

The Case for Inclusion 2022

Blazing Trails to Sustainability for Community Disability Services



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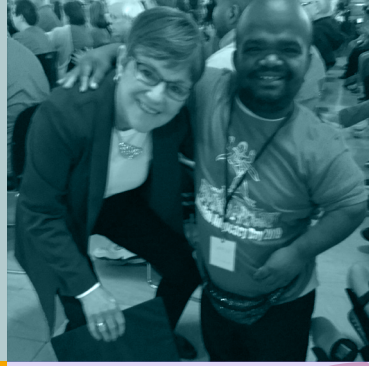


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FOREWORD

As the COVID-19 pandemic lingers, the system of care for people with intellectual and developmental disabilities (IDD) remains in crisis. In many ways, this crisis is far worse than before the pandemic, with the direct support workforce shortage threatening access to long-term services and supports for people with IDD and with hundreds of thousands of people with IDD on states' waiting lists to receive services that have the potential to significantly enhance their quality of life.

For decades, the US has witnessed a significant shortage of direct support professionals (DSP) due to stagnant Medicaid reimbursement rates and the rising cost of care. For some time now, the inability of service providers to offer competitive wages has meant losing qualified workers to other hourly wage industries, such as fast food, retail and convenience. With the pandemic having wreaked havoc on the broader labor market, private industries like these were able to pivot by offering increased wages and hazard pay. In turn, community disability service providers—which rely almost exclusively on Medicaid funding—were left struggling to sustain operations and without solutions for retaining their workforce.

For community IDD providers, crisis is nothing new. But the COVID-19 pandemic brought new challenges and added new contours to existing crises. The very nature of supporting people—often in their homes—requires close contact. With close contact came the need for capacity limitations, personal protective equipment (PPE), ongoing testing, technology to facilitate remote supports, overtime wages to cover the shifts of quarantined workers and more—all of which have driven costs sky-high.

Compounding these pressures was the realization that people with IDD are at increased risk of severe illness from COVID-19. Research has

consistently demonstrated that although people with IDD are no likelier than their peers in the general population to contract COVID-19, they are about twice as likely to die in the event that they become infected.¹ This reality drove community service providers to take even more seriously the responsibility of ensuring the health, safety and well-being of those relying on their support.

As they always do, providers and other advocates rose to the occasion, fighting to ensure people with IDD and the DSPs on which they rely were given priority access to vaccines, testing and PPE—all while reminding lawmakers about the ways in which decades of underinvestment in Medicaid-funded services made this system more vulnerable to the public health emergency.

At the same time, there have been some ways in which—no matter how dedicated—providers simply cannot make any more magic than they already have. Surveys of ANCOR's 1,800+ provider members have indicated that the increased costs of delivering high-quality care combined with an exodus of DSPs from the field have forced community providers across the nation to stop accepting new referrals, delay the implementation of new programs and, in too many instances, shutter existing services altogether.²

Furthermore, services that were once moving toward more individualization have seen their progress stalled or have even regressed, with providers moving to smaller group services out of necessity.

These compounding challenges don't just matter for the 7.43 million people with IDD in the US—they matter for the 2.4 million home care workers and the families who rely on their income.³ Between providers' rising expenses and states' stagnant reimbursement rates, the average hourly DSP wage has hovered for several years between \$12 and \$12.50.

This injustice comes into especially sharp contrast when considering who comprises this workforce: 63% are Black, indigenous or people of color.⁴ This means that the professionals of color supporting people with IDD on the frontlines are disproportionately reflected in the one in six home care workers who live in poverty and the 53% who rely on some form of public assistance despite working full time—a hidden cost of our failure to invest. Thought of another way, investing in the direct support workforce means investing in a more equitable economy.

The effects of these challenges aren't hard to imagine. More families than ever are languishing on states' waiting lists for HCBS services. State and federal regulations that foster independence, such as the federal HCBS Settings Rule, remain in holding patterns. Whereas jobs supporting people with disabilities were seen a generation ago as middle-class jobs—or at least pathways to the middle class—providers now report that they're losing workers to fast food restaurants and gas stations at higher rates than before. Meanwhile, fewer people with disabilities than before are finding meaningful work. And people who once had options for how to spend their days in meaningful ways are seeing the effects of long-term isolation as too many day programs remain shut down, even two years into the pandemic, due to inadequate staffing.

Rather than being reasons why providers and advocates are left feeling jaded, these harsh realities are the very reasons we continue to fight. In just the past year, the Medicaid HCBS program has commanded a new legislative focus. From laws like the American Rescue Plan to proposals such as the Better Care Better Jobs and Build Back Better Acts, our advocacy has paved the way for heightened awareness about the need for the direct support workforce crisis to be defined, measured, prioritized and solved. If there's a silver lining, it is that a significant amount of new funding has already been delivered and more is on its way, offering a

beacon of hope after years of darkness. Since its inception, the *Case for Inclusion* has highlighted national and state-specific data illustrating the extent to which programs are supporting people of all abilities to be included in their communities. In our most recent release in 2021, however, we placed less emphasis on data and more emphasis on policy solutions, in large part because extant data couldn't begin to account for the impact of COVID-19 on community services. Nevertheless, with the 2021 release, we seized the opportunity to build a blueprint for a more sustainable future.

The lack of data about the impact of the pandemic on programs supporting people with IDD remains true, with the best available data not yet fully capturing how COVID-19 has amplified long-standing crises in our system. But data—and the powerful stories behind the data—are more important than ever. Therefore, the approach we've taken to the 2022 edition of the *Case for Inclusion* is a marriage between our 2021 format and the approaches we took previously. This year's report, along with its many accompanying resources, pairs data depicting barriers to community inclusion with sensible policy solutions designed to overwhelm the dual crises that define community services in the current era.

We journey into this next chapter with a sense of cautious optimism. Indeed, despite not fully reflecting the impact of the pandemic, the latest available data paint a grim picture of the state of community inclusion in America. But we know that a more sustainable system is in our future because of the relentless advocacy of people like you, our reader. To hasten our progress toward that future, this report and its accompanying online tools are designed to strengthen your advocacy through 2022 and beyond, so that we may together build a system that sits on an unshakeable foundation of community inclusion for people with disabilities.

EXECUTIVE SUMMARY

The *Case for Inclusion 2022* tells the story of community IDD services in two parts: one focused on the cracks and faults in the current system, and one focused on policy objectives for rebuilding a foundation of inclusion. Part 1 is intended as a data-driven review of the extent to which state programs are supporting people with IDD to be included in the community, while Part 2 builds on the challenges outlined in Part 1 to deliver specific action plans tailored to a range of actors. We offer a brief interlude between these two main sections to reflect on the need for more intersectional data to truly understand how key challenges play out differently for people representing diverse communities.

The Challenges

Part 1 of this report leverages the best available data over four of the *Case for Inclusion's* issue areas: Addressing a Workforce in Crisis, Promoting Independence, Promoting Productivity and Tracking Health, Safety & Quality of Life. Among its many findings, the *Case for Inclusion 2022* finds that:

- Nationally, the average DSP turnover rate in 2020 increased by about one percentage point to 43.6%. Meanwhile, vacancy rates for full-time direct support positions increased from 8.5% in 2019 to 12.3% in 2020—a roughly 45% increase.
- As of 2018, 16 states and the District of Columbia had closed their last remaining large, state-run institutions. Joining the ranks of states to have fully deinstitutionalized since last time the *Case for Inclusion* reported these data are Montana and Tennessee.

- 1 in 5 (21.1%) people with IDD who received employment or day supports were participating in an integrated employment service. Within the 33 states that report that they collect data on the number of people working, 19.3% of individuals participating in integrated employment services were working for pay.
- There were 589,940 people on states' waiting lists for home- and community-based services nationally. Nearly 4 in 5 (78%) of those waiting were concentrated in just five states.

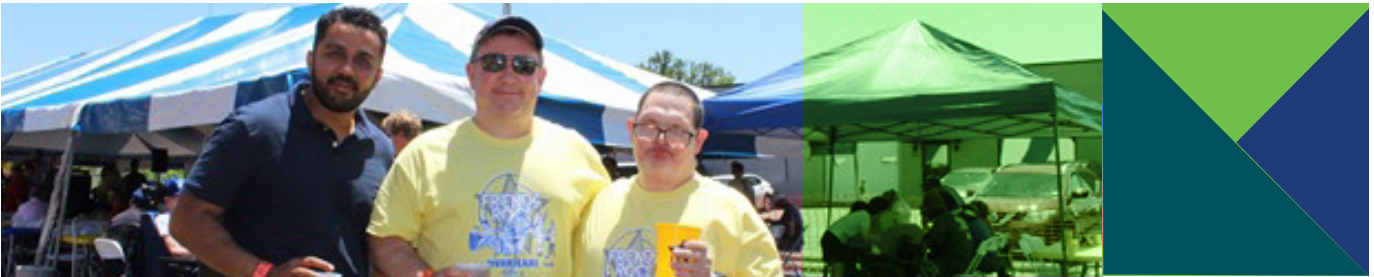
Because this key findings report cannot cover every data point across all 80 measures contained in the *Case for Inclusion's* seven main issue areas, we invite you to learn more and explore the data at caseforinclusion.org.

