had killed more than 1 million people in the United States and infected over 87 million others. COVID-19 disproportionately affected people with disabilities, both young and old, who lived in congregate settings, and, at 20 percent of the 1 million deaths, they bore the brunt of the pandemic. But this understates the reality due to the failure to collect data on deaths from COVID-19 among group home residents, even after it was clear that those with intellectual disabilities were very susceptible to contracting and dying of the coronavirus. As with other inequities permeating the standard of care for people with disabilities, the continued

institutional bias that makes it easier to house certain populations of people with disabilities in congregate settings, such as group homes and nursing homes, put them in the bullseye of COVID-19. More than 800,000 people with disabilities are currently in institutionalized settings, where infections such as COVID-19 are proving most deadly, awaiting supports of caregivers and accessible housing to live among their family and friends in their homes in their communities.

In March 2020, when the public health emergency started in the United States, people with disabilities were immediately affected, acquiring the disease and many subsequently dying. In New York, for

example, hospitals knowingly sent patients still ill with COVID-19 back to nursing homes, contributing to uncontrolled outbreaks that would take the lives of many. Group homes for people with intellectual and developmental disabilities (ID/DD) in New York saw high numbers of infections and hospitalizations, but the residents of these settings were denied access to the state's stockpile of tests and equipment because group homes were not deemed "essential health

care settings.” The virus spread rapidly through group homes via contact with direct care workers who entered such settings on a daily basis without the benefit of personal protective equipment. A study of New York State residents found that the mortality rate of those with ID/DD in residential group homes was nearly eight times higher than the general population.<sup>2</sup> While COVID-19 was an unexpected public health emergency, the dangers inherent in congregate care facilities had previously been well established. The COVID-19 response devalued the lives of people with disabilities who resided in congregate settings and resulted in unacceptable, unnecessary deaths.

As seen in New York and Ohio, corruption worsened the already deadly impacts of COVID-19.<sup>3,4</sup> In 2021, an ongoing FBI investigation was instigated to examine New York governor Andrew Cuomo’s underreporting of COVID-19 deaths

in nursing homes. The underreporting may have been motivated by widespread criticism by lawmakers and advocates<sup>5</sup> of New York’s March 25, 2020, directive requiring nursing homes to accept patients with COVID-19 after they had been discharged from hospitals.<sup>6</sup> Ohio’s deception in the pandemic response was later revealed by CMS who found falsified data and backdated test results. The public interest in COVID-19 had waned by then, and state officials faced minimal questions about their role in nursing home accountability to keep residents safe. Current policies overlook potential conflicts of interest between state politics and the

nursing home industry. The Ohio nursing home industry invested \$6 million in state politics over a five-year period.<sup>7</sup> Accountability for past corruption and oversight to prevent future violations were missing from the United States’ COVID-19 response.

Despite the civil rights protections of Sec. 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act, and the *Olmstead* Supreme Court decision, a federal bias toward institutionalization (institutional bias) continues to make it easier to place a person with a disability in a congregate facility rather than in their home with supports.

Through Home- and Community-Based Services (HCBS) waivers, which provide states flexibility

in how and to whom they offer Medicaid benefits, an alternative to institutionalization can be offered by providing services in the community, but that requires there to be accessible,

affordable housing in the community, which overwhelmingly there is not. As a result, that prevents transition to community living and makes it easier to institutionalize people with disabilities. HCBS services vary by state, and HCBS waivers are not portable. Additionally, the direct care worker shortage leaves many at risk of remaining institutionalized or at risk of being institutionalized in the future—a situation that worsened during the pandemic.

While the pandemic was the impetus for some policy and law changes that aimed to keep people safer, the pandemic elevated the chronic problems and weaknesses in the HCBS system

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*A study of New York State residents found that the [COVID-19] mortality rate of those with ID/DD in residential group homes was nearly eight times higher than the general population.*

that need dire resolution. The preventable deaths of residents of congregate setting screams for an end to institutional bias. This will take efforts on several fronts, as discussed here, beginning with a greater federal investment in HCBS and less investment in institutionalized settings. The nation's demographics speak to this need as well, as age is a predictor of disability: by 2030, more than one in five people

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in the United States will be 65 or older, and by 2035, the number of people over 85 will nearly double.

Living in one's home with necessary services and support systems is safer than living in an institutionalized setting, costs less, and is the desire of most individuals. We have come a long way in the quest for deinstitutionalization, but not far enough. COVID-19 showed the danger of continued reliance on the institutionalization model, and the hundreds of thousands preventable deaths must lead to immediate, concrete actions to remedy the weaknesses in our current HCBS system now, before the next public health emergency.

Building on NCD's report

#### *Deinstitutionalization:*

*Unfinished Business* (2012) and the 2021 *Progress Report: The Impacts of COVID-19 on People with Disabilities*, this report describes the weaknesses in the HCBS system, the lack of affordable and accessible housing, and the shortage of the direct care workforce, and provides a plan and recommendations to

address these chronic problems that will be responsive to the nation's present and growing need for community-based living.

## **Key Findings**

- During the pandemic, conflicting guidance issued by the Federal Government combined with the patchwork state system of HCBS waivers resulted in a maze of fragmented supports for people with disabilities in need of diversion from institutionalization.
- While long-standing laws and court precedent (e.g., *Olmstead*) declare that people should receive care in integrated settings, the institutional bias hinders the goal of community integration: institutional settings continue to receive waivers or exceptions to meet the expectation of an individual being in an integrated setting. It continues to be significantly easier to place someone in a nursing home or a group home than in their own home in the community.
- The need for direct care workers to assist people with disabilities to live independently in the community is at an emergency level, and the shortage of direct care workers adversely affects millions. Contributing factors to the labor shortage include low wages and poor benefits,

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### *The preventable deaths of residents of congregate setting screams for an end to institutional bias.*

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### *Living in one's home with necessary services and support systems is safer than living in an institutionalized setting, costs less, and is the desire of most individuals.*

resulting in chronically high staff turnover rates, surges in demand due to COVID-19, and a history of racism and sexism that has led to segments of the care economy being undervalued.

- The nation lacks the necessary millions of affordable, accessible housing units to meet its needs. The United States cannot achieve an adequate system of HCBS without a substantial investment in affordable, accessible housing for people with disabilities. The lack of accessible, affordable housing is exacerbated by a lack of oversight during federal financially assisted multifamily housing construction where the required accessible units are not constructed or not properly constructed—leaving people with physical disabilities without housing options for years.

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*The United States cannot achieve an adequate system of HCBS without a substantial investment in affordable, accessible housing for people with disabilities.*

administrative costs associated with the program.

- Congress should pass the Fair Housing Improvement Act of 2022, a bill to amend the Fair Housing Act to prohibit discrimination based on source of income, veteran status, or military status, to provide more housing opportunities people with disabilities, enabling more people to transition from institutionalized settings to the community, and supporting the nation's HCBS system.
- Congress should increase HUD's appropriation to fund at least one compliance specialist in each of HUD's ten regional offices to enable

U.S. Housing and Urban Development (HUD) to increase its ability to monitor compliance with newly constructed housing, substantially altered housing, housing with other alterations,

and program accessibility. These staff would have expertise in construction and federal regulations on housing accessibility and proactively monitor federally financed housing construction in the ten federal regions.

- Congress should increase HUD's appropriation to fund a pilot program to engage local planning and codes compliance departments across the United States in identifying potential federal accessibility issues in new construction, substantial alterations, housing with other alterations, and existing housing to enable HUD to

## Key Recommendations

- Congress should enact legislation that includes significant funding for HCBS, similar to the \$150 billion in HCBS funding in the Build Back Better Act, and increase pay for the direct care workforce, to facilitate individuals to live in the community.
- Congress should enact legislation within the next year, which ends the institutional bias by making HCBS a mandatory Medicaid service under 1905(a) as proposed in the discussion draft of the HCBS Access Act.<sup>8</sup> A single, comprehensive HCBS authority would alleviate complexity, inequity, and

broaden its efforts at compliance with both Fair Housing Act Accessibility Standards and Section 504 requirements.

- Congress should assist HUD in increasing the stock of accessible housing by increasing its appropriation to fund a Home Modification Fund Program or Home Modification Voucher to assist people with disabilities to make modifications to their existing homes. This will help people avoid institutionalization if they become disabled and live in an inaccessible home and open housing opportunities for people with disabilities who are transitioning out of institutions that require accessible housing.
- Congress should require the Centers for Medicare & Medicaid Services (CMS) to maintain the Appendix K Waiver,<sup>9</sup> which allows for paid family caregivers. Use of Appendix K Waiver saved lives and avoided institutionalization of people with disabilities during the COVID-19 public health emergency and was responsive to the direct care workforce shortage.<sup>10</sup>
- Congress should require the Department of Labor (DOL) to immediately devise a plan to address the direct care workforce labor shortage by, for example, creating apprenticeship programs to incentivize individuals to become direct care workers and setting and raising standards for pay, benefits, and working conditions.
- The Department of Labor and CMS should jointly or separately establish a public-private partnership that matches federal dollars with productive private capital to increase funding for HCBS and increase wages and benefits for direct care workers.
- Congress should commission a special bipartisan committee to investigate the local, state, and Federal Governmental failures during the pandemic that led to the disproportionate deaths of those residing in congregate settings.
- Congress should require the U.S. Department of Health and Human Services (HHS) to work with state, local, Tribal, and territorial health departments to establish efforts to track and report the health and health status and outcomes of people in congregate settings.
- The Centers for Disease Control and Prevention (CDC) should collect data on all people living in all types of congregate settings and ensure that they are kept on a priority status for testing, vaccinations, and movement to lower census setting in case of a similar public health emergency.
- Congress should require CMS to adjust the payment methodology and quality metrics for Medicare Home Health Services to ensure that beneficiaries with multiple comorbidities or complex care needs have access to the level of care required in their homes, including the support of home health aides.

According to the most recent estimates from the Centers for Disease Control and Prevention (CDC), 4.5 million people were consumers of home health in 2016—to have 58% of providers discontinuing some amount of in-home services to a population this large has had serious implications for independent living and continued ability to live in one's home.

To understand the magnitude of the loss and disruption of services and supports caused by the pandemic, it is essential to recognize who is not counted by the estimates. An estimated 820,000 people with disabilities in the United States were not included in loss estimates as they did not lose services during the pandemic because they never had the services to begin with—even though they had applied for them. They were on waiting lists waiting-sometimes decades long-to receive HCBS services.



## Introduction

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People with disabilities living in congregate settings, which include nursing homes, acute rehabilitation centers, intermediate care facilities, developmental centers, and various group settings for people with intellectual and developmental disabilities, are at the greatest risk of death from COVID-19. A 2020 analysis estimated

that 35,000 nursing home residents died due to COVID-19, representing 42% of the total deaths in the United States in the first year of the pandemic.<sup>11</sup> This number represents both seniors and non-aging disabled residents. That is the equivalent of a Boeing 747 crashing every single day for

75 days. While vaccine rollouts slowed the number of deaths, low vaccination rates among congregate living staff led to outbreaks and more casualties of people with disabilities who were unable to transition out of congregate

settings despite decades of the community living mandate.

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*A 2020 analysis estimated that 35,000 nursing home residents died due to COVID-19, representing 42% of the total deaths in the United States in the first year of the pandemic . . . That is the equivalent of a Boeing 747 crashing every single day for 75 days.*

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*Approximately 14 million Americans need LTSS; these services serve people of any age, from children to seniors. . . 40% of adults who need these supports are younger than 65 years old.*

Almost all people with disabilities who have died in congregate settings from COVID-19 have been served by the United States long-term services and supports (LTSS) system. Approximately 14 million Americans need LTSS; these services serve people of any age, from

children to seniors.<sup>12</sup> In fact, 40% of adults who need these supports are younger than 65 years old.<sup>13</sup> LTSS encompasses a broad range of medical and personal care assistance, for example, assistance with activities of daily living (such as eating, bathing, and dressing) and instrumental

activities of daily living (such as preparing meals, managing medication, and housekeeping). Long-term services and supports include, but are not limited to, nursing facility care, adult daycare programs, home health aide services, personal

## Financial Savings of HCBS

### Median cost of care, congregate facility:

- \$105,850 / resident / year, private room
- \$94,900 / resident / year, semi-private room

### Median cost of care, caring for a person at home:

- \$67,760 / person / year, home health aide
- \$20,280 / person / year, adult day services

in, the community requires a strong workforce of direct care providers, like home health aides. However, the longstanding direct care workforce shortage, made worse by the pandemic and by federal policies that create barriers to receipt of home health services, has created a national emergency for people with disabilities - increasing the risk of institutionalization, or remaining in an institution, for those who cannot obtain their services. This leaves older persons unable to receive basic supports in their homes and at risk for going without assistance or being institutionalized.

care services, transportation, and supported employment as well as assistance provided by a family caregiver. The LTSS that help people live in their homes or in other community-based settings are called Home and Community-Based Services (HCBS).

Medicaid, administered by the Centers for Medicare and Medicaid Services (CMS), is the primary payer of formal LTSS, financing approximately 62% of LTSS costs.<sup>14</sup> Research is clear: Almost all individuals who need LTSS want to live at home.<sup>15</sup> The financial savings of supporting people at home instead of congregate settings has long been established.<sup>16,17,18</sup> According to a 2021 study, the annual median cost of care at a congregate facility, like a nursing home, is \$105,850 per resident per year for a private room and \$94,900 for a semi-private room, compared to \$67,760 for a home health aide and \$20,280 for adult day services caring for a person at home.<sup>19</sup> But saving taxpayer funds while ensuring maximum integration into, or remaining

## Direct Care Workforce Crisis

In a 2021 survey, home health agencies were asked if they could provide aides for 8 hours a day or 28 hours a week, the amount provided by Medicare. Only 2% of responding agencies reported that they would be able to provide 20 or more hours of services per week.<sup>20</sup> Home health agencies attribute this to the inability to recruit and retain staff.<sup>21</sup>

The Americans with Disabilities Act integration mandate, the U.S. Supreme Court's Olmstead decision, and federal programs have contributed to progress in shifting from requiring people with disabilities to receive services primarily in nursing homes and other institutional settings to a HCBS.<sup>22</sup> Nationally, in 2018, 56% of Medicaid LTSS spending was for HCBS.<sup>23</sup> Despite this investment, people with disabilities

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*[P]eople with disabilities younger than 30 years old make up the fastest growing nursing home population . . .*

younger than 30 years old make up the fastest growing nursing home population, and 820,000 people with disabilities are on wait lists to transfer out of these settings—settings which turned out to be the most dangerous places to be during the pandemic—hundreds of thousands of people with disabilities died of COVID-19 in in congregate settings.<sup>24,25</sup>

More than 75% of states (41 of 50) have an HCBS Waiver waiting list for at least one waiver type.<sup>26</sup>

Because states can limit

HCBS spending based on budgetary restrictions, they can choose-and limit-how many people they serve.

