



2023
THE CASE FOR
INCLUSION

*Making Good on
Our Nation's Promise of
Community Inclusion for All*



2023 THE CASE FOR INCLUSION

ACKNOWLEDGMENTS

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A LETTER TO ADVOCATES

Dear advocate,

As they say, the more things change, the more they remain the same.

In our community of providers, in our society and across the globe, so much has changed in the past few years. Seismic shifts in the labor market and the broader economy, directly or indirectly the result of the COVID-19 pandemic, have left us working and thinking differently—for better or worse.

To be sure, the pandemic set in motion some positive shifts in the landscape of services available to people with intellectual and developmental disabilities. New and new uses of technology made possible the expansion of remote supports, for example, while temporary funding increases enabled direct support professionals to see the first meaningful increase in median wages in nearly a decade.

Nevertheless, so much remains the same. A dire recruitment and retention crisis in the direct support workforce looms large. So too do substantial disparities between people of color and white people, both among people with disabilities and the professionals who make their access to the community possible. Meanwhile, we continue to see significant deficiencies in our ability to fully understand these disparities due to an ongoing dearth of data.

If these situations have changed, they have done so only by their order of magnitude. As this year's *Case for Inclusion* illustrates, a situation we have long feared is now being born out in the data: people with IDD are increasingly unable to access the services they need. At alarming rates, providers are turning away new referrals and discontinuing existing services due to a lack of staffing. In turn, people are having to travel significant distances or forgo services altogether because even when their state approves them to pursue services, too few providers exist to offer them.

That's why we need decisive action and we need it now. To stem the tide of growing instability in our service delivery system, it will take lawmakers and regulators at all levels of government, as well as providers and advocates, working together in lockstep, demonstrating the promise of community inclusion for all *and* the power of investing in a qualified workforce to deliver on that promise.

In that spirit, this report and its accompanying online tools are designed to strengthen and support your advocacy for the direct support workforce and the people they support so we may work together to build a better future for *all* of the people who contribute to our communities.

Thank you for being on this journey with us.

Sincerely,



Armando A. Contreras

Armando Contreras
President &
Chief Executive Officer
United Cerebral Palsy



Barbara Merrill

Barbara Merrill
Chief Executive Officer
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EXECUTIVE SUMMARY

The *Case for Inclusion 2023* provides insight into the impact of the direct support workforce crisis on community inclusion and reaffirms the policy solutions necessary to stabilize the workforce and begin to rebuild the community-based services infrastructure.

The national impact to community-based services is addressed in Part 1, *The Crisis Impacting Community-Based Services*, highlighting the best available data to demonstrate the state of services across the country. Part 2, *Opportunities to Stabilize Community-Based Services*, summarizes current policy trends and offers specific policy solutions tailored for the 118th Congress, the Biden administration, state governments, providers and other stakeholders.

The Crisis Impacting Community-Based Services

Part 1 of this report highlights select data from the *Case for Inclusion's* seven issue areas: Addressing a Workforce in Crisis, Promoting Independence, Promoting Productivity, Reaching Those in Need, Serving at a Reasonable Cost, Keeping Families Together and Tracking Health, Safety & Quality of Life. Not all issue areas, nor all 80 measures that comprise these issue areas, are discussed in this report, but the full suite of state-by-state data can be found at caseforinclusion.org.

Among the top findings in the *Case for Inclusion 2023*:

- ◆ **There were 481,601 people with IDD on states' waiting lists for home- and community-based services.** Although this represents an 18.3% decrease since the 2022 edition of this report, most of this improvement can be accounted for by select states' changes to their methodologies for measuring the scope of unmet need.
- ◆ **Thirty-six states participated in the Money Follows the Person program.** This represents a slight increase after five consecutive years in which this measure trended downward, suggesting that temporary funding authorizations have dissuaded states from continuing to access the program's federal dollars, which are earmarked to support people with IDD to transition from institutions into community-based settings.
- ◆ **State funding for supporting families of people with IDD increased by approximately \$978 million between FY 2017 and FY 2019.** This data does not account for the increase in people with IDD looking to family members to provide support services through the COVID-19 pandemic because of the inability to access care delivered by direct support professionals.
- ◆ **Twenty-two percent of people with IDD who received employment or day services were participating in integrated employment.** Although this is the highest level reported since 2001, the percentage of people with IDD working in integrated employment has stagnated between 19% and 22% since 2013. Meanwhile, of the 36 states that report data on the number of people working, only 19% were working for pay.

NOTE: Unless otherwise noted, the data highlighted in this report is sourced from the Kaiser Family Foundation's State Health Facts (kff.org/statedata), National Core Indicators (nationalcoreindicators.org), *The State of the States in Intellectual and Developmental Disabilities* (stateofthestates.org) and the University of Massachusetts Boston's StateData.info.