The Solutions

Part 2 of this report pivots to recommend solutions and opportunities for the federal and state legislative and executive branches, along with providers and other advocates, to strengthen the ability of people with IDD to live a fully inclusive life in the community. The following is a brief overview of the recommendations that are detailed in Part 2 of this report.

The *Case for Inclusion 2022* maintains that the Biden Administration should:

- Incentivize states to use federal funding to address each component of the workforce crisis.
- Require the Centers for Medicare and Medicaid Services (CMS) to include HCBS under the equal access rule.
- Require the U.S. Department of Labor to establish a Standard Occupational Classification (SOC) for DSPs through the U.S. Bureau of Labor Statistics.



The Case for Inclusion 2022 maintains that the 117th Congress should:

- Appropriate funding to rebuild the DSP workforce, as well as the broader HCBS infrastructure.
- Prioritize funding to incentivize the development of DSP pipeline programs.
- Predicate state funding opportunities on commitments to review and adjust payment rates at least once every three years.
- Compel the U.S. Bureau of Labor Statistics to establish a SOC for DSPs.

The Case for Inclusion 2022 maintains that states should:

- Apply for each federal funding opportunity targeting supports and services for individuals with IDD and focus spending plans on stabilizing the direct support workforce crisis.
- Adjust reimbursement rates in the immediate term; then enact legislation or regulations to guarantee regularly recurring reimbursement rate reviews to ensure DSP wages are competitive against other industries.
- Prioritize people with IDD and the community providers that support them in the distribution of tools for mitigating the risk of COVID-19, including vaccines, testing and PPE.

The Case for Inclusion 2022 maintains that providers and other advocates should:

- Advocate with state and federal leaders to ensure community providers and people with IDD can access life-saving tools to provide support and adapt through the COVID-19 pandemic.
- Stay current with and apply for state and federal funding opportunities created to offset the impact of COVID-19.
- Urge state leaders to leverage federal funding opportunities to stabilize the direct support workforce crisis by increasing reimbursement rates and creating systems of review to ensure rates keep pace with inflation, rising minimum wages and other drivers of increased labor costs.
- Encourage states to develop and contribute to as deep an understanding of the workforce crisis as possible by participating in the NCI Staff Stability Survey.

Not every policy objective impacting the lives of individuals with disabilities is discussed in this report. There are always opportunities to do more, and an understanding of the situation in your state is often the most meaningful source of policy innovation. For these reasons, we encourage you to visit caseforinclusion.org to access full datasets, policy and advocacy checklists, and other resources to strengthen your advocacy.

PART 1: THE SCOPE OF THE CHALLENGES TO INCLUSION FOR ALL

A Note to the Reader



The data snapshots found in Part 1 on this report include highlights of key measures within four of the *Case for Inclusion's* seven issue areas. To find comprehensive data for the full set of 80 measures spanning all seven issue areas, please visit caseforinclusion.org.

The vast network of providers of community IDD services in the United States is nothing if not diverse. Community providers operate in a variety of different ways, deliver a wide array of long-term supports, and serve people whose hopes, dreams, aspirations and needs are all unique. At the same time, community providers share much in common: significant challenges recruiting and retaining DSPs, triggered by decades of underinvestment in Medicaid and exacerbated by the COVID-19 pandemic.

If there were such thing as a typical provider, United Cerebral Palsy of Georgia might fit the bill. With two pandemic years compounding its recruitment and retention struggles, UCP of Georgia lacks enough personnel to keep all of its group homes fully operating. Therefore, it has been forced to implement a plan wherein a group home is closed temporarily so staff can be redirected elsewhere. During the closures, which last 60-90 days, the people living there either stay with family members or move to a different home on a temporary basis.

Diane Wilush, Chief Executive Officer for UCP of Georgia, emphasized how reluctant she was to implement this plan, recognizing the disruptive impact it can have for the people living in the temporarily shuttered homes. “There is nothing great about this plan,” Wilush says, “but temporary disruptions spread across a slightly larger segment of our operations is better for the people we support than permanent displacement would be.”

Wilush also noted that she's eager to abandon this strategy as soon as her organization is able, given how the DSP workforce crisis is interfering with the mission and values of the organization. One impact is that UCP of Georgia cannot accept any new referrals. “We exist to support individuals,” Wilush explains. “However, returning to operations that look more normal would require assuring each home we offer has at least 5-7 direct support staff, something that is simply impossible considering that we have 120 vacant DSP positions. That's fully a third of our DSP workforce.”

So how did organizations like Wilush's get to this point? Decades of underinvestment in our services have challenged access to support for the entirety of the 21st century and, in many states, years beyond that. Community-based providers rely almost exclusively on reimbursement rates fixed by state Medicaid programs to cover the costs and necessities of delivering high-quality community-based supports and services to people with IDD. Despite how the cost of labor continues increasing—especially in our current period of heightened inflation and heightened demand for services—reimbursement rates across the US have remained largely stagnant. In turn, community providers are left operating at significant deficits and are now struggling to stay afloat.

Low reimbursement rates and the depressed DSP wages they trigger are at the core of almost every issue facing the disability services system. Depressed wages subsequently lead to high turnover and vacancy rates. In the short term, this means instability and inconsistency of staffing, which presents barriers to the ability of people with IDD to leverage person-centered supports, live independently and be included in the community. In the longer term, this means that providers are unable to sustain appropriate staffing levels to maintain operations, resulting in permanent closures or discontinuations of specific programs and residential supports and, in the worst cases, entire provider agencies going out of business. With

fewer providers operating fewer programs, fewer people with IDD have access to services that meet their needs in the community.

Of course, the COVID-19 pandemic only created new pressures and hazards that further exacerbated this longstanding workforce crisis. The close-contact nature of providing direct support puts DSPs at greater risk of contracting and spreading COVID-19 to the people in their care. In many cases, this led DSPs to quarantine with the people they support to help keep them safe, but these efforts to go above and beyond were rarely compensated. Whereas many workers in the private sector received hazard pay or could work remotely to avoid infection, DSPs found themselves on the frontlines earning less than they would on unemployment benefits. In turn, DSPs left the field in droves for better-paying positions that carried less risk in hourly-wage industries such as gas stations, fast food and convenience stores.

Although it will be years before we fully understand the extent of the pandemic's impacts, a range of recent research illustrates how the pandemic is exacerbating the issues facing community IDD services. In *The State of America's Direct Support Workforce Crisis 2021*, ANCOR surveyed community providers to quantify the impact of the COVID-19 pandemic on the DSP workforce.⁵ The survey found that as of fall 2021, 77% of providers were turning away new referrals and 84% were delaying the launch of new programs and services due to lack of staffing. Additionally, more than half of respondents indicated that they had discontinued programs or service offerings due to insufficient staffing, representing a 70.6% increase since the beginning of the pandemic.

Survey results further indicated that one in three (29%) providers have spent more than \$500,000 annually in costs related to high turnover and vacancy rates, while more than 1 in 6 respondents reported spending in excess of \$1 million annually. With 92% of providers in agreement that the COVID-19 pandemic continues to deeply impact their ability to hire and retain DSPs, the ongoing

costs of labor and resources are simply too severe for some providers to stay afloat.

At the end of 2020, the emergence of COVID-19 vaccines promised hope for combating the pandemic and mitigating the risks facing people with IDD and direct care workers. From the onset, advocates fought diligently to ensure people with IDD and DSPs were prioritized in vaccine distribution—steps most states ultimately took. Despite this, a recent survey conducted by the University of Minnesota and the National Alliance for Direct Support Professionals found that only 69% of DSPs nationally and as few as 60% of DSPs in select states were fully vaccinated against COVID-19.⁶ Among unvaccinated respondents, 54% reported they did not feel the vaccines were safe, 22% reported they did not feel they needed to get vaccinated, and 21% reported they did not believe in the worth of the vaccines.

As our nation continues to grapple with COVID-19, the direct support workforce crisis poses an even greater threat to the future of services. Without a strong and stable DSP workforce, too few people will have access to the system of community-based IDD services. To better understand the depth of the cracks in this system, the remainder of this section offers a series of four data snapshots, each corresponding to one of the main issue areas that comprise the *Case for Inclusion 2022*.

To be sure, the data highlighted in the sections that follow—though the most recent available—do not adequately capture the extent to which the COVID-19 pandemic is exacerbating the workforce crisis and complicating access to community-based services. We are just beginning to glean a deeper sense of the impacts of the pandemic, and we anticipate being able to tell a more comprehensive story in future editions of this report. However, we use the best-available data to offer these snapshots as a way of illustrating how the workforce crisis is playing out across the country and what it means for the people whose access to services can make or break their ability to be included in the community.