The devastation of COVID-19 has been felt worldwide, but its impact has not been evenly distributed among populations. The public health emergency created an intense urgency

to move people from congregate settings to the community. For example, the jeopardy caused by living in close quarters resulted in a dramatic decision by the criminal justice system. Recognizing the risk of massive loss of life, it responded by releasing more than 100,000 people from federal and state prisons between

March and June 2020.<sup>26</sup>

People living in homeless shelters were relocated to lesser density settings. Positivity rates in a Chicago shelter dropped

from 50% to 2% after residents were moved from congregate settings to housing in the community that allowed for social distancing.<sup>27</sup>

Despite great risks, however, the systems responsible for the institutionalization of people with disabilities did not mirror this swift response to move people with disabilities to lower density

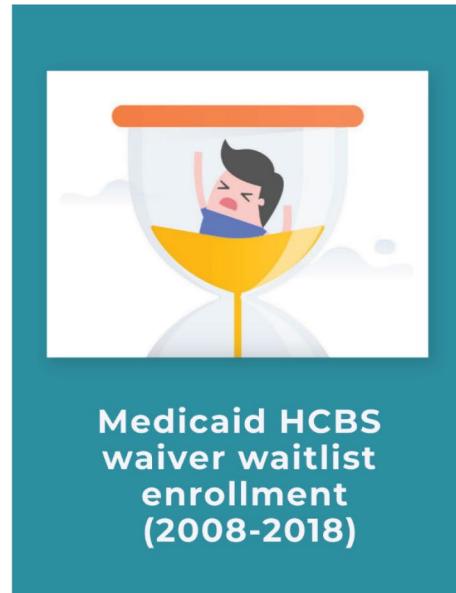
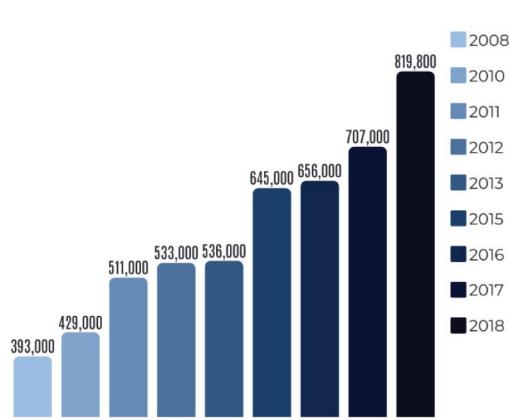


Figure 1: Bar graph showing that the amount of people on wait lists for HCBS waivers has grown every year since 2008.

settings. For example, people with intellectual and developmental disabilities (ID/DD) were more likely to become infected with COVID-19, need hospitalization, and die. Early in the pandemic, it became imminently clear that people with ID/DD living in congregate care settings were at an even greater risk for severe COVID-19 outcomes,<sup>28</sup> but rather than moving them to safer settings, they were told to shelter-in-place. Confirmation of deadly errors and mass deception has emerged from nursing homes resulting in the shocking reality that many decision-makers were very aware of the risks and consequences of keeping people with disabilities in congregate settings. Some advocates have commented that the result of this policy was “dying in place.”

The unnecessary deaths of people with ID/DD living in congregate settings during the COVID-19 pandemic revealed the weaknesses in the

system and the critical need to recognize of the disproportionate impact of COVID-19 on people with disabilities who were institutionalized and create a response that is equitable, immediate, and transformative. Improving our current HCBS system to safeguard people with disabilities from the disproportionate death and illness that took place during the COVID-19 pandemic must be a top policy priority so that the tragedy that occurred is never repeated.

This report expands on NCD’s findings in our *2021 Progress Report: COVID-19’s Impact on People with Disabilities*, describes the main weaknesses in the HCBS system, and proposes a plan to substantially strengthen the HCBS ‘ecosystem’ that will increase community living options with necessary services and supports to meet the current and future needs of people with disabilities across the life span.

## Methodology

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This report is based on multiple sources of data, information, and experiences. Six convening sessions were held between October and December 2021. Four of these sessions were made up of a mixed group of healthcare policy experts, Center for Independent Living directors and staff, policy think tank members, advocates for the aging, community living experts, direct support providers, and HCBS users. Two sessions were designated for specific stakeholder groups: One session was designed for the staff of the Administration on Community Living in HHS, and another for state Medicaid directors and staff. From November 2021 through February 2022, approximately twenty-five interviews were conducted. Convening session and interview participants answered a series of open-ended questions.

Second, an ongoing literature review took place from August 2021 through May 2022 on the impacts of COVID-19 on community living, institutionalization, and HCBS for people with

disabilities. Scientific journals, legal journals, news coverage, policy briefs, and white papers were reviewed. Previously published pieces about these core topics were included in the review. Relevant state and federal policies and guidance related to the topic were analyzed. On January 27, 2022, public comment on HCBS and its need for change in light of the COVID-19 pandemic was heard during the NCD Quarterly meeting. NCD asked: What federal and policy state levers hold the greatest potential to transition people out of congregate care facilities? What funding streams have you seen, or do you think could be effective in bolstering or building up HCBS? What are potentially positive solutions, for example, pilot programs, to many of the barriers encountered by people trying to acquire HCBS? The comments from these convening sessions and interviews are integrated into this report. Figure A illustrates our initial framing of the challenges and barriers for Home and Community-Based Services.



Figure A: An iceberg graphic illustrates challenges and barriers for home and community-based services. Above the surface of the water, a lack of funding and workforce shortages are described. Below the surface, the following barriers are listed: a confusing patchwork HCBS, ableism and paternalism in public policy, historical exclusion of disability in community, lack of accessible housing, institutional bias, and a strong, well-funded nursing home lobby.

# Chapter 1: A History of Institutionalization of People with Disabilities

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The last century has seen a significant shift in the government's role in supporting efforts to include people with disabilities into their communities.<sup>29</sup> At the start of the twentieth century, people with disabilities who required assistance in their daily lives received that assistance in a large public institution or from their families, who largely didn't receive financial or social support from the federal or state government.<sup>22</sup> Hundreds of thousands of people with, intellectual disabilities, and developmental disabilities (ID/DD) and those with psychiatric disabilities were considered to require institutionalized care - separated and segregated from their communities. Many institutions had terrible

living conditions and abused residents. Advocates like Dorothea Dix advocated fiercely for states to open institutions as a path to alleviate the oppression she witnessed people with disabilities experience without needed supports.<sup>30</sup>

A 2022 publication detailing the history of institutionalization documents reports of medical experimentation, controlling staff, neglect, and racism.<sup>31</sup> Dr. William Bronston, a doctor from the notorious Willowbrook State School in

New York, described institutions as "places of such towering misery and human humiliation and violence."<sup>32</sup> Pressure mounted for the U.S. government to intervene. In the 1960s a series of class action lawsuits and greater scrutiny of institutions' dehumanizing conditions, ignited a long-term deinstitutionalization movement that would eventually create a service delivery system to support people with disabilities to live in their communities. Early reforms led to a wave of decrees directing states to improve conditions

in institutions, however, the abuse of people with ID/DD who are living in institutions, including children, continues today.<sup>33</sup>

In the 1970s, legal challenges moved the goal from improving

conditions in public institutions to the elimination of institutions. There was a growing understanding that many people with disabilities who needed substantial care could live in their communities if provided supports rather than being hidden away in abusive, degrading, conditions. Even in the absence of abuse and neglect, residents of institutions lacked basic privacy, had no control over how they spent their time, and no freedom – all because they had a disability.<sup>34</sup> A recognition

*Even in the absence of abuse and neglect, residents of institutions lacked basic privacy, had no control over how they spent their time, and no freedom – all because they had a disability.*

that grew that people with disabilities should not have to be institutionalized despite history's failure to respect their humanity.<sup>35</sup> Mostly parent-led advocacy organizations leveraged this recognition to catalyze deinstitutionalization of people with intellectual and developmental disabilities.<sup>36</sup>

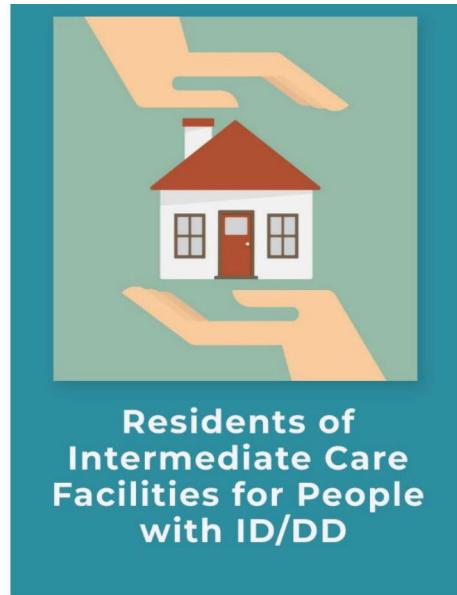
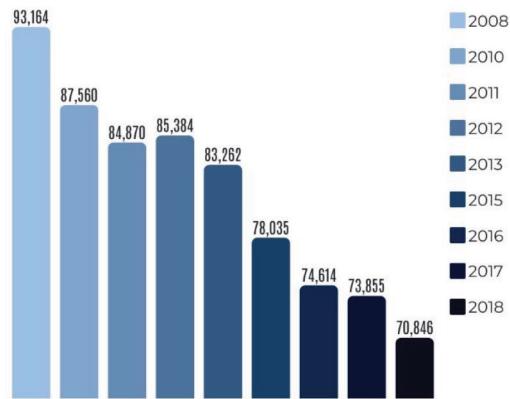
Later, grassroots organizations led by people with disabilities, including Centers for Independent Living, amplified the efforts for deinstitutionalization.

In the 1970s, states began a slow and uneven path to deinstitutionalization. By 2018, 17 states closed all large state-run institutions for people with intellectual or developmental disabilities. However, 17,557 people still lived in 115 large state-run institutions in thirty-four states. The

number of people living in large state-run IDD institutions was fewer than 100 in 8 states, between 100 and 1,000 in 22 states, and more than 1,000 in 4 states.<sup>37</sup> More people with ID/DD began receiving services from their state ID/DD agencies in their homes or smaller census congregate settings. Comparison of people in and outside of institutions provided considerable evidence of numerous

measurable beneficial outcomes of living in the community for people with disabilities.<sup>38</sup> Community living improves behavioral outcomes, life satisfaction, and the ability to independently perform daily living tasks.<sup>39,40</sup>

The historical failures and successes of the deinstitutionalization movement culminate in two starkly contrasting conclusions. For people with



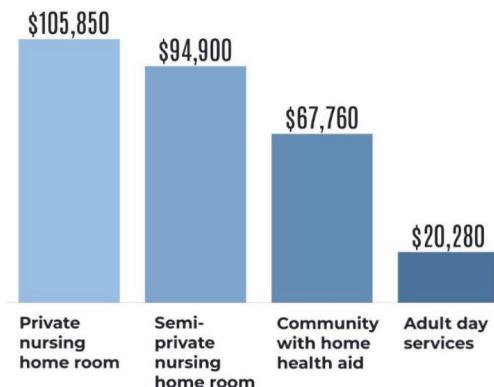
**Figure B:** Number of people served by state ID/DD/DD agencies by fiscal year has increased steadily.<sup>41</sup> While the number of people with ID/DD living in these congregate settings is declining, it has stalled in the last few years.

psychiatric disabilities, many scholars describe its consequences as “disastrous” because the closing of psychiatric institutions without transitional support led to homelessness for many former residents.<sup>42</sup> The positive outcomes of closing these institutions has been less reported than the challenges related to a growing homeless population in the United States, which policy makers continue to disagree on how to address.<sup>43</sup> The deinstitutionalization of people with developmental and intellectual disabilities has been less controversial but also a quagmire in the dynamics of public policy. The paternalization of people with ID/DD, or the desire to control their lives with stated intentions of ensuring safety, is a major barrier for the integration of people with ID/DD into our communities. While the deinstitutionalization of psychiatric institutions was hindered by people’s unfounded fears of their own safety from people with psychiatric

disabilities, the freedom of people with ID/DD is hindered by claims that their safety will be endangered by living in the community, discounting the dangers of congregate living. For the purposes of this report, we will consider one urgent call for deinstitutionalization of all people with disabilities, regardless of type of disability.

Shared by both deinstitutionalization movements is the significant cost-savings in supporting people in communities rather than institutions. Even with costs of deinstitutionalization, the annual expenditures for HCBS (approximately \$42,486 per person) are significantly less than the annual cost of state institutions (approximately \$188,318 per person).<sup>44</sup>

While the cost of living in the community with supports is lower, it is still largely out of reach for most families and has increased over time. See Figure C for median annual costs of LTSS in 2020.<sup>45</sup>



**Figure C: Compares average annual costs of a private nursing home room (\$105,850), a semi-private nursing home room (\$94,900), living in the community with a home health aide (\$67,760), and adult day services (\$20,280).**

As more people with disabilities began to live in their communities, more began to advocate for their preference of smaller settings. People wanted a range of care options. Various groups, advocating for differing interests helped shape policy on community living. Deinstitutionalization advocates in the 1970s and 1980s, demanded due process procedures before depriving a person of their freedom, to try to affect change, while opposition came from parent organizations and from labor unions who objected to institution closures because of the loss of jobs in large institutions.<sup>28</sup> Some parent organizations continue to oppose community integration citing what they view to be unfair burdens of time, effort,

and money on caregivers and family members of people with disabilities.

Earlier due process efforts were successful but lacked the infrastructure necessary to build supports in the community. While an important focus was maintained on ending institutionalization, efforts to date have lacked clarity in building community-based supports, including HCBS, mutual support networks, and the direct support provider workforce, to facilitate community living instead of institutionalization. In the 1990s, advocates shifted their attention to federal antidiscrimination policies and state funding to build community support service delivery systems. In large part, this is where the current focus remains.

# Chapter 2: Law and Federal Policies on Transitioning People with Disabilities from Institutional to Community Settings

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## The Americans with Disabilities Act and the Olmstead Decision

The preamble of the Americans with Disabilities Act of 1990 (ADA) states:

Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem . . . the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living. . . .<sup>46</sup>

Title II of the ADA specifically identifies unjustified "segregation" of persons with disabilities as a form of discrimination,<sup>47</sup> and prohibits public entities from discriminating against qualified people with disabilities

or excluding them from participating in, or denying them the benefits of the entities' services, programs, or activities.<sup>48</sup> The ADA regulation implementing Title II specifically requires public entities to "administer services, programs, and activities in the most integrated

setting appropriate to the needs of qualified individuals with disabilities." This is referred to as "integration regulation."<sup>49</sup>

In 1999, nearly a decade after the passage of the ADA, the Supreme Court considered whether institutionalization qualified as discrimination under Title II of the ADA and marked the first time the U.S. justice system addressed a public entity's obligation to provide programs and services in an integrated setting.<sup>50</sup> The case was brought on the behalf of two women with psychiatric and intellectual disabilities who were residents of a psychiatric institution in Georgia.<sup>51</sup> Although their treatment professionals concluded that each of the women could be cared for appropriately in a community-based program, the women remained institutionalized.<sup>52</sup>

The lawsuit alleged that Georgia violated Title II by not placing them in a community-based program once treating professionals determined that such placement was appropriate. The

Court held that, under Title II, states are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care

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*Title II of the ADA specifically identifies unjustified "segregation" of persons with disabilities as a form of discrimination . . .*

## Olmstead Three-Prong Test

- (1) A doctor authorized by the state determines whether an institutionalized person is capable of living in the community;
- (2) the institutionalized person must want to live in the community; and
- (3) a state can consider budgetary limitations when determining how many people with disabilities to support in the community.

to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.<sup>53</sup> As a result, states developed frameworks within which to make these decisions.