Data Snapshot: **Addressing a Workforce in Crisis**

DSPs assist people with IDD to live a self-determined life in the community of their choosing with as much independence as possible. This includes delivering a range of services, from assistance with sensitive activities of daily living, to supporting the establishment of meaningful relationships, to career planning for long-term integrated employment. Whereas a range of industries in the US now face significant shortages of workers due to COVID-19, the shortage of workers in the direct support sector reached crisis levels well before the pandemic.

COVID-19 disruptions have resulted in significant challenges for states' developmental disabilities systems, including program closures, DSP turnover, dislocation of people receiving services and other challenges within the DSP workforce. Data from the National Core Indicators 2020 Staff Stability Survey and its COVID-19 Supplement from 2020 provide a graphic picture of these issues and the challenges faced by staff, providers and state agencies during the first year of the pandemic.⁷

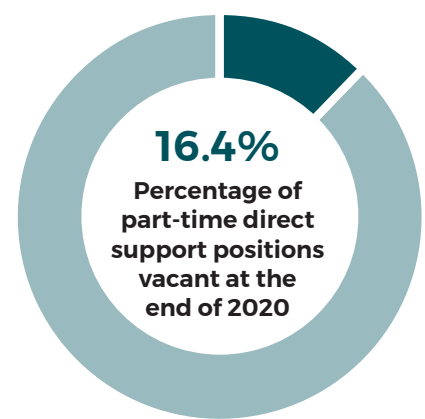
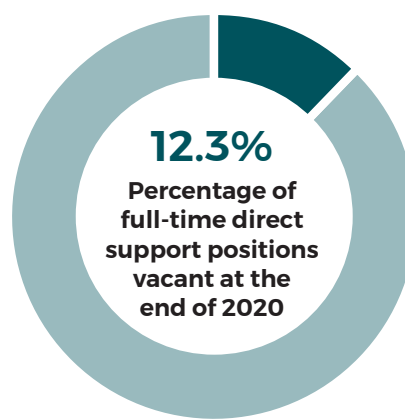
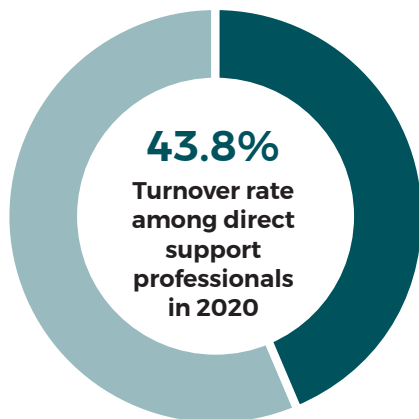
Almost one fifth (18.7%) of responding providers put DSPs on furlough during 2020. This percentage varied significantly by state, with

5.3% of providers in South Carolina reporting that they furloughed DSPs. On the other end of the spectrum, 31.7% of providers in the District of Columbia reporting they had furloughed DSPs.

Across states that included the COVID-19 Supplement in their data-collection efforts, one-third of agencies reported having closed locations or sites in response to the COVID-19 pandemic. Almost half (47%) reported stopping the delivery of some supports either temporarily or permanently. About 15% reported paying family members to serve as support providers during the pandemic.

In terms of wage bonuses or salary increases to retain DSPs during the pandemic, 38.3% of responding providers reported implementing at least one bonus for all DSPs, while 25.5% reported implementing temporary wage increases to all DSPs supporting adults with IDD. Roughly one quarter (24.8%) reported that no wage bonuses or wage increases were implemented for the purposes of retaining DSPs during the pandemic.

COVID-19 also added health risks for DSPs, but not all provider agencies had the ability to provide PPE to mitigate those risks.



Less than six in 10 respondents (58.9%) reported consistently having an adequate supply of PPE for DSPs and people receiving services in 2020. To increase, maintain or supplement their supply, 42.6% of responding agencies reported working with local or state emergency management or COVID-19 response entities to secure PPE, while 40% sought or requested donations of homemade PPE, 35.2% sought or requested donations of non-homemade PPE, and 57.5% paid significantly higher prices to purchase more PPE.

Providers reported the following changes in health and safety protocols to protect DSPs and those receiving services:

- **85.5%** reported requiring DSPs to wear masks or other PPE
- **79.2%** reported taking the temperatures of all people upon entrance to facilities
- **82.2%** reported the implementation of health and safety training related to COVID-19
- **51.4%** reported requiring COVID-19 testing for some or all DSPs

FROM THE FIELD

The Cascading Impacts of Discontinuing Services



Although high turnover and vacancy rates have always left providers scrambling, the cracks in the system have been made deeper by COVID-19—so much so that providers now worry about maintaining access to care for the people they support. The impact of inadequate staffing for the people who rely on community-based IDD services is probably obvious. As Kay Moore, Director of Adult Services for Arizona-based Accel, put it: “Eligible individuals are no longer receiving access to the services to which they are entitled.”

What may not be obvious, however, are the ways the pandemic is exacerbating the workforce crisis and the cascading impacts these dual crises are triggering every day for providers like Accel and countless others. Consider the recent Omicron variant, for example, which was highly contagious and swept through workplaces of all shapes and sizes. If one employee gets sick, others have to quarantine; in the worst cases, this means no one is available to staff day programs, deliver job coaching or work shifts in people’s homes or in group homes.

Moore describes that at her agency, these challenges can set off a domino effect. If a day program has to close or operate at limited capacity to maintain appropriate staffing ratios, for example, the people who would have otherwise been supported end up staying home with a family member. “But that takes yet another person out of the workforce, which is already hurting for employable adults,” Moore says. The impacts start expanding beyond the service provider into the broader community. “It feels like a never-ending cycle.”

Data Snapshot: **Promoting Independence**

People with IDD have a long history of unnecessary institutionalization. In a landmark decision for people with disabilities, the U.S. Supreme Court in *Olmstead v. LC* (1999) held that where community placement was appropriate, undue institutionalization of people with disabilities represents a form of discrimination prohibited under Title II of the Americans with Disabilities Act. Specifically, the court found in the *Olmstead* case that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”⁸

Unfortunately, high turnover and vacancy rates complicate people’s ability to leverage support to live where they choose, as well as states’ ability to close institutions and transition the people living there to home- and community-based settings. In the best-case scenarios, a community provider is located in or near the community of the person seeking home- or community-based supports and they have the capacity to accept new referrals. However, people with IDD are often forced to travel far distances to find a provider equipped to deliver services. And, in the worst-case scenarios, the person is left without any support at all, putting them at heightened risk for crisis and institutionalization or re-institutionalization.

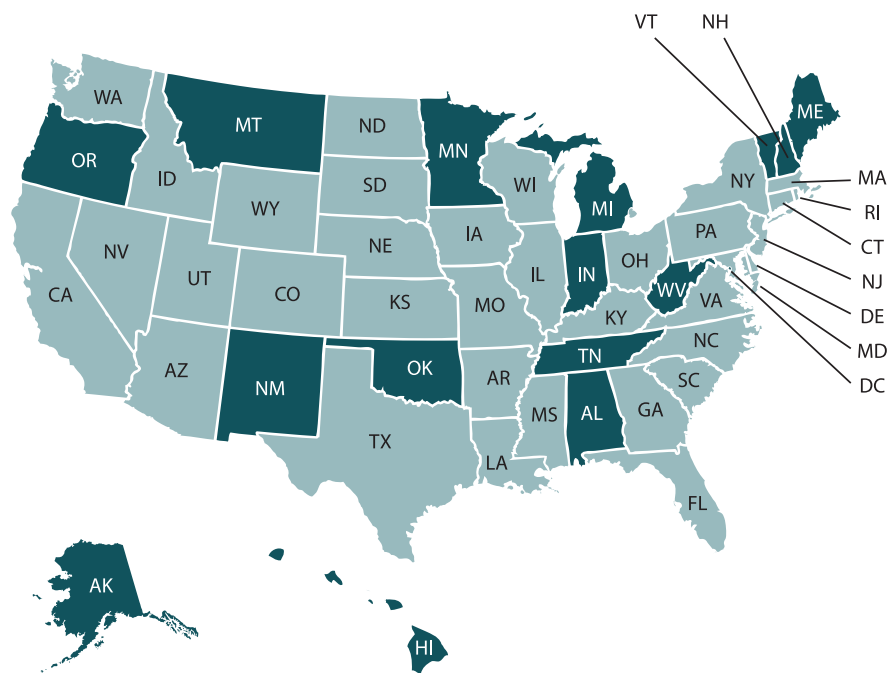
Public Residential Facilities, or PRFs, are large, state-operated institutions that warehouse people with IDD. According to the Residential Information Systems Project (RISP), an initiative of the Institute on Community Integration at the University of Minnesota, only 16 states and the District of Columbia had closed all of their PRFs as of 2018, with Montana and Tennessee joining the list since the *Case for Inclusion 2020*.⁹

Although fewer PRFs are operating now compared to just a few years ago, there were 115 PRFs still in operation as of 2018, according to the latest RISP data.¹⁰

Within the 36 states that still operated at least one PRF as of 2018, there were 17,557 people with IDD estimated to be living in these institutions, a nominal decrease compared to the year prior. States that had the largest number of PRFs in operation were Texas with 13, Ohio with eight and Illinois with seven. In terms of the number of people living in PRFs, Texas and Illinois had the dubious distinction of topping that list, with 2,969 and 1,664 residents, respectively, followed by New Jersey, with 1,325 people with IDD living in a PRF.