Although the ADA and the Olmstead decision were considerable victories for the deinstitutionalization movement, they did not result in as massive of transition from institutions to the community that many hoped. Moreover, the Olmstead three-prong test created limits that hinder the pace of deinstitutionalization:

- (1) A doctor authorized by the state determines whether an institutionalized person is capable of living in the community; (2) the institutionalized person must want to live in the community; and (3) a state can consider budgetary limitations

when determining how many people with disabilities to support in the community.<sup>40</sup>

## Federal Incentives on Home- and Community-Based Services

For certain people with disabilities, living in the community requires help with carrying out activities of daily living. Assistance with many of these activities are not covered by typical health care and private insurance. Many people rely on unpaid family members to provide this assistance but the severity of one's disability, the absence of such supports to live in one's home, or personal preferences means reliance on family support alone is not a sustainable over a person's lifetime.

Medicaid is the primary payer for both the acute health care needs and long-term supports needs of people with disabilities living in the community, which centers the Federal Government as the entity which created, and must fix, the current HCBS infrastructure. Funding

mechanisms for programs that address the needs of HCBS consumers, like housing, health, and community living, combine federal and state funds. As the United States has moved toward deinstitutionalization, federal programs have been created to assist this movement and address emerging needs.

## Money Follows the Person

Money Follows the Person (MFP) is a Medicaid demonstration program that provides funding to states to enable more people to receive long-term

services and supports in community settings, rather than institutions. The federal grant program assists individuals transition from nursing homes and congregate settings back to their homes and communities by helping states to remove barriers in state laws and budgets that promote institutional care. States have the option of participating in MFP and MFP services vary by state.<sup>54</sup> Over 107,000 MFP program participants have transitioned from institutions back into their community between 2008 and 2020.<sup>55</sup> Many hundreds of thousands more remain on waiting lists to return to the community.

The Consolidated Appropriations Act of 2021 authorized the Centers for Medicare & Medicaid Services (CMS) to provide new funding opportunities for states to participate in MFP. As of August 2022, there were more than forty states and territories participating in the program.<sup>56</sup>

On March 31, 2022, CMS notified current MFP grantees that it is increasing the reimbursement rate for MFP “supplemental services.” These services are now 100% federally funded with no state share.<sup>57</sup> CMS also announced that it is expanding the definition of supplemental services to include additional services that can support an individual’s transition from an institution to the community, including short-term housing and food assistance.<sup>58</sup> These changes will help to address barriers to community transition for eligible

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***As of August 2022, there were more than forty states and territories participating in the program.***

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***MFP has been more successful transitioning people with physical, psychiatric, and adult-onset cognitive disabilities (e.g., dementia) than it has been in transitioning people with intellectual and developmental disabilities.***

individuals in institutions, increase community transition rates, and increase the effectiveness of the MFP demonstration.

As shown in Figure D, MFP has been more successful transitioning people with physical, psychiatric, and adult-onset cognitive disabilities (e.g., dementia) than it has

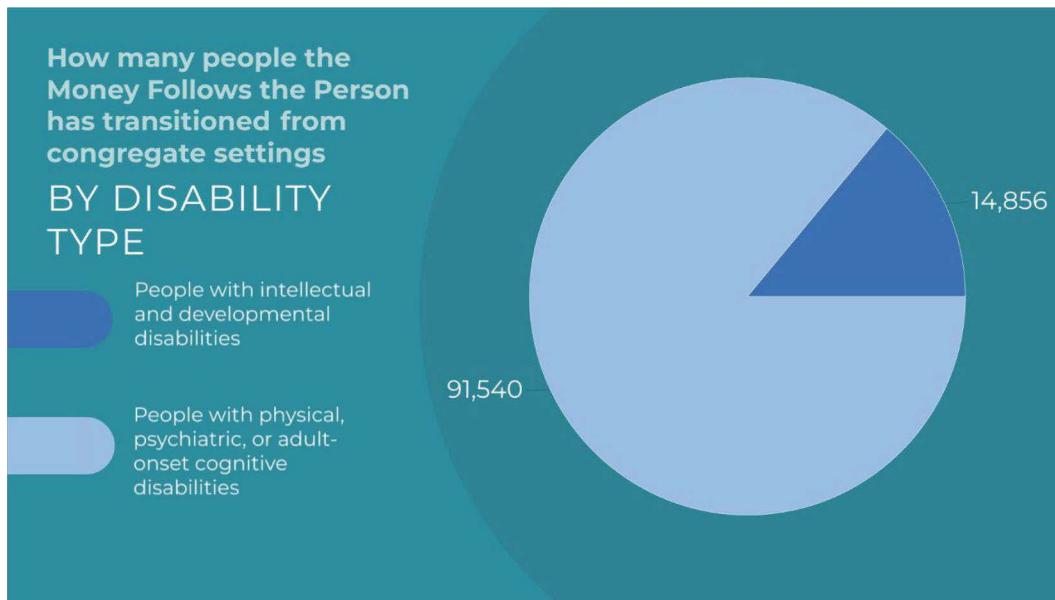
been in transitioning people with intellectual and developmental disabilities.<sup>59</sup> Causes of this disparity are unknown.

The bundle of MFP programs and services are categorized as Home and Community-Based Services (HCBS). MFP provides federal funding support for HCBS for the first 365 days after the program participant moves from the institution and

to a home in the community.<sup>60</sup> After the first year, the MFP program participant is funded under other available state Medicaid programs, like waivers.

**Table A: Examples of available benefits through the MFP program.**

Personal care assistance	Home modifications for safety and accessibility
Respite care for unpaid and informal caregivers	Adult day services
Home health care	Personal emergency response systems
Home delivered meals	Assistive technology



**Figure D:** Many more people (91,540) with physical, psychiatric, or adult-onset cognitive disabilities have been transitioned out of congregate settings through the MFP program compared to fewer people with ID/DD (14,856).

And although home based care and community living is less expensive and has been shown to have numerous benefits for individuals, all states are required to pay for care in a nursing home but are not required to pay for HCBS. This shows the contradiction in federal policy towards community living: a recognition of cost effectiveness and human benefit, as well as the ability to implement the ADA, but continuing to require states to pay for nursing homes and not HCBS. Along with the federal bias toward nursing home care, many states share or act on this bias by

continuing to house people with disabilities in institutions when they need ongoing medical and other support needs, rather than invest in HCBS. MFP helps work against institutional bias by providing a financial benefit to states for an individual's first year of community living.

*This shows the contradiction in federal policy towards community living: a recognition of cost effectiveness and human benefit, as well as the ability to implement the ADA, but continuing to require states to pay for nursing homes and not HCBS.*

to a smaller census but still segregated setting, does not achieve the vision of community integration. In 2014, CMS issued the Medicaid Home and Community-Based Services (HCBS)

## Funding for HCBS

### Money Follows the Person

- Federal funding for first 365 days after participants moves from institution to a home in the community

Other available state Medicaid programs, like waivers

- After the first year following an individual's transition from institution to a home in the community

Settings Rule (Settings Rule), which added specific requirements to ensure integrated settings were truly

community-based. All settings that receive Medicaid HCBS funds must ensure participants have choices about their daily lives and can participate in the community in ways

that reflect their individual interests. States were initially given a March 2022 deadline to complete this transition. Despite opposition from many in the disability community to a delay, this target date has been pushed back to March 2023.

The Settings Rule is necessary to standardize definitions of community-based living. Some Medicaid providers describe their programs as "community-based" but still enforce restrictions on how a person can decorate their personal space, when they can access food, and who can visit them in their home. The Settings

Rule raises the bar for providers to ensure that recipients of their Medicaid-funded services are afforded rights and freedoms comparable to those without disabilities in the community. When implemented, the Settings Rule will apply to all HCBS-funded programs, including day and employment supports. To continue to receive Medicaid funding, states are encouraged to provide individualized rather than program-wide services and schedules.

Much of the requirements to meet the Settings Rule are reflected in self-directed waiver services. This service delivery model of self-direction for HCBS has grown substantially over the last several decades. Self-direction provides individuals who receive HCBS greater flexibility and control over their own services. There are two forms of self-

direction: (1) Individuals have control over hiring and supervising their personal care attendants and direct care workers and (2) Individuals have control over an individualized budget and decide what services and

supports are purchased.<sup>61</sup> The former is 'employer authority,' and the latter are 'budget authority'. An extensive body of literature, including evaluation of various HCBS demonstrations, has highlighted the benefits of this model. An evaluation in 2022 shows that there are 260 self-directed programs nationally<sup>62</sup> with two-thirds of these funded by Medicaid.

States have been planning their transition to comply with the Settings Rule standards of community-based services for years. They have submitted Transition Plans to be approved by CMS and are required to identify which settings

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***The Settings Rule raises the bar for providers to ensure that recipients of their Medicaid-funded services are afforded rights and freedoms comparable to those without disabilities in the community.***

might warrant “heightened scrutiny.” Heightened scrutiny settings will require special permission to use HCBS funds because they may limit some freedoms for recipients. By recognizing them through a transparent process, state entities and CMS can collaborate to determine whether these settings meet criteria for funding. If settings or programs do not meet the new requirements, they may transition their funding structure to rely on private funds. If implemented and enforced as intended, the Settings Rule would prevent federal funding from continued support of segregated, restrictive settings, which claim but do not meet standards of community integration.

The Administration for Community Living (ACL) and CMS held a webinar in June of 2022 to provide updates on the Settings Rule. They recognized concerns that not every setting in the country will be fully compliant with all requirements of the settings rule by the

March 17, 2023, deadline, and developed a strategy that aligns the focus of federal support and state compliance activities with the realities of the direct care workforce crisis that was exacerbated by the COVID-19 pandemic. This multi-faceted approach contains the following components, in order to continue federal reimbursement of HCBS beyond the transition period: States must receive final Statewide Transition Plan approval; States and providers must be in compliance with all settings criteria NOT directly impacted by pandemic disruptions, including pandemic-related workforce

challenges; Time-limited corrective action plans (CAPs) are available to states to authorize additional time to achieve full compliance with settings criteria that ARE directly impacted by pandemic disruptions, when states document the efforts to meet these requirements to the fullest extent possible, and are in compliance with all other settings criteria.<sup>63</sup>

### ***No Wrong Door Systems: Federal Partnership***

ACL, CMS, and the Veterans Health Administration (VHA) partnered in 2011 as part of the Balancing Incentive Program to establish the

No Wrong Door (NWD) Systems to enhance consumer choice and help states create a more efficient and cost-effective system for Long-Term Services and Supports (LTSS). A wide range of organizations can be designated by states to assist people in getting assessed

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***Self-direction provides individuals who receive HCBS greater flexibility and control over their own services . . . An evaluation in 2022 shows that there are 260 self-directed programs nationally with two-thirds of these funded by Medicaid.***

and connected to services that best meet their needs. Centers for Independent Living (CILs), Aging and Disability Resource Centers (ADRCs), Area Agencies on Aging (AAAs), Medicaid agencies, and Peer-to-Peer programs are among the wide range of organizations involved in NWD systems.

As illustrated in the Figure E, the NWD schematic starts with coordinated public outreach with key referral systems.<sup>64</sup> The next step is person-centered counseling, which results in a Person-Centered Plan. Individuals and their families are helped to determine their eligibility



for a wide range of public programs and how these fit with privately funded options. Finally, State programs and their leadership deliver services.

NWD invokes crucial elements of connecting people who need HCBS to the services that exist. The scale of its impact, however, has been limited by its funding and reach year to year. The federal funding made available to states to carry out NWD systems change activities is seed money for states and local partners agencies to influence system-wide change with other existing funding streams and is not enough to

fund a state's NWD implementation efforts in full. People continue to feel disconnected from and confused by the complex, multi-layered HCBS system.

Potentially, the NWD schematic could have been leveraged to rapidly connect people with

disabilities who wanted out of institutions during the peaks of pandemic to what they needed to move into their communities. NWD Project Coordinators were not consistently deemed essential employees during lockdowns.<sup>65</sup> In this case, the doors that should have been propped wide open during the time of a public health emergency,

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*The scale of [the No Wrong Door system's] impact, however, has been limited by its funding and reach year to year.*

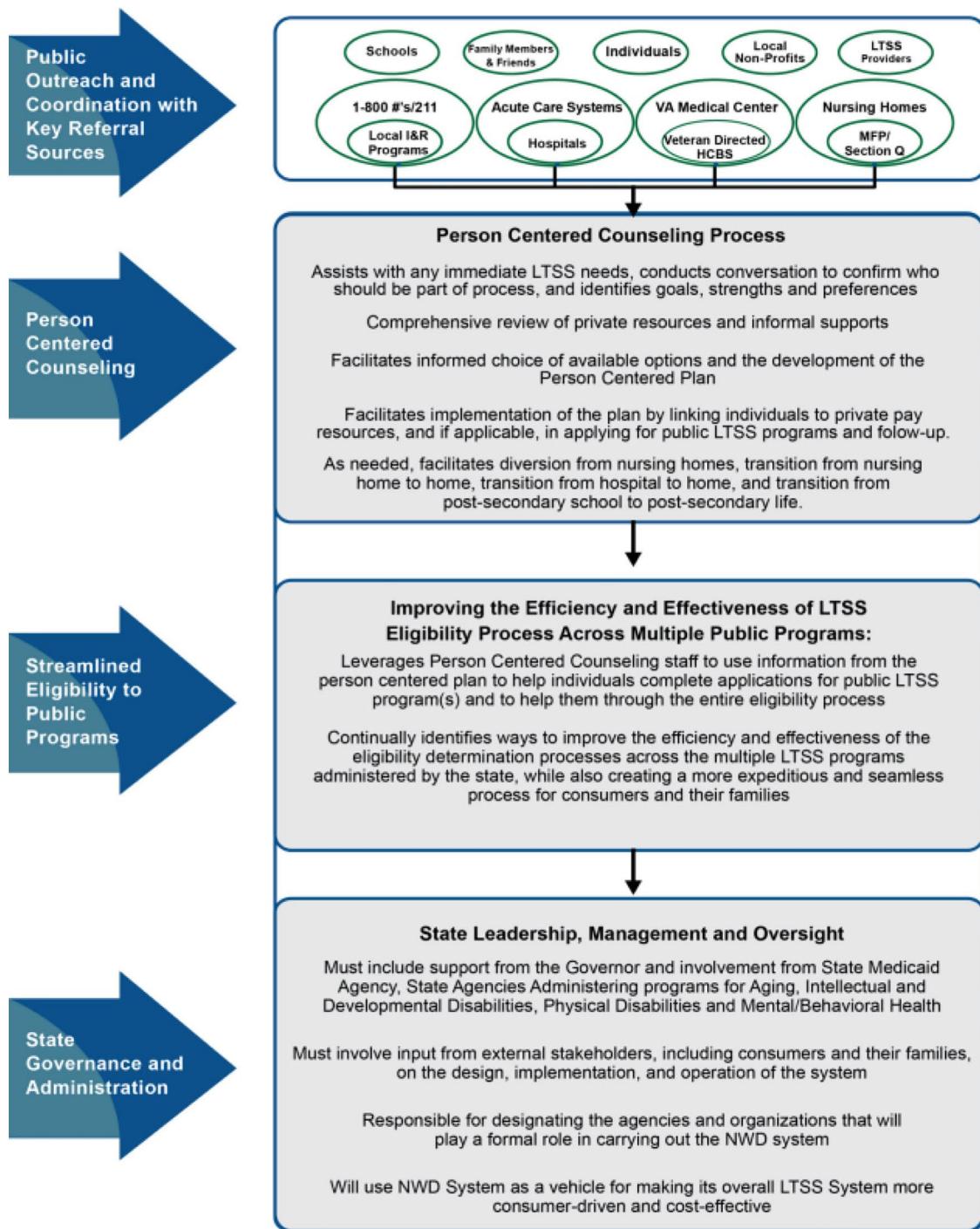


Figure E describes the schematic or framework for the No Wrong Door collaboration. The four key elements include state governance, public outreach and coordination with key referral sources, person-centered counseling, and streamlined eligibility for public programs). A brief overview on each key element is included in the illustration.

were too frequently left closed or were unknown entirely.

## The U.S. Department of Justice's Enforcement of the ADA Integration Mandate

The U.S. Department of Justice (DOJ) enforces the ADA's integration mandate to ensure people with disabilities live in the most integrated setting possible. DOJ has investigated allegations of discrimination based on Olmstead against several states and entered into settlement agreements that help thousands of people with disabilities to live in their communities with necessary supports. The importance of these enforcement efforts cannot be overstated; they are critical to implementing the integration mandate and realizing the intent of the ADA for full inclusion. Although every action taken by DOJ cannot be reflected in this report, we note several that were taken or resolved during the COVID-19 pandemic.

In January of 2022, DOJ filed a Statement of Interest (SOI) in an action on behalf of children with mental health disabilities who allege they have experienced a revolving door of institutionalization due to Colorado's failure to arrange and provide for medically necessary care. The plaintiffs allege that they are currently segregated, or at risk of segregation in, institutions because of the State's failure to provide them with intensive HCBS. The SOI clarifies that (1) plaintiffs who are segregated or at serious risk of segregation due to a lack

of community-based medically necessary services can establish they have an injury in fact sufficient to confer standing, and (2) unnecessary segregation constitutes discrimination on the basis of disability under the ADA and the Rehabilitation Act.<sup>66</sup>

In March of 2022, DOJ notified Colorado that it is violating the ADA's integration mandate in its provision of Long-Term Services and Supports to adults with physical disabilities. Following an investigation, DOJ found that Colorado has failed to meet its obligations under the ADA by unnecessarily segregating adults with physical disabilities in nursing facilities and failing to ensure that individuals have a meaningful

opportunity to live in community-based settings appropriate to their needs.<sup>67</sup>

In May of 2022, DOJ entered into a settlement agreement with Rhode Island to resolve allegations that the State failed to provide a minor with community-based Medicaid services that

the State had authorized, and that allowed him to remain in his parent's home rather than a residential treatment facility. His parents alleged that while the State authorized their son to receive 25 to 34 hours per week of community-based services, their son only received, on average, half of the weekly authorized hours. As a result, the parents feared that their son would be forced to leave their home and move to an institution. Under the agreement, Rhode Island will, for example, modify its policies so that children with intellectual and developmental

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*NWD Project Coordinators were not consistently deemed essential employees during lockdowns. In this case, the doors that should have been propped wide open during the time of a public health emergency, were too frequently left closed or were unknown entirely.*

disabilities will receive the community-based services that they are authorized; allow families to receive services from different providers; and provide oversight to make sure children with disabilities receive authorized community-based services. The minor will have an individualized service plan with the services necessary for him to live at home, and the State will pay \$75,000 in damages.

In 2021, DOJ entered into a settlement agreement with Maine to resolve a complaint alleging that its restrictions on services placed a young man with intellectual disabilities at serious risk of having to move from his own home to a group home or institution.<sup>68</sup> In 2020, DOJ found that Maine was violating Title II of the ADA's integration mandate in its provision of services under one of the State's Medicaid waiver

programs by failing to provide the complainant with necessary services in the most integrated setting appropriate to the complainant's needs, and failed to reasonably modify its service program to avoid discrimination, placing the complainant at serious risk of unnecessary segregation. The agreement requires Maine to implement remedial measures, including establishing and implementing a process for individuals to obtain an exception to the waiver program's cap on in-home services, and modifying the program to ensure that members' individual needs and preferences determine the services they receive and the setting(s) in which they receive them. It also requires Maine's Department of Health and Human Services to provide the young man access to all needed in-home services and pay \$100,000 in damages.



DOJ entered into an Olmstead settlement agreement with North Dakota in December of 2020.<sup>69</sup> The settlement requires the state to support community living and divert people with disabilities from nursing homes, provide greater access to HCBS waivers, and fortify peer support programs.

In December 2019, DOJ filed a Statement of Interest (SOI) in the case of *Alexander v. Mayhew*. In Alexander, individuals on a wait list for a home and community-based services Medicaid Waiver allege that Florida's administration of its long-term care system for people with physical or age-related disabilities who qualify for nursing facility care places them at risk of nursing facility placement. The SOI highlights the well-settled principle that a state

may violate the ADA even while carrying out CMS approved state plans, waiver services, and amendments because a state's obligations under the ADA are independent of, and distinct from, Medicaid requirements.<sup>70</sup>

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DOJ's commitment to upholding the ADA is a demonstrated impactful driver of change in the movement toward community integration, but more is needed. The Department's initiation of investigations, development of settlement agreements,

and intervention in class action lawsuits has forced systemic change in several states, where, without its intervention, there is no indication that these states would have achieved needed improvements.



## Chapter 3: Weaknesses in HCBS Are Laid Bare and Amplified by the Pandemic

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The COVID-19 pandemic and stay-at-home orders presented unique challenges for HCBS recipients, leading to diminished access to supports in the community.<sup>71</sup> Many adult day centers closed or drastically reduced attendance. Some people were reluctant to allow caregivers inside their homes. Some HCBS providers became ill and needed to quarantine. Reduced access to HCBS caused an exacerbation of other needs, like access to regular healthcare. Several states allowed for emergency modification to HCBS with the goal to reduce transitions of people from the community to congregate settings.

A variety of HCBS are necessary to meet unique needs of recipients. There are also several diverse kinds of HCBS providers—combined, they provide a net of services that are individualized to meet the various needs of people with disabilities to live in their communities. The direct care workforce shortage already plagued the HCBS system but there is universal agreement that it worsened during the COVID-19 pandemic. Most states

reported the permanent closure of at least one Medicaid HCBS provider during the pandemic.<sup>72</sup> A study by the American Network of Community Options and Resources (ANCOR) found 58% of HCBS providers planned to discontinue programs and services, a 70.6% increase in providers discontinuing services since the start of the pandemic.<sup>73</sup> Adult day health programs were most likely to close followed by providers of in-home services.

According to the most recent estimates from the Centers for Disease Control and Prevention (CDC), 4.5 million people were consumers of home health in 2016—to have 58% of providers discontinuing some amount of in-home services to a population

this large has had serious implications for independent living and continued ability to live in one's home.

To understand the magnitude of the loss and disruption of services and supports caused by the pandemic, it is essential to recognize who is not counted by the estimates. An estimated 820,000 people with disabilities in the United

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States were not included in loss estimates as they did not lose services during the pandemic because they never had the services to begin with—even though they had applied for them.<sup>74</sup>

They were on waiting lists waiting-sometimes decades long-to receive HCBS services. While some states do not maintain waiting lists, no state has an adequate HCBS system for the residents who need it. Most of this estimated number are people with ID/DD.<sup>75</sup> Compounding the problem, the demand for HCBS is expected to increase by 60% over the next 20 years.<sup>76</sup> Waiting lists could get even longer, causing some to wonder whether the system could collapse.<sup>77</sup>

One convening session participant for this report stated, “At some point, our supply (of HCBS) is so much less in capacity and competency than our demand that we have to recognize we’re going backwards not forwards.”

This concern was echoed in the 2021 ANCOR study that found 77% of providers were turning away new referrals, a

16.7% increase since the beginning of the pandemic.<sup>57</sup> Quality, too, has gone down with 40% of providers reporting higher frequencies of reportable incidents compared to pre-pandemic levels.<sup>56</sup> Waiting lists are numeric representations of the institutional

bias because placement in a nursing home or institutional setting is mandatory but home and community-based services are not, so states can and do limit HCBS.

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## I. The Direct Care Workforce Shortage Intensified

Direct care workers (DCWs) are an essential workforce, and there are several titles used to describe them, including personal care assistants, personal assistance services, home health aide, certified nursing assistant, and home care aide. They are the most

important individuals for directly assisting people with disabilities so that they can live in their communities, but as has been long recognized, the United States has had a critical level shortage of DCWs that has impacted HCBS. As detailed in our 2021 progress report,<sup>78</sup> the direct care workforce shortage has been a serious barrier to HCBS for a long time and is caused by several

factors that have yet to be addressed, including low wages, high turnover, no health insurance, and limited opportunities for career advancement.

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*[T]he demand for HCBS is expected to increase by 60% over the next 20 years.*

Home health and personal care workers had a median hourly wage of only \$11.57 in 2019. The wages are so low that nearly 20% of care workers live in poverty and more than 40% rely on some form of public assistance.<sup>79</sup> Many HCBS

workers are also immigrants with a large fraction undocumented.<sup>80</sup>

A 50-state survey conducted by Kaiser Family Foundation found direct care workforce shortages to be the pandemic's most significant impact on HCBS.<sup>81</sup> The President's COVID-19 Health Equity Task force also recognized the seriousness of the direct care workforce shortage and the need to invest in community living options. It recommended federal investment and pandemic response that helps people in congregate settings transition successfully to safer settings, plans for stepdown between settings, and improved wages and benefits for the direct care workforce.<sup>82</sup>

As COVID-19 spread across the United States, DCWs continued to shoulder the responsibilities of providing essential care to millions of people with disabilities and older people, and demand for them surged, however, the pandemic exacerbated the shortage of DCWs due to lack of testing and sufficient personal protective equipment (PPE), fear of exposure

to COVID-19 infection, lack of COVID-19 testing, required long hours of work, reliance on public transportation, lack of accessible childcare, competing family obligations and potential infection risk to family members. Also, DCWs

were not recognized as "essential workforce" by local law enforcement and were not prioritized for vaccination.<sup>83</sup> Many more DCWs left the workforce after contracting the virus. Others left to take care of family members or protect themselves from exposure, making an already too small of a workforce to support

people with disabilities to live in the community, even smaller. Structural deterrents to maintaining this crucial workforce had also remained largely unaddressed, including a history of racism and sexism that have

historically contributed to the devaluing of DCWs.<sup>84</sup> While the workforce demand has exceeded supply for decades, one convening session participant summarized, "I've worked in this space for more than 25 years. It's always been bad. But never this bad."

In addition to the need for DCWs to support younger people with disabilities to live in the community, the demand for such workers is constantly increasing because of the growing aging population who need these services. By 2030, more than 1 in 5

people in the United States will be 65 or older, and by 2035, the number of people over 85 will nearly double.<sup>85</sup> According to the most recent projections from the Bureau of Labor Statistics, employment of home health and personal care

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***Waiting lists are numeric representations of the institutional bias because placement in a nursing home or institutional setting is mandatory but home and community-based services are not, so states can and do limit HCBS.***

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***Home health and personal care workers had a median hourly wage of only \$11.57 in 2019. The wages are so low that nearly 20% of care workers live in poverty and more than 40% rely on some form of public assistance.***

aides is projected to grow 33 percent from 2020 to 2030, much faster than the average for all occupations; about 599,800 openings for home health and personal care aides are projected each year, on average, over the decade.<sup>86</sup> This is a result of an increasing amount of people, both younger and older, receiving care in their homes rather than in congregate settings.

Every convening session held in the preparation of this report reached the same conclusion: DCWs must be better compensated.

This is even more important with an increased competition for entry-level workers across the larger labor market. Many states have increased their minimum wage, which raises the floor for all low-income workers, but may narrow the gap for compensation for challenging jobs in HCBS service compared to less demanding employment options. The dual crises of workforce shortages and the pandemic have spurred new legislation, notable innovative practices, and the potential for significant new public investments.<sup>87</sup>

With respect to older persons' ability to obtain home health aides to enable them to remain in their homes and avoid institutionalization, a 2022 report by the Bipartisan Policy Center on the Medicare Home Health Benefit, revealed that changes to Medicare's home health payment system is jeopardizing the ability of beneficiaries with

complex needs and/or those with long-term or permanent disabilities to remain in their homes. Changes in the payment system encourage home health agencies to choose shorter term patients and deprioritize home health aides.<sup>88</sup> The report includes a 2021 survey of home health agencies where they were asked if they could provide aides for 8 hours a day or 28 hours a week, the amount provided by Medicare. Only 2% of responding agencies reported that they would be able to provide 20 or more hours of services

per week.<sup>89</sup> Home health agencies attribute this to the inability to recruit and retain staff.<sup>90</sup> This leaves older persons unable to receive basic supports in their homes and at risk for going without assistance or being institutionalized at a time when the need is strong and ever increasing.

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***Changes in the [Medicare] payment system encourage home health agencies to choose shorter term patients and deprioritize home health aides.***

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***Many states have increased their minimum wage, which raises the floor for all low-income workers, but may narrow the gap for compensation for challenging jobs in HCBS service compared to less demanding employment options.***

These ideas are important, and their development must be continued as part of finding a national solution to this workforce crisis. To meet the growing demand of DCWs, it is essential to create a

workforce pathway. Based on a trade model, high school students could complete direct care training while earning their diploma and then move directly into their job after graduation. Opportunities for post-secondary educational credit and a career ladder where workers could envision upward movement could also fortify a

## **2022 ODEP Listening Session on Direct Care Workforce Shortage**

In recognition of the severity of the shortage of DCWs, in February of 2022, the Department of Labor, Office of Disability Employment Policy (ODEP), hosted a listening session for federal partners on the direct care workforce shortage. The session provided findings and suggestions from national experts, including on strategies to strengthen career ladders, professionalize the field, enhance job quality, and make the profession more inclusive of individuals with disabilities. The challenges identified were that funds for services (78% which go to benefits/wages) are not adequate to create a sustainable career ladder that includes training, workforce development, and career pathways. Second, that it is difficult to recruit and retain qualified people into a career with no career pathway, no opportunity for growth in a ladder or lattice, and no living wage, and third, that the industry does not have a competency-based national credentialing framework mandated by federal agencies.

Some of the possible solutions proposed by ODEP included:

- Providing federal funding that includes requirements that states invest in entry-level training and career pathways training and implement percentage increases in payment levels commensurate with increased credentialing.
- Collaborate across federal Departments to align policies and invest in career pathways training for direct care works, and exercise existing administrative federal departmental authority to provide policy guidance outlining minimum requirements for competency-based credentialing for distinct categories of DCWs.
- Provide clear federal requirements for states on elements they must include when building their reimbursement rates (including adequate wage, benefits, training and specialization in Medicaid, including clear DCW reimbursement rate methodologies that consider the full cost and value of services and labor including wages, benefits, employment supports; and wage and benefit progression based on experience, skills, and credentials.

pipeline to bring more people into the workforce while retaining those who are there. DCWs workers could be a meaningful entry-level position for physical therapists, occupational therapists, social workers, nurses, and childcare workers. Work/study, practicum, or internship programs in each of these fields could provide an influx of entry-level workers to the direct care workforce.

Apprenticeship programs also hold potential (as shown in Table C below) but currently there are few and they are largely underutilized.