Although there can be a complex array of challenges preventing a state from closing its institutions and transitioning people into community-based settings, the reality is simple: without an adequate workforce, large, state-run institutions are too often the only choice people with IDD have regarding where to live.

STATES NO LONGER OPERATING PUBLIC RESIDENTIAL FACILITIES



Data Snapshot: **Promoting Productivity**

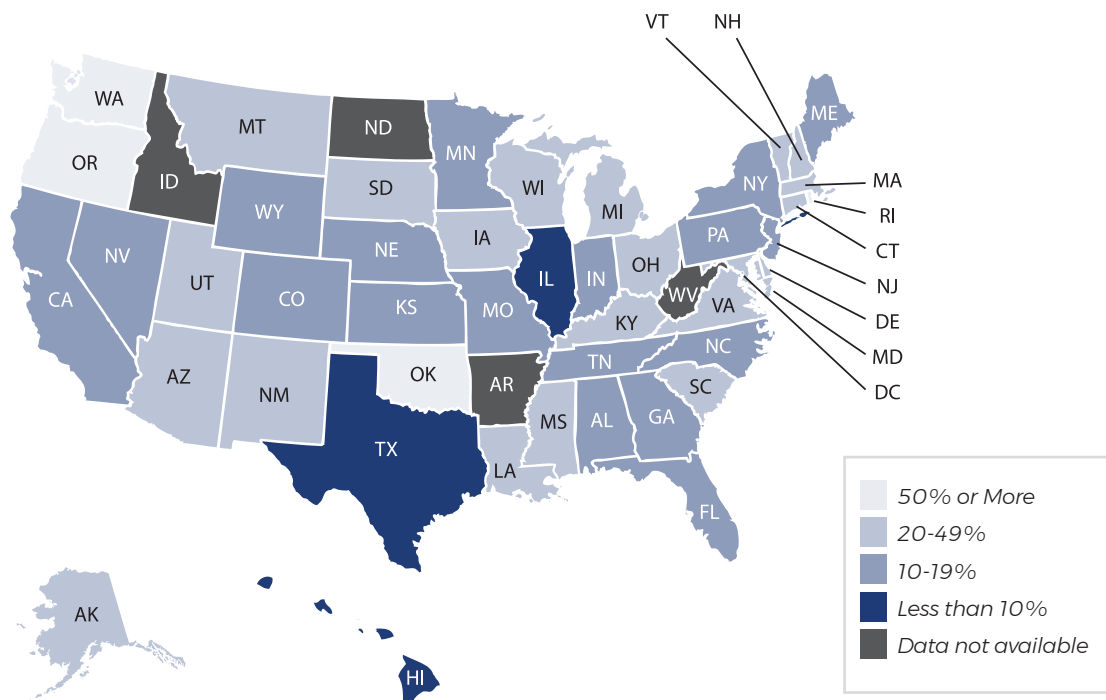
For all of us, the opportunity to work and contribute to a community of friends and colleagues is an important component of inclusion. Beyond earning a salary and benefits, work fosters connections forged through interest and circumstance that would not otherwise have been formed. But without access to support services, many people with IDD are excluded from the same work opportunities enjoyed by workers without disabilities.

Community providers offer an array of supports and services to assist people with IDD to obtain and maintain employment. Career planning and employment supports offer opportunities to explore potential work goals and assistance preparing for, getting to and sustaining jobs in the community.

According to data from the Institute for Community Inclusion at the University of Massachusetts Boston, in Fiscal Year 2018, slightly more than 1 in 5 (21.1%) people who received any employment or day service were participating in an integrated employment service.¹¹

A closer look at the data reveals that people with IDD are far from reaching parity with workers in the general population. In Program Year 2019, only slightly more than a quarter (27%) of people with intellectual disabilities who received services from their states' Vocational Rehabilitation (VR) programs had been rehabilitated within one year, meaning they became employed within 365 or fewer days from when they began receiving VR supports. Among the VR participants with an intellectual disability who became employed, the average number of hours worked each week was only 22—about half of what most industries consider a full-time work week.

PERCENTAGE OF PEOPLE WITH IDD PARTICIPATING IN AN INTEGRATED EMPLOYMENT SERVICE



The state where someone lives can play a significant role in the likelihood that they are receiving support to participate in integrated employment. On one end of the spectrum, there were four states—Washington (85%), Oklahoma (66%), Oregon (57%) and Rhode Island (52%)—where at least half of adults with IDD receiving day or employment services were receiving support to find or keep a job in their community. On the other end of the spectrum, 10% or less of adults with IDD in five states—Hawaii (3%), Texas (6%), Illinois (9%), Florida (10%) and New Jersey (10%)—were receiving a service to help them find or keep a job in the community.¹²

Underpinning these troubling outcomes is, once again, the workforce crisis. When providers lack an adequate number of qualified DSPs, they are forced to prioritize the basic essential needs of the people they support over those activities—like work—that enhance life in the community. Without consistent access to staff to provide transportation, job coaching and one-

on-one support, people with IDD have fewer opportunities to market themselves to employers.

This has been an area in which the COVID-19 pandemic has played an especially pronounced role, and we anticipate these abysmal numbers will look even worse once data for 2020 and 2021 are available. During the pandemic, many businesses that employed people with IDD were forced to shut down, and often, workers with IDD were the first to be furloughed or laid off. Even when those businesses began to reopen, the people with IDD who worked there might have been eager to return to work, but if staff at their employment program remained furloughed, workers may have lacked the job coaching needed to transition back to the workplace. As a result, prospects for working in the community that were extremely limited before the pandemic have likely been eroded further by the public health emergency.

FROM THE FIELD



Lockdown May Be Over, But Employment Programs Remain Shuttered

Early in the pandemic, countless workers with IDD were pushed out of the workforce by dual factors: closures of their places of employment during lockdown and the discontinuation of supported employment programs.

While the former of these proved to be mostly temporary, many supported employment program closures turned out to be long-lasting or even permanent. For Alaska-based Fairbanks Resource Agency (FRA), the supported employment program remains shuttered

due to inadequate staffing. Emily Ennis, FRA's Executive Director, indicates that the inability to maintain staffing levels has forced her agency's supported employment and day habilitation programs to remain closed. In some cases, people who were working before the pandemic have been unable to return to the workforce because they no longer have access to the job coaching they once relied on. In other cases, people eager to enter the workforce have been unable to do so because they lack the support needed to build skills or engage in interviews with potential employers.

In all cases, however, the impact is further isolation from the community. "Individuals have lost opportunities to work and participate in the community," Ennis says. "Initially, the problem was COVID—but now it's a lack of staffing."

Data Snapshot: **Reaching Those in Need**

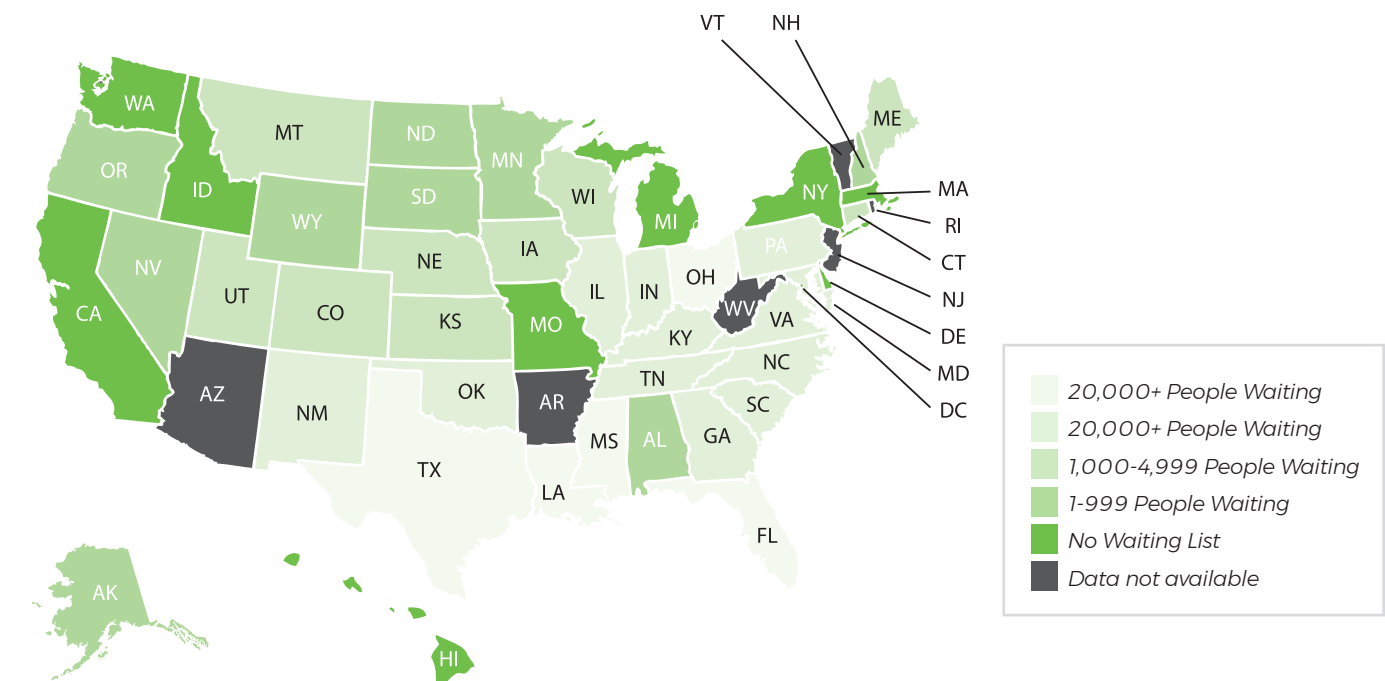
Elsewhere in this report, we have described how inadequate staffing inhibits providers' ability to support the full number of people in need in their communities. In these circumstances, states are often forced to create waiting lists for Home and Community Based Services. But even when a state allocates additional funding to serve the people languishing on the waiting list, that doesn't necessarily mean those in need of services can access them. When too few community providers have too few staff to support those being cleared from waiting lists, people are forced to either forgo services altogether or live in hospitals and institutions—assuming such settings are even available to them.