## **II. The Lack of Affordable and Accessible Housing Impedes Ability to Transition to Community Living**

The persistent lack of accessible and affordable housing in the United States has been a major

**Table C: Direct Care Apprenticeships**

State	Program Name	Funder	Approach
Alaska	Direct Support Professional Apprenticeship <sup>91</sup>	A public-private partnership with Alaska Primary Care Association and state entities	A competency-based model that matches apprentices with mentors and provides wage increases commensurate with increased competency.
Maryland	Direct Support Professional Apprenticeship Program <sup>92</sup>	A public-private partnership with human services organization Humanim and Maryland Department of Labor	Provides on-the-job training combined with classroom instruction while apprentices earn certification through the National Alliance for Direct Support Professionals
New York	Direct Support Professional Apprenticeship Program <sup>93</sup>	A public-private partnership between a community college and New York's Department of Labor	Free tuition and on-the-job training to apply toward a bachelor's degree and a credential as an apprentice.
Tennessee	Quality Improvements in Long Term Services and Supports or QuILTSS <sup>94</sup>	A public-private partnership that includes managed care organizations (MCOs), TennCare, and state entities	Values-based approach that provides paid on-the-job training and rewards higher level of training with wage increases

contributor blocking people with disabilities from transitioning to living in the community. All states cite insufficient accessible and affordable housing options as a major detriment to transition people to their communities.<sup>95</sup> The scope of the reasons for this are beyond the scope of this report, but contributing to this problem is the failure of recipients of the U.S. Department of Housing and Urban Development (HUD) funding to construct and correctly allocate affordable, accessible housing – a source of housing for individuals with low incomes. Most often, these construction failures are identified after construction is completed because of gaps in oversight during the design and construction

phases of taxpayer funded low-income housing development, leaving people with disabilities without the housing options that they could have had if HUD had the resources and a requirement to consistently conduct proactive monitoring of construction by recipients of HUD funding.

#### The disconnect

means costly and time-consuming retrofitting of housing units—a loss to communities, who cannot adequately house residents, and

*All states cite insufficient accessible and affordable housing options as a major detriment to transition people to their communities.*

taxpayers who funded the housing—a failure that has impacted the ability of people with disabilities to transition from institutionalized settings to the community. Waiting lists for accessible units have been notoriously long for decades and advocacy

groups have consistently asked HUD to increase the percentage of required accessible units, but this has not occurred.

Recipients of federal housing development funds must comply with federal accessibility laws, including Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act, and the Fair Housing Act, and HUD has responsibility for ensuring compliance by recipients. For federally assisted new construction housing projects, Section 504 requires 5% of the dwelling units, or at least one unit, whichever is greater, to be accessible for persons with mobility disabilities. An additional 2% of the dwelling units, or at least one unit, whichever is greater, must be accessible for persons with hearing or visual disabilities.<sup>96</sup>

Recipients of federal financial assistance must adopt policies and procedures to ensure that people who need the accessibility features of particular units occupy them, and designate at least one individual to coordinate accessibility efforts if the recipient employs 15 or more persons.<sup>97</sup> HUD regulations do not require recipients to maintain a publicly available list of accessible units with their disability features, except for Housing Choice Voucher units,<sup>98</sup> but has included this as a provision in Voluntary Compliance Agreements and settlement agreements.<sup>99</sup>

HUD funds units, which state and local Public Housing Authorities, community development organizations, and non-profit organizations build and acquire. HUD has responsibility for compliance with federal law by all recipients of its funds; however, its Section 504 regulation, for

example, has limits that should be addressed to enable it to proactively address accessibility in the construction phase. Currently, the regulation allows, but does not require, HUD to conduct compliance reviews. It states that HUD “*may periodically review* the practices of recipients to determine whether they are complying with this part. . . .”<sup>100</sup> This does not require or authorize HUD to check on accessibility during the design or construction phase. Furthermore, it requires an investigation only when “a compliance review, report, complaint or any other information indicates a possible failure to comply with this part.”<sup>101</sup> These provisions prevent the agency from

proactively checking to ensure accessible units are being constructed.

If the Section 504 regulation were amended to allow for this additional responsibility, HUD should seek and Congress should approve additional

funding for compliance staffing. If HUD had designated employees in its regional or local offices to conduct compliance checks during the construction phase, instead of relying on recipients of federal funding to self-comply with the accessibility requirements as part of their obligations for receipt of federal financial assistance, issues could be caught early. Though federal oversight was designed to count on recipient assurances, this has been shown to be costly when it fails in the housing context: thousands of accessible units not being constructed or constructed incorrectly while recipients continue to receive millions in taxpayer dollars and people with disabilities remain on

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*Currently, the regulation allows, but does not require, HUD to conduct compliance reviews . . . These provisions prevent the agency from proactively checking to ensure accessible units are being constructed.*

waiting lists. Further, localities' planning and codes compliance departments have no duty to check for compliance with federal accessibility requirements and largely do not have expertise in the FHAct Accessibility Requirements or Section 504 requirements, although they would be considerable assets in assisting the federal effort to ensure local housing developments comply with federal accessibility requirements.

Recent examples of developers failing to construct such units and the federal and private actions to seek compliance illustrate the ongoing problem of enforcement after the inaccessible units are constructed—a highly ineffective manner to ensure contract compliance for federally assisted housing development in the United States.

A lawsuit filed in 2012 by the Independent Living Center of Southern California, Fair Housing Council of San Fernando Valley, and Communities Actively Living Independent and Free, alleged that the city of Los Angeles, California, misused federal funds for housing development by failing to comply with its duty to create accessible apartments in more than seven hundred affordable housing projects—buildings with nearly 47,000 units—approved over nearly three decades. Disabled residents reported going to apartment buildings that were advertised as accessible, only to find they were not. In some locations, apartments had doorways that were too narrow to accommodate wheelchairs, the

lawsuit states. Bathrooms and kitchens lacked the room to accommodate wheelchair users.<sup>102</sup> In 2016, the lawsuit was settled without HUD involvement, and required the city to ensure that 4,000 units are accessible to people who use wheelchairs, have hearing impairments or live with other disabilities. The city could reach that goal by building additional apartments, redesigning existing ones or demonstrating that units already built are, in fact, accessible.<sup>103</sup>

HUD has the authority to withhold federal funding if developers fail to meet federal accessibility requirements. The power of this as a lever to compel compliance was shown in 2019, when HUD threatened to withhold eighty million dollars in federal funding from the City of Los Angeles, California,<sup>104</sup> spurring the city to take seriously its responsibilities and resulting in a settlement that resolved longstanding HUD findings of noncompliance with

Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act with respect to the City's affordable housing program. HUD's 2019 Voluntary Compliance Agreement (VCA) with the City requires the development of 10,000 units of new affordable housing over the subsequent 10 years, including 1,500 accessible units, exceeding existing state and federal requirements. The City further committed to retrofitting existing housing developments that do not meet federal accessibility standards to create an additional 3,100 accessible housing units for

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*Though federal oversight was designed to count on recipient assurances, this has been shown to be costly when it fails in the housing context: thousands of accessible units not being constructed or constructed incorrectly while recipients continue to receive millions in taxpayer dollars and people with disabilities remain on waiting lists.*

individuals with disabilities.<sup>105</sup> In addition, the City and HUD will work together on an “Enhanced Accessibility Program” to incorporate innovative accessibility features into future affordable housing developments.

In a similar suit, in May of 2018 Access Living, a Center for Independent Living in Chicago, Illinois, filed a lawsuit alleging that the City of Chicago failed to comply with the accessibility requirements of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act of 1973 (Section 504), and the Fair Housing Act (FHAct). From 2004 to 2016, Access Living received approximately 50,000 inquiries from people searching for accessible, affordable housing. Typical stories include: a woman with a mobility impairment who had to climb twenty-five stairs because she could not afford to live

elsewhere; and a man forced to live in a nursing home for decades because he could not find affordable housing with wide enough doors for his wheelchair.

In 2016, Access Living began an investigation to determine whether Chicago’s Affordable Rental Housing Program was complying with the accessibility requirements of the ADA, Section 504, and the FHAct. It revealed that many developments were not constructed to allow individuals who use wheelchairs to enter and/or use buildings, rooms, and amenities. The case is still in the beginning stages of litigation. A ruling in Access Living’s favor would impact more than 50,000 rental homes in more than 650 developments and require Chicago to take steps to ensure that future developments comply with federal accessibility



requirements,<sup>106</sup> however, the litigation could take years to conclude, leaving people with disabilities waiting indefinitely for much needed affordable, accessible housing.

Non-compliance with federal accessibility standards is also found in multifamily properties that do not receive federal funding. The FHAct applies to all multifamily dwellings of four or more units, constructed after March of 1991, and requires an accessible route and certain accessibility features in every unit.<sup>107</sup> HUD does not have the capacity to check every multifamily development built in the United States, and local inspectors rarely check for federal FHAct compliance.

Violations are therefore reported by consumers seeking accessible housing or fair housing advocacy organizations. The current system of after-construction identification of violations allows

inaccessible units to be constructed across the nation and costly and time-consuming retrofits only after HUD, DOJ or consumers get involved in enforcing the FHAct—a lengthy process.

In a recent example of a successful enforcement effort, in 2021, DOJ filed a lawsuit against the developer and owners of eight senior living complexes in Alabama, Florida, Georgia, South Carolina and Tennessee, after an investigation that showed that they violated the FHAct and the ADA by failing to build these properties with required accessible features for

people with disabilities. As part of the settlement, the defendants agreed to make substantial retrofits to remove accessibility barriers at the complexes, including more than 1,500 units and pay \$450,000.<sup>108</sup>

### **Wait Lists for Low-Income Housing**

A lack of sufficient rental vouchers and strict programmatic restrictions are consistent barriers for people with disabilities to live in their communities. Public Housing Authorities are utilizing vouchers from HUD to transition people out of institutions, but demand for affordable housing still far outpaces supply: a recent report estimates that there is a shortage of 3.4 million affordable rental units, which pales in comparison to what is a largely unknown estimate of the shortage of affordable and accessible rental homes.<sup>109</sup>

There are several types of housing vouchers. Housing vouchers, administered by

Public Housing Authorities (PHAs) are one path out of congregate settings for institutionalized people with disabilities, but a lack of funding and available accessible units has created waitlists which delay their use—leaving many to remain institutionalized.

Mainstream Vouchers assist non-elderly persons with disabilities afford housing and are administered using the same rules as other housing choice vouchers. They were created to divert people with disabilities and members of their household from becoming homeless.<sup>110</sup> People with developmental disabilities as well as

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*The current system of after-construction identification of violations allows inaccessible units to be constructed across the nation and costly and time-consuming retrofits only after HUD, DOJ or consumers get involved in enforcing the FHAct—a lengthy process.*

physical disabilities are eligible for the program. Mainstream Vouchers are prioritized for people with disabilities age 18 to 61 who are living in a nursing facility or at risk of institutionalization. A 30% increase in Mainstream Vouchers was authorized in May 2020, shortly after the pandemic struck the United States,<sup>111</sup> but no guidance or suggestion was provided on how that increase should

be used. In September 2020, HUD issued a notice that stated that many communities were “working urgently to house homeless populations to help prevent the spread of COVID-19 among those living in shelters or

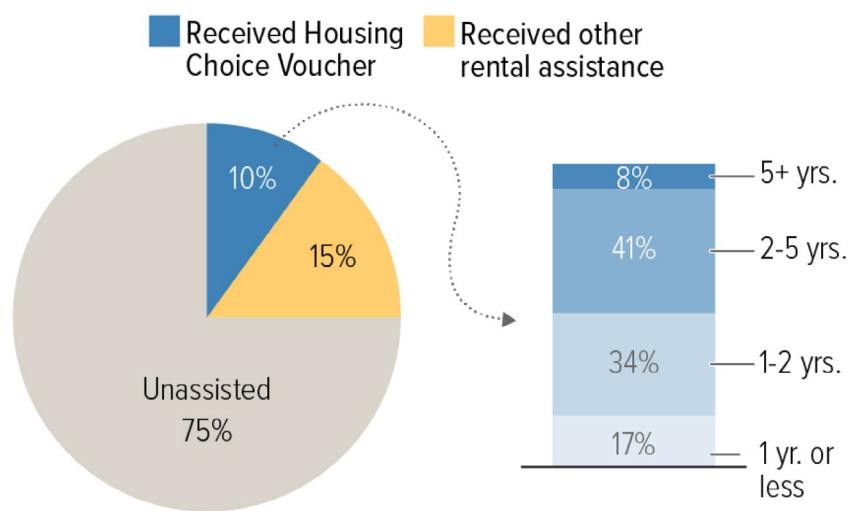
other close quarters.” There was no mention of using these Mainstream Vouchers to help those with disabilities transition from institutionalized settings where people were most susceptible to the worst impacts of the virus.<sup>112</sup> In fact, the only mention of institutionalized people was under criminal screening, indicating that it was referring to transitioning people from penal institutions.

Despite the demonstrated benefits of rental assistance and effectiveness of vouchers specifically, resources fall far short of need. Only 1 in 4 households eligible for rental assistance receive it due to funding limitations. See

### ***Only 1 in 4 households eligible for rental assistance receive it due to funding limitations.***

## **Small Share of Eligible Households Receive Vouchers and Typically After Long Wait**

Share of eligible households receiving rental assistance and agency's average wait time for voucher recipients



Source: HUD custom tabulations of the 2019 American Housing Survey; 2018 HUD administrative data; FY2020 McKinney-Vento Permanent Supportive Housing bed counts; 2019-2020 Housing Opportunities for Persons with AIDS grantee performance profiles; and the USDA FY2020 Multi-Family Fair Housing Occupancy Report; HUD 2020 Picture of Subsidized Households

Figure G for an illustration of how few eligible households receive vouchers and how long they wait for the assistance they need. Because the need is so much greater than the supply of vouchers, housing agencies establish waitlists for households interested in receiving assistance.<sup>113</sup> For both the Non-Elderly Disabled (NED)<sup>114</sup> and the Mainstream Housing Vouchers, PHAs vary extensively in their approach to handling waitlists. Some use a lottery system to allocate vouchers. It is difficult, however, to get a true picture of vouchers. For example, databases maintained by HUD and the Technical Assistance Collaborative (a nonprofit that advances solutions for housing for people with disabilities), display conflicting numbers of vouchers and many PHAs reporting zero of either type of voucher specifically intended for people with disabilities.<sup>115,116</sup>

Millions of other families eligible for rental assistance never receive it because their names never rise to the top of the waiting list or they live in communities where the housing agency has closed or doesn't keep a waiting list.<sup>117</sup> Significantly expanding the federally funded voucher program, which helps households with low incomes rent a modest unit of their choice in the private market, would help more people with disabilities who are trying to transition from institutionalized settings to community living

instead of facing years of waiting for a housing opportunity.

### ***Source of Income Laws: Helping Voucher Holders to Obtain Housing***

For people with disabilities who have a housing voucher, the next step is finding housing, but many find that landlords refuse to accept them if part of their rent is paid with a federal housing voucher. To address this ongoing issue states began enacting "Source of income" protections, and by 2022, thirteen states and the District of Columbia had enacted state laws or local ordinances providing "source of income" protections for housing.<sup>118</sup> Though not disability specific, these laws provide protection against source of income discrimination—breaking down another barrier to obtaining housing. Advocates have long called for a federal law prohibiting source of income discrimination to address housing disparities on a national level. To that end, in June of 2022, Senator Tim Kaine introduced the *Fair Housing Improvement Act of 2022* (S. 4485) to protect veterans and low-income families from housing discrimination.<sup>119</sup> If enacted, S. 4485 would expand protections under the federal FHAct to ban discrimination based on source of income, giving more individuals and families access to affordable housing and a shot at economic mobility.