People on states' waiting lists can find themselves there for months and, more commonly, years, waiting for authorization to seek services. Families are rarely, if ever, provided a timeframe for when they can expect support to become available. How states manage their waiting lists to determine who gets cleared varies across the country; some states operate on a first-come, first-served basis, while others consider the extent to which people waiting are at risk for abuse, neglect and exploitation.

Meanwhile, states' waiting lists aren't a perfect measure of the scope of unmet need in a particular place. Confusion and fear can prevent families from undertaking the application process in the first place, while states' efforts to clean up their waiting lists or adjust eligibility standards can lead those in need to be removed from lists despite not receiving services after years of waiting. In other words, we use waiting lists to assess how many people would likely take advantage of community IDD services if offered them today, but we acknowledge that doing so underestimates the number of families in need.

As of the 2022 edition of the *Case for Inclusion*, there were 589,940 people on states' waiting lists for Home and Community Based Services according to the Kaiser Family Foundation.¹³ This marks an increase of nearly 117,000 since the publication of the *Case for Inclusion 2020*. Strikingly, more than 78% of people on states' waiting lists live in the five states with the largest waiting lists: Texas (323,434), Ohio (68,644), Louisiana (27,509), Florida (21,864) and Illinois (19,354).

NUMBER OF PEOPLE ON STATES' WAITING LISTS FOR HCBS (IDD) SERVICES



It should be noted that in addition to waiting lists being an imperfect measure of unmet need, waiting lists can obscure another reality, which is that the size of a waiting list isn't necessarily correlated to the number of people being supported. For example, a state that spends considerably less per person can maintain a smaller waiting list or none at all by offering less support to more people. Meanwhile, a state could offer higher levels of support to those receiving services, but in turn be forced to keep more people on the waiting list.

Further complicating the barriers to understanding the scope of unmet need in a state is the fact that waiting list data don't always permit apples-to-apples comparisons. For instance, some states might count all people with IDD awaiting services, while others may only count those waiting who have already been deemed eligible to receive services. Similarly, some states may not operate a waiting list in the traditional sense of the term but may have "planning lists" or "priority lists" that reveal there are, in fact, individuals and families seeking to receive some level of long-term services and supports.

Therefore, it is essential that states not only make investments that enable them to support more people, but also to enhance the support being offered to those already being served. But here again, states' ability to do so will demand a larger pool of qualified direct support workers, which will itself require deeper investments in the provider workforce.

FROM THE FIELD



Longer Waiting Lists, Longer Waits

A survey of 450 community providers fielded by ANCOR in 2021 found that 77% of providers were turning away new "referrals," meaning they were unable to support additional people beyond those already being supported, due to the direct support workforce crisis.

One such provider is United Cerebral Palsy of Stanislaus County. Chris Martin, the agency's Executive Director, explained that, "During the beginning of COVID, we closed all programs down and transitioned to an online model [for day supports]. We developed a plan to phase back into in-person supports, but we have yet to move onto Phase 2 because we cannot hire enough staff." Like so many providers, UCP of Stanislaus County has lost many long-time staff members who found better-paying opportunities elsewhere, and is finding it close to impossible to attract new staff who can find other industries where they can work fewer hours while earning better pay and benefits.

Providers being unable to take on new referrals means longer waiting lists—and longer waits for those waiting. Although Martin's organization supports people with IDD in California, which doesn't have a waiting list for HCBS services, UCP of Stanislaus County has had to start its own waiting list. "We are trying to keep in contact with people through technology, remote supports and home visits, but it's not the level of service we want to offer."

INTERLUDE:
WHY IT
MATTERS
THAT MOST
OF THE
NATION'S
DISABILITY
SUPPORT
PROFESSIONALS
ARE WOMEN
OF COLOR

*By: James E. Garcia,
United Cerebral Palsy*



As in previous years, the *Case for Inclusion 2022* reports on the major industry and workplace challenges that for decades have plagued the country's estimated 1.3 million direct support professionals, while also recommending solutions on how to improve employment conditions for this critically important segment of our nation's overtaxed health care system.

As a supplement to this year's *Case for Inclusion*, this article takes a closer look at why it should matter to policymakers, advocates, researchers, politicians, people with disabilities and the public at large that nearly 60% of DSPs are people of color, mainly Black or Latino, and the great majority are women.

According to PHI, a national nonprofit that researches and advocates for direct care workers and the people they support, women were 87% of the nation's direct care workforce in 2019.¹⁴ This includes people who serve older adults and other populations, but also the DSPs who support people with intellectual and developmental disabilities, such as cerebral palsy, Down syndrome, spina bifida and a range of others.

According to PHI, a growing percentage of the country's direct care workforce consists of people of color. In 2019, direct care workers were 39% white, 32% Black, 19% Latino and seven percent Asian American Pacific Islander, with three percent from other groups. Notably, the percentage of white DSPs in this workforce dropped by 10% from 2009 to 2019.¹⁵

PHI Data & Policy Analyst Steven McCall indicates that among direct care workers, Hispanic women make up the fastest-growing segment. While the number of Black female direct care workers increased from about 906,000 to 1.4 million, or 60%, between 2009 and 2019, the number of Hispanic women in the field more than doubled, from about 418,000 to 888,000, a jump of 112%.

The percentage of immigrants is growing fast as well. They now account for at least one in four direct care workers in the United States, said McCall, and a large majority of that segment are women of color. McCall adds that the percentage of immigrant workers is almost certainly higher, given how difficult it is to count undocumented immigrants who get hired off the books.

Growing Intersections & "Data Oppression"

In a series of recent interviews about the expanding presence of DSPs of color, the range of topics discussed touched on the intersections between race, ethnicity, gender, poverty, education, employment, disability and the lack of sufficient data in many of these categories.

Dr. Bonnielin Swenor is Director of the Disability Health Research Center (DHRC) at Johns Hopkins University. She's been a vocal critic, especially during the pandemic, of what she labels "data oppression," which she defines as the unwillingness of many researchers to acknowledge, much less track, the growing importance of gathering comprehensive data about historically disenfranchised communities.

"Who counts depends on who is counted" is a common refrain at DHRC, said Swenor. "The idea being that when you don't have data about these groups [referring to communities of color or people with disabilities], it is as if these inequities

are absent. [But] the lack of data collection removes the opportunity for good policy [and] strategies to address inequities. It's actually a question in my mind of social justice and human rights to collect the data."

The irony is that data related to race or ethnicity is often collected but not disseminated, said Swenor. That's what happened when health officials across the country began tracking COVID-19 infections and deaths during the early days of the pandemic. At first, relatively little was known, from a data standpoint, about how severely communities of color were being ravaged by the spread of the virus.

It was not until civil rights organizations and other advocates for communities of color, especially Latino, Black and Native American communities, began demanding answers that data collection began to shift. These advocates sought to understand why so many people in their neighborhoods were being sickened or killed by the coronavirus, and their advocacy led to state and federal health authorities, including the White House, to improve the processes used to gather and deliver that information to the Centers for Disease Control and Prevention.

Incomplete data and "data gatekeeping," said Swenor, can result in social inequities that hinder the ability of health officials to address public health threats in marginalized communities. But as incomplete as data on communities of color can sometimes be, Swenor said data about people with disabilities is often far less comprehensive—if it's gathered at all.

"For the disability community, we still don't have that data [about the full impact of COVID-19] and the community is still fighting to collect it," she said.

Data deficiencies regarding people with disabilities and communities of color also make it difficult to determine what happens when populations like this intersect with each other, as well as a variety of other economic and social factors, such as poverty, discrimination, education, housing, employment and politics.

Although it has been more than 30 years since the Americans with Disabilities Act became law, identifying a disability is still not a standardized, core component of most health records, said Swenor, because a person's disability is still viewed by many policymakers, health officials and researchers only as a medical condition. Disability is infrequently viewed through a social framework or a civil or human rights lens.

"There was a day, decades ago, when race wasn't a part of those medical questionnaires either," said Swenor, "but that's still where we are today with the disability community. That's why we still can't [accurately] track COVID-19 in the disability community" or fully understand the impact of the pandemic on people with disabilities, including those who also are part of communities of color.

DSPs of Color Matter

Brandiss Pearson, a former social worker who is now a nurse practitioner, hosted an online lecture last year for the National Alliance for Direct Support Professionals. Her presentation was part of a three-part series of webinars titled "Black DSPs Matter."¹⁶

Pearson said her research found that "[Direct support professionals] felt unseen. Like many other frontline workers, they didn't think they were being given the same regard as nurses, who had people standing outside of hospitals cheering and saying thank you."

“As a parent of a child who has Down syndrome,” Pearson added, “I don’t think the work [DSPs] do is elevated enough.” Like their fellow DSPs and other essential workers nationwide, DSPs of color have had little choice but to work longer hours and put themselves at greater risk of infection from the coronavirus.

Black DSPs, while deeply committed to caring for the people they support, confided to Pearson about having to face inequitable workloads, microaggressions, tokenism, and race and gender-based pay gaps.

“These were all things that were pervasive before COVID-19,” Pearson said in an interview for this report. But now these factors are colliding with the trauma of living through the pandemic and trying to keep up the “superwoman” persona that compels Black women to come off as strong and stoic. “I’m a Black woman, therefore I can carry a heavier load. [At the same time] I have to cross my t’s and dot all of my i’s. And I have to show up in a larger way to be seen as equal.”

Pearson said many Black DSPs believed they didn’t have the option to quit their jobs or even call in sick. “So, when other people didn’t come to work, they had to take on the extra workload.”

Adding to their stress, despite the low wages most DSPs receive (the national average is about \$12.36 an hour), DSPs of color and those who are immigrants are often the main or even lone breadwinners for their families.

In a 2021 survey of nearly 9,000 DSPs across the country, the Institute on Community Integration (ICI) at the University of Minnesota identified a range of inequities between Black DSPs and their white colleagues.¹⁷ The survey found 43% of Black DSPs, compared to 26% of white DSPs, worked an additional 16 hours per week during the

pandemic. The survey also found that 60% of Black DSPs versus 40% of white DSPs reported living in households that earned under \$40,000 annually.

At the same time, according to PHI, about 45% of the nation’s DSPs live near the poverty line, which for a single person in 2021 was \$12,880. PHI also found that the median pay for a direct care worker is about \$20,000 per year. These dynamics have cascading effects beyond the direct support professionals themselves; without a living wage, these full-time workers are often forced to rely on public benefits programs, such as SNAP and TANF.

“I often get the question of why is it that this workforce is so underpaid and undervalued,” said PHI Vice President of Policy Robert Espinoza. “One of the answers is that the primary demographic of this workforce are people of color and especially women of color who have long been excluded and marginalized, not just in direct care but in society at large.”

Pursuing Equity

As the U.S. population and the number of people with IDD continue to grow—and as the elderly become a bigger share of the country—the need for DSPs will also increase. PHI estimates the direct care workforce will need to fill nearly 8 million jobs, including 1 million new positions, by the end of this decade. About one in four of those new jobs will have to be filled by DSPs.

The nation’s population, meanwhile, is also growing more diverse. About 40% of people born in the US today are people of color, and Census figures show non-Hispanic white people will comprise a minority in the US by 2045.

Dr. Leonor Vanik is a co-founder of the National Coalition of Latinx with Disabilities. She says direct support professionals need to be better valued



and formally trained for the important roles they play in providing a vital health care service for people with IDD. But Vanik, whose sister has Down syndrome, said the industry also needs to stop pigeonholing Latinos and other people of color, as well as immigrants, into what have been unjustifiably regarded for too long as low-wage, entry-level jobs that promise little chance for advancement. Treating jobs in the field as if they should be low-paying perpetuates employers' practice of underpaying DSPs, said Vanik.

Back at Johns Hopkins, Dr. Swenor points out that while women of color make up most of the DSP workforce, it's also important to understand that "People are more than one thing. The equation to address inequities includes many variables. And if you're only including one variable, like race or gender, you're not going to solve that equation."

Swenor said employers and society at large also need to respond, for instance, to the needs and interests of LGBT workers and people with disabilities who are DSPs.



Photo credit: Institute on Community Integration, University of Minnesota

The DSP workforce is also, on average, attracting older workers, even as they spend more time caring for aging individuals in the IDD community.

"I firmly believe that whenever you're collecting data about race, gender, ethnicity, age and so on, you should also be including disability questions in all surveys. This is the type of thing where there is no [final] destination. You're always striving to gather better data. In the pursuit of equity, better democracy and social justice, there is no end game."

PART 2: SOLUTIONS FOR A MORE SUSTAINABLE FUTURE

Part 1 of this report paints a bleak picture for the state of community inclusion in America, and that's despite not accounting for the social and economic fallout from COVID-19. Preliminary research and survey data reflecting the situation wrought by the pandemic indicate that total system collapse is likely unless significant, concerted efforts are made to strengthen the DSP workforce. With only the barebones of service remaining, one thing has become clearer than ever: access does not exist without an adequate workforce to support it.

It is in that spirit that this section considers the scope of the problems laid out in Part 1 of this report to assess federal efforts thus far and recommends a roadmap for actions that can shore up the direct support workforce and bring the community IDD services system back from the brink.

Public Policy in the Pandemic Era

As the COVID-19 pandemic drew new attention to disability supports and risks within congregate care settings, the state of the direct support workforce became impossible to ignore. As a result, historic federal investments were made to support services and build the physical and social infrastructure necessary to weather and recover from the pandemic. From the Provider Relief Fund authorized in the CARES Act (2020) to the American Rescue Plan Act (2021) and the Build Back Better proposal (2021-2022), funding that targets the service delivery system has been earmarked for community providers in unprecedented ways.

Established under the Coronavirus Aid, Relief and Economic Security Act (CARES Act), the Provider Relief Fund continues to disburse funding to providers of a wide array of health care services to offset health care-related expenses and lost revenue resulting from the COVID-19 pandemic. Although the initial rollout of the Provider Relief

Fund was wrought with challenges, it has been essential to community providers struggling to remain operational.

To date, Provider Relief Fund distributions have been carried out over four separate phases:¹⁸

- **Phase 1 distributed \$46.02 billion** proportionate to providers' share of annual patient revenue billed for Medicare fee-for-service.
- **Phase 2 distributed \$5.98 billion** equal to two percent of providers' total patient care revenue for Medicaid, including Medicaid managed care plans and the Children's Health Insurance Program (CHIP).
- **Phase 3 distributed \$24.5 billion** for previous applicants to apply for additional payments that take into account their financial losses and changes in operating expenses caused by COVID-19.
- **Phase 4 seeks to distribute \$17 billion** to all providers who bill Medicare, Medicaid and CHIP to cover changes in operating revenues and expenses from July 1, 2020, through March 31, 2021.

On March 11, 2021, President Biden signed the American Rescue Plan Act of 2021 (ARPA) into law. With its passage, Medicaid-funded home- and community-based services were acknowledged and appropriated targeted funding for the first time. Section 9817 of ARPA invites states to apply for a 10 percentage-point increase to the federal matching rate (known as "FMAP," or the Federal Medical Assistance Percentage) for HCBS over a one-year period from April 1, 2021, to March 31, 2022. The funds are to be used to enhance, expand or strengthen states' HCBS programs.

By July 2021, participating states were required to submit for approval by CMS a spending plan

and narrative describing their proposal for how ARPA funding would be used. A topical analysis of states' ARPA Spending Plans issued by the National Association of State Directors of Developmental Disabilities Services reported 44 of the 49 spending plans reviewed included initiatives aimed at addressing workforce issues.¹⁹ Those initiatives generally included increased compensation for DSPs and/or workforce development strategies.

Much like the Provider Relief Fund, disbursement of ARPA funding has been delayed, making it difficult to assess the impact of the funding. With distributions only beginning to trickle out as of the end of 2021, accessing funding may be further delayed in states where legislative review is necessary to include the funding in a new state budget. Although this funding is undoubtedly positive and represents a significant step in the right direction, it will be quite some time before we can assess the full impact of the federal government's investment in ARPA.

Finally, with the proposal of the Build Back Better Act (BBB), Congress began to debate solutions to the fundamental cracks in our social infrastructure and offer sustainable ways of addressing the direct care workforce crisis. Of principal importance, BBB led to a proposed investment of nearly \$150 billion in funding for HCBS. Although the future of BBB remains uncertain as of the publication of this report, BBB's proposed investment in HCBS continues to attract bipartisan support. If this particular provision becomes law, participating states can opt into a six percentage-point FMAP increase over a 10-year period. A potential additional two percentage-point FMAP increase is available for states that implement a program for self-directed care.