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***Millions of other families eligible for rental assistance never receive it because their names never rise to the top of the waiting list or they live in communities where the housing agency has closed or doesn't keep a waiting list.***

## **A Federal Visitability Law Would Help People with Mobility Impairments Remain in the Community**

The majority of single-family homes in the United States do not have an accessible entry for a wheelchair user or a person with a mobility impairment; have narrow doorways to bathrooms, and no bedroom on the first floor. The lack of these features has serious implications for the ability of people to age in their own homes and live in the homes of family members, even temporarily, if needed or desired. This fact has severely impacted people with disabilities' ability to remain in the community or return to the community after a hospitalization or disabling injury, and continues the segregation and isolation of millions of elderly and disabled people—of all ages. The implications of this lack of basic access include:

- Severely limits choice in renting or purchasing;
- Segregation into residences or communities built especially for people who are aging or disabled;
- Isolation and prevention of visiting the homes of their friends and extended family;
- Requires non-disabled people who develop either temporary or permanent disabilities—and do not have the resources available to modify their homes—to leave their homes to live in other houses or even institutions; or remain in their homes with barriers still in place, unsafe and unable to exit; and
- Forces people with disabilities to live in nursing facilities, state hospitals, or other institutions.<sup>120</sup>

For decades, disability advocates have proposed that single-family homes that are newly constructed, have “visitability” features to address the need for housing for people with mobility disabilities, to allow people to remain in their homes as they age or become disabled, allow people with mobility disabilities to rent rooms in homes, and to allow relatives and friends with mobility disabilities to visit. “Visitability” has three features:

1. At least one zero-step entrance (does not have to be front entrance)
2. All main floor interior doors with 32 inches of clear passage space and hallways no less than 36 inches in width
3. One bathroom on the main floor (preferably a full bathroom)

There is a smattering of state and local laws across the country that require new single family homes to have visitability features and have resulted in thousands of homes constructed with these basic features.<sup>121</sup> Most legislative proposals requiring single family homes to have

### **Features of Visitability**

1. At least one zero-step entrance (does not have to be front entrance)
2. All main floor interior doors with 32 inches of clear passage space and hallways no less than 36 inches in width
3. One bathroom on the main floor (preferably a full bathroom)



these features have been met with resistance by homebuilder associations who prefer a voluntary method of visitability features, however this resistance failed in Arizona, when an appeals court upheld the Pima County visitability law based on the governments rational interest in addressing the housing shortage for its aging population.<sup>122</sup>

In his testimony before Congress in support of the Inclusive Home Design Act (IDHA) of 2009,<sup>123</sup> Kelly Buckland, the former Executive Director of the National Council on Independent Living (NCIL), stated:

Centers for Independent Living throughout the country constantly grapple with the lack of accessible and affordable

housing. One of our biggest challenges is not only finding accessible housing for people living in the community but finding it for those who want to transition out of institutions. In many communities the biggest obstacle to people with disabilities living in their communities is the lack of affordable and accessible housing. . . . [T]he IHDA will allow for the construction of accessible single-family housing which will permit the aging population to stay in their homes, reducing the number that will enter a nursing home, allow people with mobility impairments to rent rooms in existing homes. . . . Most importantly, . . . [it] will create accessible housing which is needed in order to move people

out of institutions and back into their communities. Living in the community is essential for people of all ages and all disabilities to be true members of the community—this includes education and employment.<sup>124</sup>

The IHDA was not passed, but it is time for Congress to pass similar legislation that will increase the availability of accessible housing options as part of the burgeoning need for housing to support the nation's HCBS system and to protect people with disabilities from continued institutionalization.

### ***HHS and HUD Partnership on Housing***

In December 2021, the U.S. Department of Health and Human Services (HHS) and HUD joined to create “The Housing and Services Resource Center,” which aims to facilitate partnerships at state and local levels by serving as an information clearinghouse about community-based supports, housing programs, and transition efforts to move people out of congregate settings.<sup>125</sup> HHS partners include ACL, CMS, the Substance Abuse and Mental Health Services Administration, and the Office of the Assistant Secretary for Planning and Evaluation. Such an effort will succeed only with increased availability of affordable and accessible housing units—a critical but ongoing lack in the HCBS ecosystem.

### ***III. Inequity in Data Collection Obscured Information on People with Disabilities***

When disability advocates raised the alarm that people with disabilities must be prioritized in the vaccination roll-out, “insufficient data” was frequently cited as a reason to deny prioritization. Disability representation at all levels of federal and state decisions on data collection is an important strategy towards more equitable data collection, measure development, knowledge translation, and the development of data driven policies.<sup>126</sup>

While states were required to report deaths due to COVID-19 in nursing homes, they were not required to report deaths in low census settings, like group homes. Nor were states required to report infections and deaths of

direct support providers in these settings.

This has resulted in an impossible task to summarize casualties in these settings. We know even less about the impact of COVID-19 on individuals receiving Medicaid HCBS in their homes. The

Centers for Medicare and Medicaid Services (CMS) CMS reported COVID-19 related data for HCBS beneficiaries in 2021.<sup>127</sup> In a survey to better understand state-level COVID-19 data, few states posted data about cases and deaths in congregate care settings for people with intellectual disabilities.<sup>128</sup> Among those who participated, states were inconsistent in collecting and reporting residential setting, race,

age, or health needs.<sup>129</sup> Moreover, the standard death certificate form used in the United States does not capture the presence of disability.<sup>130</sup>

Although inconsistent, data began to drive pandemic responses in the summer of 2020 as policymakers grappled with how to best spend infusions of federal funding to bolster a system in disarray. Targeted payment strategies for providers, modifications to service modality (i.e., adult day program transitioned to in-home services) and adjusting case-management from in-person to remote monitoring were among the strategies utilized

across states during the pandemic. A national framework for data collection that includes people in all congregate settings, and interoperability across data systems, remains an unmet need which continues to hinder the ability of the Federal Government to fully understand the impacts on individuals who live in congregate settings and therefore undermines any effort to create a well-planned, well-informed federal and state response. Without the gathering of this important data people with disabilities will continue to be left behind and treated inequitably.

The need for data-driven policies should drive decisions about data aggregation and bifurcation, or categorization, of data. In nursing facilities, “aging” and “disabled” are bifurcated without consideration that aging individuals are gradually developing disabilities. Some people are captured as “aging” in the data only because of their age and without consideration of disability

status. Presumably nearly everyone residing in a nursing facility also has a disability. The bifurcation of data renders less valuable data for people with disabilities, the aging, and people who are part of both groups.

## Racial, Ethnic, and Age Inequities in Data Collection

COVID-19 impacted poorer communities the hardest, no matter race or ethnicity. However,

the studies identified for this report pointed out that significant racial and ethnic disparities in mortality rates and

adverse outcomes from COVID-19 have been identified by researchers.<sup>131</sup> Research by Shippee and colleagues (2020) predicted a worsening of racial and ethnic disparities in long-term services and supports, as well as HCBS.<sup>132</sup>

Between 1998 and 2008, the percentage of non-Hispanic white people decreased use of nursing homes while the population of people of color in nursing homes grew.<sup>133</sup> A 2018 study by Fabius and colleagues found that Black HCBS

users were more likely to be female and need more assistance with activities of daily living than White HCBS users.<sup>134</sup> An analysis of secondary data also showed Black HCBS users

were less likely to receive case management services, equipment, technology, environmental modification services, and nursing services. Black men had the lowest HCBS expenditures while White men had the highest.<sup>135,75</sup> Future research is needed to understand cultural and social

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*[T]he standard death certificate form used in the United States does not capture the presence of disability.*

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*A national framework for data collection that includes people in all congregate settings, and interoperability across data systems, remains an unmet need . . .*

mechanisms, to close the gap in the provision of HCBS services between people of color and their white counterparts.

Intersectional inequities are also present in an analysis of HCBS outcomes and successful interventions. A 2019 study focused on the potential of HCBS waivers to reduce disparities in unmet need among children of color with autism spectrum disorder.<sup>136</sup>

States with 1115 waivers from the Federal Government offered expanded eligibility for HCBS, which differed in the “generosity” (i.e., the amount of services offered, number

of participants allowed and duration). The study found that waivers with the highest

“generosity” were most effective in closing disparities between Black and White children with autism.<sup>137</sup> The State of Washington also used 1115 waivers to expand access to HCBS services to “pre-Medicaid” individuals to divert institutionalization.<sup>138</sup>

These findings provide

important implications that the presence of a waiver alone, without consideration of the inequitable baseline, may not address racial, ethnic, age, or other inequities.

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*An analysis of secondary data also showed Black HCBS users were less likely to receive case management services, equipment, technology, environmental modification services, and nursing services. Black men had the lowest HCBS expenditures while White men had the highest.*



## Chapter 4: Federal, State, and Private Efforts to Support Community Living During COVID-19

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### **Appendix K, State Plan Amendments, and Medicaid Waivers**

Most states implement their HCBS programs through a Medicaid authority called 1915(c) Home and Community-Based Waivers. Appendix K is a standalone appendix in the 1915(c) waiver application that can be utilized during an emergency for states to request a change or amendment to their approved 1915(c) waivers. It's advantageous to utilize

Appendix K because it is connected to a larger set of rules and practices that have already been negotiated as allowable or nonallowable within the 1915(c) waivers during emergency situations.

Appendix K is a template states can utilize during an emergency to tailor HCBS to meet unique needs that arise in an emergency. Changes made during an emergency can be temporary or become a permanent change to the state's waiver, if permitted. Appendix K addressed several concerns during the pandemic, including access and eligibility to HCBS, provider qualifications, person-centered planning, and self-direction opportunities.<sup>139</sup> Some of the same flexibilities

afforded states under the Appendix K have been extended to states with HCBS under 1115 authority via a similar application referred to as the Attachment K.

States used Appendix K to increase payments to HCBS providers to incentivize staff or compensate for additional risk. Some states requested rate increases for HCBS workers, including Direct Support Professionals, of up to 50%. Some states have provided "retainer"

payments to providers while HCBS recipients are hospitalized or under quarantine.

Typically, a provider couldn't bill unless they provided services, but the retainer payments allowed providers to bill for services even though

the HCBS recipient may have been hospitalized or in quarantine with COVID-19. This prevents a loss of income for the provider and ideally, the loss of a provider for the recipient.

Outside of these emergency options, states were also able to submit a State Plan Amendment (SPA) to CMS. While Appendix K uses the already-approved 1915(c) waiver to build upon, a SPA seeks to update the state plan

*[T]he retainer payments allowed providers to bill for services even though the HCBS recipient may have been hospitalized or in quarantine with COVID-19. This prevents a loss of income for the provider and ideally, the loss of a provider for the recipient.*

itself. When amending a state plan, the Medicaid statute allows CMS two ninety-day periods to review a state plan amendment submission. The Medicaid statute also allows for a retroactive approval date to the first date of the quarter the SPA was submitted, under certain conditions. In response to the public health emergency, CMS eased this process for states by releasing a SPA template in March 2020 that made the process more standardized and added clarity to states about their options.

States could integrate multiple HCBS state plan authorities, including the Self-Directed Personal Assistant Services (1915(j)) and Community First Choice (1915(k)) when requesting these temporary changes. States also used SPAs to suspend prior authorization requirements. Two additional authorities (1135 and 1115) also allowed states to suspend prior authorization requirements to ease administrative burdens during the emergency. States varied on whether the changes they made to their HCBS systems were temporary or permanent. From interviews and convening sessions, we heard that some states decided that even temporary changes were better made through a SPA than Appendix K.

These decisions seemed largely tied to preferences of Medicaid leadership in states.

Appendix K and 1135 Waivers were impactful in addressing family caregivers and the direct care workforce shortage. The shortage of direct care workers results in family and friends filling the void. A 2021 HHS report valued annual unpaid caregiving by family and friends at \$111,000 and

even higher, around \$192,600, for individuals who don't also receive paid care.<sup>140</sup>

By April 2021, one year into the pandemic, 39 states were using Appendix K waivers to pay family caregivers.<sup>141</sup> The use of Appendix K has helped to prevent the transmission of COVID-19 by keeping people from needless institutionalization.

Appendix K waivers enable states to "pay legally responsible relatives to provide care that is extraordinary and necessary" to prevent

institutionalization. Some states expanded eligibility for family caregivers to meet minimum training requirements to be paid for the care they provide to family members with disabilities. Some states lowered the age limit to allow known family members who are 16 years of age and older to provide care and be paid. Appendix K waivers also provided families with PPE.

Likewise, "Section 1135" waivers were used to pay family caregivers. As of April 2021, 14 states were using Section 1135 waivers to pay for personal care provided by legally responsible family caregivers.<sup>142</sup> 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 and help address the direct care workforce shortage. The reduced rate of childbearing by the baby boomer generation (people born between 1946 and 1964), which is now aging, increased divorce rates, and rising participation in the workforce by working-age women suggests less availability of unpaid,

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***By April 2021, one year into the pandemic, 39 states were using Appendix K waivers to pay family caregivers.***

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***Appendix K waivers also provided families with PPE.***

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family caregivers in the future,<sup>143</sup> making it an important priority for CMS to make paid caregiving a permanent option for state Medicaid agencies, rather than part of a flexibility used in an emergency. Likewise, CMS should make paid family caregiving a requirement for state Medicaid agencies under 1915(c), 1915(i), 1915(j), and 1915(k), rather than leaving this to states' discretion.

## American Rescue Plan Act

On March 11, 2021, President Biden signed the American Rescue Plan Act of 2021 (ARPA), which provided states with a temporary ten percentage point increase to the federal medical assistance percentage (FMAP) for certain HCBS expenditures from April 1, 2021, to March 31, 2022.<sup>144</sup> FMAPs are used in determining the amount of Federal payments to a State for medical services. States have an unprecedented opportunity to access additional HCBS funding through Section 9817 of the ARPA through March 2024, to increase their capacity to offer services in compliant settings (particularly non-disability-specific residential settings), and to expand services that are truly integrated to support individual autonomy and community participation. This additional funding is an important opportunity for states to prioritize and implement changes aimed at addressing the most critical HCBS structural issues.<sup>145</sup> States have varied vastly in their approach to spending these funds.

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*States have an unprecedented opportunity to access additional HCBS funding through Section 9817 of the ARPA through March 2024, to increase their capacity to offer services in compliant settings . . . , and to expand services that are truly integrated to support individual autonomy and community participation.*

See Table B for HCBS Medicaid Authority and associated services eligible for the ARPA Section 9817 funding, which provided the temporary increased FMAP.

In addition to funding for services, ARPA helped states raise provider rates, recruit and train workers, and implement assistive technology programs to lessen needs for in-person supports.