In addition to—and perhaps equally important to—the HCBS funding proposal included in BBB, the legislation would also direct states to develop systems of reimbursement rate review starting two years after the approval of each state's HCBS improvement plan and then every three years thereafter. Requiring regularly recurring reviews

of reimbursement rates holds states accountable for stagnant wages that created and have perpetuated the direct support workforce crisis.

The third pillar of the BBB proposal targets the direct care workforce through pipeline legislation that capitalizes grant programs to invest in strategies to recruit, retain and advance the workforce. It includes more than \$1.6 billion in funds for long-term care facilities to address disparities in staffing. It also would permanently reauthorize the Money Follows the Person program to ensure people with disabilities can transition smoothly from institutional settings into more inclusive, less isolating home- and community-based settings.

With initial funding to stabilize the workforce, ongoing reimbursement rate reviews and investments in direct support workforce pipeline programs, the provisions of BBB—in whatever form they may ultimately become law—offer a clear opportunity to rebuild the community IDD services system and help providers compete against other industries for labor.

A Roadmap for Supporting Those Who Support

Together, the Provider Relief Fund, ARPA and BBB reveal new federal interest in addressing the instability of community IDD supports. As such, it is more important now than ever before to leverage this moment to remind lawmakers at all levels of government of the need to wield their authority in service of people with IDD and the provider workforce on which they rely.

To support advocates' efforts, the following section outlines actions that key actors should take to strengthen community IDD supports. These actions are broken down according to key actors, including the 117th Congress, the Biden administration, state governments, and providers and other stakeholders.

How the 117th Congress Should Invest in Community IDD Services

Although BBB is a meaningful step toward addressing the instability of HCBS and the direct support workforce, it represents a long-overdue downpayment toward undoing decades of underinvestment in disability supports and services.

In his American Jobs Plan, President Biden called on Congress to invest \$400 billion to expand access to HCBS and address the direct support workforce crisis.²⁰ This figure, which was pared down to just under \$150 billion during negotiations over BBB, would come much closer to beginning to address the gaps in support, including for the nearly 600,000 people on states' HCBS waiting lists.

- ✓ The 117th Congress should pass the HCBS-specific provisions of BBB, including a minimum of \$150 billion and ideally as much as \$400 billion in funding, as well as mandating that states regularly review Medicaid reimbursement rates.

Beyond ensuring appropriate funding, the 117th Congress should do more to support DSPs as professionalized employment by compelling the U.S. Bureau of Labor Statistics (BLS) to establish a Standard Occupational Classification (SOC) for DSPs. Currently, BLS classifies DSPs in the broader occupation of personal care attendants and home health aides. However, the highly specialized nature of DSPs' work makes their duties more diverse and requires different sets of skills than those held by DSPs' counterparts in adjacent professions. The absence of a SOC situating DSPs in a distinct profession also enables states to keep DSP wages low by using extant data about these other professions to justify depressed reimbursement rates.

- ✓ The 117th Congress should compel the U.S. Bureau of Labor Statistics to establish a Standard Occupational Classification for Direct Support Professionals.

How the Biden Administration Should Invest in Community IDD Services

Should Congress pass the HCBS provisions of BBB, CMS would be tasked with creating interpretive guidelines and promulgating regulations to govern the newly implemented programs. While the legislation is explicit in some regards, there is room for interpretation and guidance to support states to leverage new federal funding where critically needed. Though there are strict maintenance of effort provisions, states will otherwise have flexibility to determine covered activities and will look to CMS to guide where to focus the newly authorized funding.

The Biden administration should incentivize states to focus federal funding opportunities on addressing each component of the direct support workforce crisis. DSPs are the backbone of service provision, but targeting funding to expand services without ensuring an adequate workforce will only serve to further delay practical availability of those services.

- ✓ The Biden administration should issue clear guidance that supports states to direct newly authorized funding in a way that balances the need to expand services against the need to shore up the direct support workforce.

How State Governments Should Invest in Community Services

States should continue to apply for each federal funding opportunity targeting supports and services for people with IDD. Community providers and the people who rely on them are in desperate need for funding to increase wages for DSPs and create stability of supports and services in the community. These funding opportunities offer states meaningful opportunity to create consistency in access to community supports without increasing costs to the state.

When applying for these federal funds, spending plans should focus first on stabilizing the direct support workforce. Ensuring adequacy of the direct support workforce is critical to the success of any initiative to expand or enhance existing services by creating availability and sustainability of those supports. States should also focus efforts to review payment rates and consistency of rate reviews to ensure reimbursement is not contributing to inadequate wages for DSPs.

- ✔ State governments should seek to leverage as many opportunities as possible to secure additional funding from the federal government.
- ✔ When determining how to prioritize newly authorized funding from federal sources, state governments should prioritize initiatives that strengthen the direct support workforce, while also considering measures that expand services.
- ✔ Regardless of whether proposed BBB requirements become law, states should establish systems for regularly recurring reviews of reimbursement rates to support providers in their quest to pay livable wages to DSPs.

How Providers & Advocates Should Invest in Community Services

Throughout this report, we have documented that we have a long way to go in ensuring the sustainability of the community IDD system. But that observation should in no way diminish another important point: we've come a long way already, thanks in large part to the providers, advocates and other stakeholders who have been relentless in their efforts to ensure people with IDD have options and resources to live life without limits.

As we continue the fight together, we urge you to stay current with the latest developments regarding state and federal laws and proposals

surrounding the HCBS landscape. Where possible, seek out and apply for state and federal funding opportunities created to offset the impact of the COVID-19 pandemic. Similarly, urge your state to leverage federal funding opportunities to stabilize the direct support workforce crisis by increasing reimbursement rates and creating systems of review to ensure DSP wages can keep up with rising labor costs wrought by inflation and increased demand for services.

- ✔ Access state-specific *Case for Inclusion* data to fuel your advocacy by visiting caseforinclusion.org.
- ✔ Browse resources from UCP and ANCOR at their respective websites, ucp.org and ancor.org.
- ✔ Stay informed about one-click opportunities to take action using the ANCOR Amplifier at amplifier.ancor.org.

Staying the course also means staying safe and healthy through the COVID-19 pandemic. This includes getting vaccinated and encouraging the people you support and employ to do the same. Do as much as possible to ensure the people you support and employ can access life-saving tools, including vaccines, PPE, antiviral treatments, telemedicine and other technology. Continue to educate DSPs about the heightened risk of death facing people with IDD who contract COVID-19 and encourage DSPs to protect those they support by getting vaccinated.

Among all of these actions, there is one to prioritize above all else: do not lose hope. Especially during the pandemic, you have demonstrated your resilience and your vigilance. We know from the unprecedented awareness of community IDD services among federal lawmakers that your efforts are making the difference. For that, we are deeply indebted, and we look forward to continuing to fight together with you.

CONCLUSION



If we were in crisis mode before, the past two years have been nothing short of catastrophe. However, we know what it takes to put community services on surer footing: will require the concerted efforts of state and federal governments, providers and advocates working together. The time is now to build on these historic investments in community IDD supports and services and to use our collective momentum to shape a solid foundation of community inclusion.

It will take the Biden administration providing guidance and consideration that prioritize funding and data collection to address the direct support workforce crisis.

It will take Congress creating programs and pipelines like those proposed in BBB that create incentives for people to become DSPs and that professionalize the direct support workforce.

It will take every state government fully leveraging federal funding and flexibilities to begin rectifying the damage done by decades of underinvestment in community services.

And, it will take every one of us.

The COVID-19 pandemic may have caused irreparable damage to the current system of supports, but it also laid bare the patchwork of stopgaps and band-aids holding the system together. With this clarity of purpose, there is only one thing left to do. It is time to rebuild.

WE NEED YOUR ADVOCACY AND SUPPORT, NOW MORE THAN EVER.

The *Case for Inclusion* is a tool for advocates to stay informed and access data that make the case for communities where inclusiveness defines their character. This year is a uniquely important time for us to stay connected to each other and learn from one another as new opportunities arise to make meaningful changes to our national IDD support system.

If you're ready to join us, here are three ways to take action today:

- 1** Visit the *Case for Inclusion 2022* website at caseforinclusion.org to access stories, data and other resources beyond this report that can aid in your advocacy.
- 2** Use the ANCOR Amplifier at amplifier.ancor.org to call on your elected officials to take meaningful action in service of this shared vision.
- 3** Connect with a UCP Affiliate in your community at ucp.org to see how you can get involved at a local level.