The Money Follows the Person (MFP) program, which had been refunded through a series of short-term efforts, was extended for three years to 2023 by the Consolidated

Appropriations Act of 2021. Two important changes also altered eligibility criteria: 1) Individuals could qualify for MFP after a 60-day (instead of a 90-day) inpatient stay in a nursing home facility or institution; and 2) If a person received all or some of their care in a skilled nursing facility, they could count the

days they received skilled rehabilitative or skilled nursing services to meet the 60-day threshold.<sup>146</sup> These changes shortened the length of time people were identified by the MFP system as eligible and in need of support to transition out into the community. For some, however, these length-of-stay requirements were still too long. One convening session participant for this report recalled her time in a nursing home in Chicago in April 2020, "My room was adjacent to the back door and every day I could hear people rolling bodies out on stretchers. As my nurses would

HCBS Medicaid Authority	Description
Home Health Care	Home health services are mandatory HCBS services. They include nursing services, home health aides, medical supplies, and equipment. They may include therapies.
Personal Care Services	Personal care services (PCS) are considered optional. They include assistance with daily activities, like bathing, meal preparation, and money management.
Self-Directed Personal Care Services	Section 1915(j) of ARPA allows for self-direction of personal care services. The HCBS users can hire their own staff and direct their own services.
Case Management	Case management assists HCBS users to gain access to medical, social, educational, and community services to address unmet needs.
School-Based Services	Section 1905(1) includes school-based services, defined as medical assistance furnished as part of a child's individualized education program (IEP).
Rehabilitative Services	Rehabilitation services include mental health and substance use disorder services as well as physical rehabilitation to restore function.
Private Duty Nursing	Private duty nursing is an optional Medicaid state plan benefit. It supports the provision of nursing care under the direction of a person's physician and in a hospital, skilled nursing facility, or in a person's home.
Section 1915(c)	Waiver authority found at section 1915 (c) gives states the option to offer LTSS in HCBS settings to individuals who would otherwise require institutional care. Eligible expenses include home accessibility modifications (i.e., installing a wheelchair ramp or grab bars), first month's rent, and security deposits to attain accessible housing.

come and go, I'd see people being pushed out. I just wondered if I could get out of there before that would be me."

### **Centers for Independent Living Assist in Transitioning People with Disabilities from Institutions**

The COVID-19 Aid, Relief, and Economic Security Act (CARES Act) provided \$85 million in supplemental funds to Centers for Independent Living (CILs) in April 2020.<sup>147</sup> This one-time appropriation from Congress provided solutions for diversion, temporary homelessness, vaccine access, and nursing home transition. But few CILs seemed equipped to facilitate the transition

of people with disabilities from congregate settings during the pandemic. The Atlantis Center, a CIL in Colorado, was an exception, demonstrating successful application of CARES Act funding to move people from nursing homes into hotel rooms for a period of quarantine while accessible housing was identified. Immediately upon leaving the nursing home, CIL staff ensured participants in the pilot program completed the steps necessary to receive HCBS waivers. The pilot provided participants a laptop and internet through the hotel. This access was paired with Atlantis Center's staff support to make telehealth visits and complete the steps needed to fully transition into the community.

Staffing a workforce to care for pilot participants was challenging but Atlantis partnered with organizations that provide wraparound services for people experiencing homelessness. Some of those individuals, who were also receiving employment support, were hired as caregivers for people residing in the hotel on a short-term basis after transitioning from the nursing home. Caregivers could be paired with participants to minimize transmission of the virus that occurs with caregiver's care for multiple people.

The Atlantis Center tried to utilize FEMA Public Assistance Category B funds, which provides emergency protective measures during a Federally Declared Disaster to support the emergency need to relocate people with disabilities from nursing homes to the community in the midst of the pandemic but were

unsuccessful. FEMA Category B funds reimburse up to 75% of expenses for shelter and temporary housing during an emergency. It can also pay for emergency equipment, PPE, staff training, and other expenses that are listed in a state's emergency plan.<sup>148</sup> Atlantis Center pilot program staff explained, "Local partners . . . were already firmly set on the fact that they were only going to contract with homeless service providers to utilize FEMA funds during the pandemic."<sup>149</sup> Some of the people with disabilities who contacted the Atlantis Center because they were in need of urgent transition from a dangerous congregate setting were living in places originally created from FEMA funding.

Another Center for Independent Living, Roads to Freedom in North Central Pennsylvania (the CIL), successfully accessed FEMA Category B



funds. On April 3, 2020, FEMA approved Category B funding for non-congregate shelters in Pennsylvania, but limited populations who could be served to people who were unhoused, first responders, and healthcare workers. On May 13, 2020, Pennsylvania disability advocates requested state and county officials to consider people with disability as a population in need of emergency transition from nursing homes to hotels where they could receive safer, individualized care. As the death toll of people with disabilities in congregate settings rose, the CIL sent dozens of emails and initiated several meetings with county, state, and federal officials to map a way to utilize FEMA-funding for its intended purposes to "provide assistance for the rescue, evaluation, care, shelter, and other essential needs of affected human populations.<sup>150</sup>"

The CIL continued to use Nursing Home

Transition funds to emergently transition 54 people from nursing facilities in 2020 during the pandemic. Six individuals died from COVID before their transitions could be completed. In late 2021, The Road to Freedom received its first FEMA reimbursement, the result of a lengthy and complicated county-by-county process. The Road to Freedom's pilot program to utilize FEMA funding for emergency relocation was an interesting and innovative approach but it faced multiple policy and procedural barriers to implementation. While the Atlantis Center and The Road to Freedom successfully accessed Category B funding, other CILs could not access those funds as there was confusion over CILs' eligibility

as "private non-profits" that could receive that funding. Individuals interviewed for this report informed NCD that the FEMA funding that was received to reimburse CILs was delayed and was insufficient to cover the costs of the work completed by the CILs.

To address the complexity and confusion regarding the availability of FEMA funds that can be used to assist in relocating people with disabilities during a federally declared disaster from congregate to non-congregate settings, in 2022, FEMA and NCD established a working group on federal disaster assistance for people with disabilities. The group is comprised of

federal agencies and aims to create a document for disability stakeholders describing the funds available, and how to access them, from FEMA and other federal sources that can be used for this purpose.

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*The Road to Freedom's pilot program to utilize FEMA funding for emergency relocation was an interesting and innovative approach but it faced multiple policy and procedural barriers to implementation.*

## Hospital Discharge Planning Partnership to Support Community Living

While CIL-based programs assisted the transition from nursing home to community, other advocates focused on changing the hospital discharge process to avoid moving people from a hospital into another congregate facility. Many people with disabilities entered a congregate care facility during or before the onset of the COVID-19 pandemic from a hospital discharge. Safe hospital discharge planning prioritizes community living for those that do not need acute, hospital-level medical care but barriers, like housing and finding caregivers, too often result

in discharge from one congregate setting (i.e., a hospital) to another (i.e., a nursing home).

Before a person with a disability leaves a hospital, their level of care is assessed. How, when, and by whom this assessment is conducted is not transparent and highly variable. Even people who make or have too much money to meet

Medicaid's income eligibility requirements are often still unable to pay for skilled nursing care because it is very expensive. Higher skilled care is more widely

available in one's home. For at least some people, current restrictions on setting of care are the only reason they are forced to live in a congregate care facility to receive the care they need rather than at home.

If a person's level of care is assessed to be compatible for community living, it far from guarantees a transition to the home. Referrals to services that support transitions often come too late. An on-site presence is needed from transition coordinators who are in hospitals; this best practice was significantly reduced

during peaks of COVID-19, when coordinators were less likely to be deemed essential staff than those with hands-on healthcare roles. Social determinants of health—Economic Stability; Education Access and Quality; Health Care Access and Quality; Neighborhood and Built Environment; and Social and Community

Context—are integral factors in successful transitions but perhaps more so in reduction of re-institutionalization, a return to the congregate setting after an attempted discharge to community. Re-institutionalization is both costly financially and dangerous to the health of people with disabilities.

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*... [O]ther advocates focused on changing the hospital discharge process to avoid moving people from a hospital into another congregate facility.*

The Hospital-to-Home program in Colorado Springs, Colorado has dismantled the pipeline from hospital to nursing home through a private partnership between the University of Colorado

Health system and The Independence Center (local CIL).<sup>151</sup> When a person with a disability is identified as ready to go home but expecting unmet needs, like meals, home health care, and housekeeping, interagency case management intervenes to connect people with resources and low-cost services. The Hospital-to-Home

program acknowledges the risk of long-term institutionalization if people discharge from the hospital to a skilled nursing facility, so it intervenes to lessen the likelihood of placement in a congregate facility. Promising pilot

programs, such as the Roads to Freedom, Atlantis Center, and the Hospital-to-Home program, offer glimpses of potential strategies that, put to scale, could divert more people from congregate care facilities and move those already living in these facilities out into the community.

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*Social determinants of health . . . are integral factors in successful transitions but perhaps more so in reduction of re-institutionalization, a return to the congregate setting after an attempted discharge to community.*



# Chapter 5: Analyses of Two Women with Disabilities Institutionalized During the COVID-19 Pandemic

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## Lynn's Story

Lynn is a 35-year-old White woman with cerebral palsy residing in a Cincinnati, Ohio, nursing home for people with neurological disabilities. She has a master's degree and volunteers for several nonprofit organizations, including her state's protection and advocacy board. Lynn lived in a dorm during college and then in her own apartment, both with the assistance of direct support providers. Around approximately 2017, she found it untenable to find and retain providers to assist her with daily living, including toileting, preparing food, and bathing. She worked with case managers from her county board of developmental disabilities and even nonprofits specializing in finding and matching providers with waiver recipients. The task of hiring, training, and then losing staff was taking up most of Lynn's time. She was frequently left stranded in bed or without the option to toilet for multiple hours at a time. Her mother frequently made unplanned trips to provide backup assistance. In 2018, Lynn made the difficult decision to move back into her mother's home.

With most of the caregiving responsibilities now the responsibility of Lynn's mother, her own needs as an aging adult were increasingly less compatible with lifting and transferring Lynn. Both Lynn and her mother worried about safety

if either of them should be hurt or become ill and need more assistance. Lynn deeply valued her life in the community but as she describes, "It seemed clear my needs couldn't be met in the community despite promises of waivers. I realized that it was likely I was going to end up in a nursing home emergently so I thought it would be a better option to choose a facility that best met my needs." Lynn researched and visited facilities. She prioritized settings near bus lines with hopes she could still remain active in her community. In late 2018, she moved into a nursing home with hopes for temporary reprieve while she, "could figure out what seemed like a maze of supports and strategies to find and keep personal assistants."

In 2019, Lynn applied and was accepted into a competitive advocacy training program. She arranged to take the bus from her facility to the training site and back each day. Lynn had noted the importance of being in the community in all her person-centered planning at the nursing facility, but she still faced significant barriers to participation in this program. The length of her training day was adjusted to ensure Lynn was not outside of the facility for more than 8 hours (a CMS regulation for nursing home residents). As such, Lynn also had to forgo trips with her training cohort because extended absences

from the nursing facility were limited and Lynn preferred to save them to spend holidays with her mom in her home.

With the onset of COVID-19, the nursing facility was placed on full lockdown for more than 10 months. Lynn could not leave her room. Her mother was not permitted to visit. She reports that she was fortunate to be well-equipped with technology, like an iPad and computer, to stay connected to the outside world, "but most other residents were not so lucky." Fearing for her safety, Lynn tried to expedite her transition from the congregate setting back into the community. She felt renewed hope that she would be able to find direct support professionals to help her upon reading about federal investments into HCBS.

She applied for housing vouchers. Upon the initiation of our interview for this root cause analysis in August 2021, Lynn was confident she would be moving into an accessible apartment

by September. She then faced a number of frustrating challenges. HUD paperwork still required paper-based completion, which was slowed or impossible due to ongoing COVID-19 lockdowns in nursing facilities. At several points, HUD offices were closed but still required paper forms that could only be submitted by mail. Lynn reports that her forms were lost more than once. Systems collided as she could not apply for services for an address she did not yet occupy, but she could not move until services were in place. Lynn estimates she's spent more than 30 hours making phone calls, sending emails, and largely handling her own case management. In May of 2022, more than two years after she

began her efforts to move out of the facility, Lynn moved into her own apartment in the community. She continues to struggle in finding direct support professionals. After just two weeks in her new apartment, a newly trained caregiver dropped Lynn during a transfer. She sustained two broken femurs that required surgery. At the time of this writing, Lynn was once again fearful she would be discharged back to a congregate care facility rather than her home in the community.

### **Debra's Story**

Debra is a 42-year-old Black woman who has been trying to transition to the community from a Chicago nursing facility for several years. In 2003,

she was injured during a violent crime. Her recovery was complicated by an infection, so she was admitted to a step-down facility, which she describes as between a hospital

and a nursing home, to receive treatment for her infection. Without warning, the step-down facility informed her she would be discharged to a nursing facility. Debra and her family wanted to research facilities to determine the best fit, but they were told there was not time, and she would be discharged immediately to the facility selected by the hospital. This was Debra's first admission to a nursing facility. For the next several years, she would rotate between hospitals and various congregate settings, including several rehab facilities and nursing homes.

In March 2020, Debra lived in a nursing home, but she wanted to live in her community. With the onset of COVID-19 conditions in her nursing

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*Systems collided as she could not apply for services for an address she did not yet occupy, but she could not move until services were in place.*

home deteriorated further. She states, "At first, they (the nursing home administrators) denied COVID and described the nursing home as mask-free." When Debra asked staff members to wear a mask while in her room, she was told the facility did not have enough PPE. Debra was not permitted to leave her room, and no one could visit her for more than 12 months.

Like Lynn, Debra described her reliance on her own technology, including her own hot spot, to stay minimally connected to the outside world. Debra said, "The nursing home Wi-Fi is unreliable. If I didn't have my own Wi-Fi, my own phone, and my own laptop, I'd be stuck." Even when visitation became available, her sister

was turned down for several reasons, like failing to show identification or mixed messages on whether testing, proof of vaccination, or both were needed at the time of visit.

Debra explained her own initial confusion with the nursing facility, "I used to believe that a setting like this would provide care, like therapy and nursing care. I can barely get someone to assist with toileting and sometimes have to wait

hours for that due to staff shortages." In her effort to transition back into the community, Debra has enlisted a wide range of supports. She works with a local nonprofit called Equip for Equality, her state's Ombudsman Program, and a national group that rescues and relocates

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***Debra was not permitted to leave her room, and no one could visit her for more than 12 months.***



people with disabilities from nursing homes into the community. Prior to the pandemic, Debra even filed a court case to appeal a medical decision made against her will. The judge came into the facility to render a decision and ruled in her favor. Debra is awaiting availability of an accessible housing unit and establishment of in-home nursing care. She is cautiously hopeful that someday she will be able to move back into the community but sees no immediate opportunity for such a transition.

Lynn and Debra's stories include barriers to community living echoed by convening session and interview participants. They are far from alone. A lack of reliable caregivers, poor hospital discharge planning, and a lack of quality in care received traps countless people with disabilities in dangerous living situations that could be improved with fortification of our HCBS system. Elements worsened by COVID-19 have added to these and other long-standing issues.

# Chapter 6: Six Focus Areas That Require Immediate and Simultaneous Change for an HCBS System That Meets the Needs of the Nation

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HCBS is an ecosystem. Each part of that ecosystem must be working to full capacity to meet the needs of throughout the country now, but also in the future where the continually increasing amount of people both disabled and elderly/disabled will grow and require appropriate community living options with necessary supports. The death toll of institutionalized people, both young and old, during COVID-19 clarified that our institutional bias is a failed model and our lack of investment in the various parts of the HCBS ecosystem contributed to that death toll and has prevented hundreds of thousands of people with disabilities on waiting lists from transitioning to community living. NCD proposes a plan that will establish a new paradigm: The Community Living Bias. Importantly, each of the actions should be addressed simultaneously to ensure that each part of the ecosystem is operating in a manner that is fully responsive to the other components of the system.

## Remove the Institutional Bias in Medicaid and Increase Funding for HCBS

The continued institutionalization bias created by the requirement that Medicaid programs

pay for nursing homes but not HCBS, makes it impossible to achieve the ADA's integration mandate. It is still too easy to institutionalize a person with a disability, younger or older, who has needs for direct care.