Appendix A: Glossary of Terms

ABBREVIATION	DEFINITION
ANCOR	American Network of Community Options and Resources; a nonprofit trade association representing 1,800+ private community IDD providers; with UCP, one of the co-presenters of the <i>Case for Inclusion</i>
ARPA	American Rescue Plan Act, legislation signed into law in March 2021 by President Biden to provide, among other provisions, funding to help community IDD providers adapt to the COVID-19 pandemic
BBB	Build Back Better Act, a proposal introduced in Congress in 2021 that included, among other provisions, a \$150 billion investment in the Medicaid Home and Community Based Services program
BLS	United States Bureau of Labor Statistics, which is responsible for defining various industries and professions through its Standard Occupational Code
CARES Act	Coronavirus Aid, Relief and Economic Security Act, legislation signed into law in March 2020 by then-President Trump to authorize, among other provisions, the Provider Relief Fund to help community IDD providers stay afloat during the COVID-19 pandemic
CMS	Centers for Medicare & Medicaid Services; the division of the U.S. Department of Health & Human Services dedicated to oversight and administration of the federal aspects of the Medicaid program, which funds community-based IDD services
DSP	Direct support professional; typically employed by community IDD providers, this is a generic term for any number of formal job titles whose responsibilities include the direct delivery of long-term services and supports to people with IDD
FMAP	Federal Medical Assistance Percentage; the rate at which the federal government matches states' investments in Medicaid-funded services
HCBS	Home and Community Based Services; the Medicaid program that funds the vast majority of supports and services that enable people with IDD to live and receive services in the community, rather than being warehoused in large, state-run institutions
IDD	Intellectual and developmental disabilities; conditions or diagnoses for which certain long-term supports and services are designed and funded
PPE	Personal protective equipment; tools such as masks, face shields and gowns that help prevent their users from contracting or spreading infectious diseases like COVID-19
PRF	Public Residential Facility; large institutions operated by the state that are home to people with IDD and generally isolate people with IDD from the benefits and amenities of community inclusion
SOC	Standard Occupational Classification; a classification within the U.S. Bureau of Labor Statistics' Standard Occupational Code to formally identify and recognize a particular occupation
UCP	United Cerebral Palsy; a national nonprofit organization whose nearly 60 affiliates across North America support people with cerebral palsy and other intellectual and developmental disabilities; with ANCOR, one of the co-presenters of the <i>Case for Inclusion</i>
VR	Vocational Rehabilitation; a set of supported employment programs that support people with IDD and others to get ready for, find and maintain a job

Appendix B: American Rescue Plan State Spending on Workforce Development

The table below indicates the types of workforce development initiatives states intend to undertake using funding received from the American Rescue Plan.²¹

	Permanent Wage Increase	Temporary Bonus or Wage Increase	Non-Wage Benefit Enhancement	Training Support	Other Workforce Expansion
Alabama	●			●	
Alaska				●	
Arizona				●	
Arkansas					●
California					●
Colorado		●	●	●	
Connecticut		●			
District of Columbia		●	●	●	
Florida		●			
Georgia		●		●	
Hawaii		●			
Illinois	●	●			
Indiana		●	●	●	●
Iowa	●	●			
Kansas		●		●	
Kentucky	●	●		●	
Louisiana				●	
Maine	●			●	
Maryland	●	●			
Massachusetts	●				
Michigan		●	●	●	●
Minnesota				●	
Mississippi					●

	Permanent Wage Increase	Temporary Bonus or Wage Increase	Non-Wage Benefit Enhancement	Training Support	Other Workforce Expansion
Missouri	●	●			
Nevada		●			
New Hampshire		●			
New Jersey	●	●			
New Mexico			●		●
New York		●			
North Carolina	●		●		
North Dakota	●	●		●	
Oklahoma			●	●	
Oregon		●			
Pennsylvania		●			
Rhode Island		●	●	●	●
South Carolina	●	●		●	
Tennessee		●			
Texas	●	●			
Utah		●			
Vermont		●		●	
Virginia				●	
Washington				●	
West Virginia				●	
Wisconsin				●	
Wyoming	●			●	

ENDNOTES

- ¹ Spreat, S., Cox, R., & Davis, M. *COVID-19 Case & Mortality Report: Intellectual or Developmental Disabilities*. Harrisburg, PA: PAR, 2020.
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- ⁴ *Advancing Equity: How American Communities Benefit from the Better Care Better Jobs Act (S. 2210)*. Washington, DC: U.S. Senate Committee on Aging, 2021.
- ⁵ *The State of America's Direct Support Workforce Crisis 2021*. Alexandria, VA: ANCOR, 2021.
- ⁶ *Direct Support Workforce and COVID-19 Survey: Providing Support During the COVID-19 Pandemic*. Minneapolis: University of Minnesota Institute on Community Integration, 2021.
- ⁷ *National Core Indicators 2020 Staff Stability Survey Report*. Alexandria, VA: National Core Indicators, 2020.
- ⁸ *Olmstead v. L.C.*, 527 U.S. 581 (1998).
- ⁹ Alabama, Alaska, District of Columbia, Hawaii, Indiana, Maine, Michigan, Minnesota, Montana, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Tennessee, Vermont and West Virginia.
- ¹⁰ Larson, et al., *Long-Term Supports and Services*, 139.
- ¹¹ ICI's National Survey of State Intellectual and Developmental Disabilities Agencies' Employment and Day Services describes people participating in integrated employment services as those "with an immediate goal of entering employment, such as job development, and those receiving long-term services to support maintaining employment." See Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J. *StateData: The National Report on Employment Services and Outcomes through 2018*. Boston: University of Massachusetts Boston Institute for Community Inclusion, 2021.
- ¹² *Ibid.*, p. 18.
- ¹³ "IDD Waiting List Enrollment for Medicaid Section 1915(c) Home and Community Based Services Waivers as of 2018," State Health Facts. Washington, DC: Kaiser Family Foundation, accessed January 24, 2022.
- ¹⁴ Espinoza, R., *Creating a Strong Direct Support Workforce: Policy Barriers & Opportunities* [presentation]. Bronx, NY: PHI, 2018, September 13.
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- ¹⁶ "Black DSPs Matter, Part 3: Practical Solutions" (webinar). Albany, NY: National Alliance for Direct Support Professionals, 2021.
- ¹⁷ *Providing Support During the COVID-19 Pandemic: Direct Support Workforce 12-Month Follow-Up Survey*. Minneapolis: Institute on Community Integration, University of Minnesota, 2021.
- ¹⁸ *Provider Relief Fund Past General Distributions*. Washington, DC: Health Resources & Services Administration, U.S. Department of Health & Human Services, accessed January 24, 2022.
- ¹⁹ *State Workforce Initiatives: ARPA Spending Plan Topical Analysis*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, 2021.
- ²⁰ *Fact Sheet: The American Jobs Plan*. Washington, DC: The White House (accessed January 24, 2022).
- ²¹ *State Workforce Initiatives: ARPA Spending Plan Topical Analysis*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, 2021. The reader will note that some states are missing from this table; states excluded either did not furnish a spending plan for analysis, or their spending plan had not been reviewed by NASDDDS by the time of the publication of the ARPA Spending Plan Topical Analysis.

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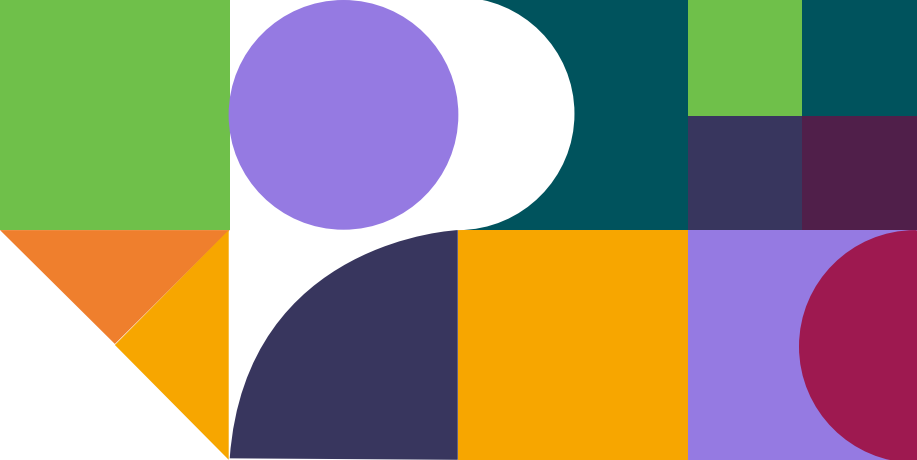
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About United Cerebral Palsy

United Cerebral Palsy (UCP) is the indispensable resource for people with cerebral palsy and other intellectual and developmental disabilities, such as Down syndrome, autism spectrum disorder and a wide range of other disabilities. Founded in 1949, UCP has 58 affiliates (56 in the US and two in Canada) that provide disability services, including information, resources and referrals, educational instruction, home- and community-based services, housing assistance, workforce training, assistive technology, rehabilitative therapy, early intervention and support for research relevant to cerebral palsy. UCP works on behalf of more than 150,000 children and adults annually at all levels of ability and stages of life and believes people with disabilities deserve to be treated as equal members of an inclusive society to achieve their fullest potential and “live life without limits.”

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