Federal legislation is needed to:

- increase funding for HCBS;
- create Community Living Bias by requiring Medicaid to cover a minimum, standard, set of HCBS services in every state;
- limit Medicaid program's ability to fund nursing home care;
- streamline HCBS waivers; and
- require states to maintain or increase HCBS with strong "maintenance of effort" (MOE) provisions.

## Build a Robust Direct Care Workforce

The lack of direct care workers has been longstanding and during the COVID-19 pandemic reached a "911" degree of urgency. Until we can recruit and retain a robust workforce of home health aides and personal care attendants to help people with disabilities live in their homes, the myriad of problems and dangers of congregate living for people with disabilities will

never be resolved. Rebuilding and expanding the workforce will take more than increased wages, however. Incentivizing entry into and elevating this work to a “profession” is critical to achieving this goal, though, for example, making direct care a Schedule A profession; creating apprenticeships and training opportunities; offering a career path and benefits such as health insurance, and requiring hazard pay and paid leave.

### **Increase the Supply of Accessible and Affordable Housing**

We cannot meet the nation’s need for community living and achieve an HCBS system sufficient to meet the needs of the hundreds of thousands waiting to transfer from institutions to the community if there without more affordable and accessible housing opportunities. We have no more time to lose—we must increase the supply of accessible and affordable housing. Part of this must be robust, proactive enforcement by HUD during design and construction phases of the development of housing built with federal financial assistance, and DOJ willingness to sue entities that violate federal requirements. The struggle for low-income people with disabilities to find housing is often impossible or delayed for years due to a lack of housing opportunities.

### **Improve Hospital Discharge Planning to Prevent Institutionalization or Reinstitutionalization**

As described in NCD’s 2019 report on *Ending Institutionalization of People with Disabilities During and After Disasters*, people with disabilities are at heightened risk of entering a congregate setting during and after a public health emergency, like the COVID-19 pandemic. Once they have entered a congregate facility,

including a hospital, it can be nearly impossible to get back out. Diversion or prevention of institutionalization is a critical priority. Hospital systems should approach discharge planning with home placement at the primary goal to prevent the unnecessary institutionalization of people with disabilities and should partner with independent living centers and state Medicaid HCBS to conduct discharge planning that prioritizes self-direction and case management support to navigate the complex web of services needed to solidify a safe and sustainable transition to the community. Joint efforts like that of the University of Colorado Health System and the Center for independent Living, described in this report, to provide the necessary supports for people with disabilities to return to their homes after hospital discharge, should be replicated by health systems across the nation.<sup>152</sup>

### **Maintain COVID-19 Flexibilities Such as Appendix K and Section 1135 Waivers**

The long existent direct care workforce shortage which grew worse during the pandemic because of the extreme contagiousness of the virus, left many people with disabilities who were living in the community without home health and personal care aids needed to remain uninstitutionalized. Unpaid family caregivers have been a constant part of the HCBS ecosystem, keeping loved ones cared for but not being paid to do so, causing impoverishment and a lack of respite, among other things. Medicaid authorities, such as state plan services and waivers, were utilized to pay family caregivers, preventing further spread of the virus, alleviating the direct care workforce crisis, and helping families maintain some income. These flexibilities

should remain permanently—family caregivers should be paid, and CMS should make this a permanent to support the nation's need for a strong HCBS system.

### **Improve Data Collection on Residents in All Congregate Settings**

Every life lost in a congregate setting was valuable, but failures in data collection about people with disabilities in all congregate settings means that we will never know the accurate death count of people with disabilities or their

caregivers who died from COVID-19 in these settings. The failure to collect data on people with disabilities in all congregate settings is part of a larger failure by government to collect data on people with disabilities in a manner comparable to other populations and continues the harms stemming from inequitable treatment and devaluation. In order to plan interventions and understand the populations residing in congregate settings, consistent data gathering by the federal government should be done across all congregate settings, for all ages and disability types.



# Recommendations for Implementation

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## Congress

- Enact legislation that ends the institutional bias in Medicaid by make HCBS a mandatory Medicaid service with a minimum, standard set of services under 1905(a) and create a new, single, HCBS authority to alleviate the complexity and administrative costs associated with so many different programs. The legislation should: align financial eligibility pathways and replace enrollment caps with functional eligibility criteria; make Medicaid portable across state lines.
- Require CMS to make permanent the authority of states to pay family caregivers through Appendix K and 1135 Waivers. This saved lives and avoided institutionalization of people with disabilities during the COVID-19 public health emergency and was responsive to the direct care workforce shortage.
- Enact legislation that includes significant funding for Home and Community Based Services similar to the proposed funding in the Build Back Better Act which proposed \$150 billion to HCBS, and increased pay for the direct care workforce, to allow individuals to live in the community.
- Pass the Fair Housing Improvement Act of 2022—*A bill to amend the Fair Housing Act to prohibit discrimination based on source of income, veteran status, or military status, to provide more housing opportunities people with disabilities, enabling more people to transition from institutionalized settings to the community, and supporting the nation's HCBS system.*
- With significant input from all stakeholders, enact legislation to require private health insurers and health plans to over a minimum set of defined-HCBS services.

(continued)

## **Congress: *continued***

- Congress should require the Department of Labor to immediately devise a plan to address the direct care workforce labor shortage by, for example, creating apprenticeship programs to incentivize individuals to become direct care workers; setting and raising standards for pay, benefits, and working conditions.
- Congress should enact legislation requiring the Department of Citizenship and Immigration Services to establish a new Employment-Based Immigration Visa with a specific preference for direct care workers.
- Congress should require HUD to proactively monitor new housing units constructed with HUD funding to ensure that the required percentage of accessible units required under federal law are actually constructed and constructed in accordance with federal accessibility standards. This is necessary to increasing the desperately needed affordable, accessible housing supply by avoiding the prolonged process of retrofitting units and litigation to correct the failure to construct, or wrongly constructed, units.
- To enable HUD to increase its ability to monitor compliance with newly constructed housing, substantially altered housing, housing with other alterations, and program accessibility, Congress should increase HUD's appropriation to fund at least one compliance specialist in each of HUD's ten regional offices. These staff would have expertise in construction and federal regulations on housing accessibility and proactively monitor federally financed housing construction in the ten federal regions.
- To enable HUD to broaden its efforts at compliance with both Fair Housing Act Accessibility Standards and Section 504 requirements, Congress should increase HUD's appropriation to fund a pilot program to engage local planning and codes compliance departments across the United States in identifying potential federal accessibility issues in new construction, substantial alterations, housing with other alterations, and existing housing. This can be done by funding contracts and cooperative agreements that include training localities in federal accessibility standards and requirements.
- Congress should assist HUD in increasing the stock of accessible housing by increasing its appropriation to fund a Home Modification Fund Program or Home Modification Voucher to assist people with disabilities to make modifications to their existing homes. This will help people avoid institutionalization if they become disabled and live in an inaccessible home and open housing opportunities for people with disabilities who are transitioning out of institutions that require accessible housing.

## **Congress: *continued***

- Congress should pass visitability legislation that requires developers to offer home buyers visitability (barrier-free access to first floor) options in all newly constructed homes.
- Pass the REAAIDI for Disasters Act and the Disasters Relief Medicaid Act (DRMA). Both bills require the inclusion of people with disabilities in emergency preparedness and response. DRMA aims to ensure individuals who live in disaster areas maintain access to Medicaid services, including Home and Community-Based services, if they are forced to relocate to another state.
- Congress should appropriate funds each year to the HHS Administration for Community Living (ACL) to fund nursing home transition services provided by Centers for Independent Living (CILs).
- Congress should appropriate funds each year to the ACL to fund emergency management services provided to people with disabilities by CILs.
- Congress should commission a special bi-partisan committee to investigate the local, state, and federal governmental failures during the pandemic that lead to the disproportionate deaths of those residing in congregate settings.
- Congress should require HHS to work with state, local, Tribal, and territorial health departments to track and report the health and health status and outcomes of people in congregate settings.

## **U.S. Department of Health and Human Services (HHS)**

### **National Institutes of Health (NIH)**

- Ensure people with disabilities in congregate settings continue to receive prioritized access to testing and early vaccination during any similar health emergency, including additional doses and boosters.

### **HHS Office for Civil Rights**

- Clarify that people with disabilities in all congregate settings have the right to receive care from vaccinated providers.

## **Centers for Medicare and Medicaid Services (CMS)**

- Standardize quality assurance systems for smaller census settings prioritized for transition from larger institutions to community living. Pilot models that expedite this transition and sustainable living in the community.
- Work with the Administration on Community Living to lead federal alignment in defining long-term settings to include the full range of congregate settings, including small census groups.
- Work with the Administration on Community Living to identify which COVID-19 measures merit permanent inclusion in state Medicaid plans based on their positive impact on community living. The Appendix K Waiver allowing paid family caregivers was instrumental in saving lives by keeping people with disabilities in their homes and should be made permanent for this reason and because it is a response to the direct care workforce shortage.
- To reduce the potential for Home Health Agencies to avoid caring for high-cost beneficiaries, CMS should correct for any unintended consequences caused by payment and quality incentives that discourage serving Medicare beneficiaries who require multiple episodes of care, are admitted from community settings, or have a limited potential to improve. This includes ensuring that risk stratification methodologies adequately capture the costs of providing care, particularly for those with chronic illness or cognitive deficits, and reflect services provided by home health aides and clinical social workers.
- In conjunction with the Department of Labor, or separately, establish a public private partnership that matches federal dollars with productive private capital to increase funding for HCBS and increase wages and benefits for direct care workers.

## **Department of Labor (DOL)**

- Designate home health aides and direct support providers as a “Schedule A” shortage Occupation.
- Devise a plan to address the direct care workforce labor shortage by, for example, creating apprenticeship programs to incentivize individuals to become direct care workers; setting and raising standards for pay, benefits, and working conditions.

## **Department of Labor (DOL): *continued***

- Establish, with the Department of Education, grants for community colleges to provide career training/courses on direct service to address the current and growing need for direct service workers.
- In conjunction with the Centers for Medicare and Medicaid Services (CMS), or separately, establish a public private partnership that matches federal dollars with productive private capital to increase funding for HCBS and increase wages and benefits for direct care workers.
- Collect data on home health care workers to track worker trends over time and help policy makers identify areas for improvement of the profession and career development.

## **Department of Citizenship and Immigration Services**

- Create a new Employment-Based Immigration Visa with a specific preference for direct care workers and work with the Department of Labor and the Centers for Medicare and Medicaid Services to inform employers, including home health agencies nationally.

## **U.S. Department of Housing and Urban Development (HUD)**

- As a part of federal implementation of Section 504, HUD is obligated to collect assurances of compliance with Section 504, including the accessibility requirements. HUD should undertake a review of its various grant programs to ensure that it is collecting appropriate programmatic and construction assurances and provide guidance to grantees to ensure they understand what this means for new construction, substantial alteration, other alterations, and program access, as well as obligations related to nondiscrimination, reasonable accommodations, effective communication, among others.
- To decrease the multi-year wait for affordable, accessible housing, HUD should amend its Section 504 regulation to increase the percentage of fully accessible housing units required in multifamily housing under its Section 504 regulations from 7% (5% mobility disability and 2% hearing and vision disability) to 25%, with at least 20% mobility units to accommodate the existing disabled population in need of housing and the growing population of elderly disabled.
- To increase the national supply of affordable, accessible housing units, HUD should amend Section 8.56 of its Section 504 regulations to require HUD to conduct compliance checks during the construction phase to ensure that accessible units are being constructed. This amendment would require HUD to conduct such checks proactively without need for an instigating event.

*(continued)*

## **Department of Labor (DOL): *continued***

- To increase transparency and assist people with disabilities to locate accessible housing units, HUD should amend its Section 504 regulations to require recipients of HUD financial assistance to maintain a publicly available list of accessible units with a description of their accessibility features.
- To increase its ability to monitor compliance with newly constructed housing, substantially altered housing, housing with other alterations, and program accessibility, HUD should request an increased appropriation to fund at least ten compliance specialists to staff each regional HUD office. These staff would have expertise in construction and federal regulations on housing accessibility and proactively monitor federally financed housing construction in the ten federal regions.
- HUD should request an increase in its appropriation to broaden its efforts at compliance with both Fair Housing Act Accessibility Standards and Section 504 requirements by piloting a program to enlist local planning and codes compliance departments across the United States in identifying potential federal accessibility issues in new construction, substantial alterations, housing with other alterations, and existing housing. This can be done by funding contracts and cooperative agreements that include training localities in federal accessibility standards and requirements.
- HUD should request an increase in its appropriation to increase the stock of affordable, accessible housing by establishing a Home Modification Fund program or voucher to assist people with disabilities to make modifications to their existing homes. This will help people with disabilities avoid institutionalization and open housing opportunities for people with disabilities who are transitioning out of institutions, and who require accessible housing.
- HUD should increase number of vouchers specifically designated for people with disabilities transitioning from institutions to support the ADA integration mandate and the Supreme Court's *Olmstead* decision.

## **U.S. Department of Homeland Security**

### **Federal Emergency Management Agency (FEMA)**

- Recognize people with disabilities in congregate settings or at-risk of institutionalization as a population of comparable risk to people who are currently homeless.

### **U.S. Department of Homeland Security: *continued***

- Require that all emergency shelters in the United States that receive FEMA funding, are fully accessible to people with disabilities, to avoid institutionalization after disasters or public health emergencies.
- Engage with disability stakeholders at multiple levels before, during, and after disasters like the COVID-19 pandemic.
- Provide guidance, training, and oversight to State, Local, Tribal, and Territorial entities (SLTTs) regarding the implementation of “Addendum: Delivering Personal Assistance Services in Congregate and Non-Congregate Sheltering.”
- Amend regulations to recognize disaster impacted CILs in the Public Assistance Program and Policy Guide as private non-profits, eligible for reimbursement,
- Clarify the process for disability organization to be funded and reimbursed by SLTTs in the Public Assistance Category B Emergency Protective Measures reimbursement process.

### **Local and State Governments**

- Create a home modification fund for residents who wish to remain in their homes but are at risk of institutionalization due to disability/illness that makes their current home inaccessible, or those in institutions that are transitioning to the community and need accessibility features to do so. Advertise this broadly to include Independent Living Centers and Medicaid Agencies.
- Provide training on the Fair Housing Accessibility Guidelines and HUD Section 504 regulation for all reviewers of plans for multifamily construction and inspectors of new multifamily construction, to assist in early identification of violations.
- Local governments, especially cities, can utilize models like Berkeley, California to fund back-up attendant care services, accessible transportation, and wheelchair repair services with city tax revenue. These services are critical for those living in the community and increase opportunities for people with disabilities to travel to the area.

*(continued)*

### **Local and State Governments: *continued***

- Restructure state departments for aging and disability to streamline state and federal funding for long-term services and supports in a newly created Department of Community Living (DCL). This new department would support community-living for people with disabilities and aging populations, regardless of income and need. Structural reorganization should focus on coordinated, integrated HCBS delivery that is not siloed by age.
- Utilize 1115 waivers (approved by CMS in 2017) to expand access to HCBS services to divert people with disabilities considered “pre-Medicaid” from institutional settings.

### **Hospitals and Hospital Systems**

- Hospitals and hospital systems should improve discharge planning to consider community living options first and should create partnerships with independent living centers like the private partnership between the University of Colorado Health system and The Independence Center (local CIL)<sup>153</sup> and state Medicaid HCBS staff, to leverage their resources to obtain the supports necessary return home or to community settings.

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**National Council on Disability**  
**1331 F Street, NW, Suite 850**  
**Washington, DC 20004**