Opportunities to Stabilize Community-Based Services

Part 2 of this report offers recommended solutions and opportunities for federal and state legislative and executive branches, along with providers and other advocates, to address the direct support workforce crisis and move forward in repairing the damage to the community-based services infrastructure. The following is a brief overview of the recommendations that are detailed more fully in Part 2 of this report.

The *Case for Inclusion 2023* maintains that the Biden administration should:

- Issue guidance that specifically addresses workforce-related regulatory flexibilities in light of the termination of the COVID-19 public health emergency.
- Require states to establish systems of access monitoring that compel regular reviews of Medicaid reimbursement rates to ensure payments stay current with increasing costs of service delivery and safeguard access to quality home- and community-based services.
- Require state and federal agencies to collect and publicly report on measures related to workforce volume, stability and compensation, as well as systemic barriers to equity and the delivery of culturally competent services within the direct support workforce.
- Expedite existing visa processes to ensure opportunities for aspiring Americans interested in joining the direct support workforce.

The *Case for Inclusion 2023* maintains that the 118th Congress should:

- Enact legislation to significantly increase the federal share of Medicaid funding for home- and community-based services to stabilize the direct support workforce.
- Mandate that states regularly review Medicaid reimbursement rates to ensure payments keep pace with increasing costs of service delivery and safeguard access to quality home- and community-based services.
- Establish a Standard Occupational Classification for direct support professionals, the primary caregivers for people with IDD.
- Enact legislation that would fund federal grant programs to support the training, recruitment, retention and advancement of the direct support workforce.
- Require state and federal agencies to collect and publicly report on measures related to workforce volume, stability, compensation and systemic barriers to equity and ability to offer culturally competent services within the workforce and to people with IDD.
- Expand opportunities for people entering the United States to join the direct support workforce.

EXECUTIVE SUMMARY

The *Case for Inclusion 2023* maintains that states should:

- Prioritize funding opportunities that strengthen the direct support workforce, while also considering measures that expand access to services.
- Establish systems which provide regular review of Medicaid reimbursement rates to ensure payments stay current with increasing costs of service delivery and safeguard access to quality home- and community-based services.
- Participate in National Core Indicators' State of the Workforce Survey (formerly known as the Staff Stability Survey) and other voluntary survey measures assessing the direct support workforce.

The *Case for Inclusion 2023* maintains that providers and advocates should:

- Seek out and engage in opportunities for stakeholder engagement and public comment.
- Access state-specific *Case for Inclusion* data to fuel your advocacy. The data can be accessed by visiting caseforinclusion.org.
- Encourage state and federal agencies to collect and publicly report on measures related to workforce volume, stability and compensation, as well as systemic barriers to equity and the delivery of culturally competent services within the direct support workforce.
- Browse resources from UCP and ANCOR at their respective websites, ucp.org and ancor.org, and stay informed about one-click opportunities to take action using the ANCOR Amplifier at amplifier.ancor.org.



A NOTE TO THE READER:

Not every policy objective impacting the lives of people 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.

COMMUNITY INCLUSION: A NATIONAL PROMISE

In its 1999 landmark decision in *Olmstead v. L.C.* (Olmstead), the United States Supreme Court concluded that undue institutionalization constitutes discrimination prohibited by the Americans with Disabilities Act (ADA), which was signed into law nearly a decade earlier. The court's ruling noted 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."¹

For people with intellectual and developmental disabilities (IDD) who leverage community-based services so that they can avoid the kind of institutionalization outlawed by the Supreme Court in its *Olmstead* ruling, the ADA's promise of access and inclusivity demands a sizable and qualified workforce of direct support professionals, or DSPs. In short, community-based services mean little if the provider organizations that offer them lack the staff needed to deliver them. Unfortunately, significant shortages of DSPs have forced providers to close up shop or turn away new referrals.

Thus, our nation's ability to carry out the promises of the ADA are directly dependent on our ability to resolve our ongoing and worsening direct support workforce crisis.

It is within this context that the *Case for Inclusion*—now in its 15th edition—has served as a source of data and policy recommendations regarding the effectiveness of state programs supporting people with IDD and their families to be included in their communities.

This latest edition of this report, a collaboration between United Cerebral Palsy (UCP) and the ANCOR Foundation, points clearly to the mounting challenges providers face as they seek to safeguard the promises of *Olmstead* through the delivery of home- and community-based



services. Each day that passes without redress of the direct support workforce crisis leaves people with IDD at greater risk of institutionalization and with greater barriers to the things that transform places into communities.

As the single greatest barrier to accessing long-term services and supports for people with IDD, the direct support workforce crisis can largely be attributed to stagnant funding to deliver increasingly expensive services. Because community providers are funded through reimbursements by Medicaid for the services they deliver, and because underinvestment in Medicaid has led to decades of largely stagnant reimbursement rates, providers struggle significantly to pay wages to DSPs that are competitive with those of other hourly-wage industries, such as fast food, retail and convenience stores.

COMMUNITY INCLUSION: A NATIONAL PROMISE



These challenges have been amplified dramatically by the COVID-19 pandemic, which in turn has accelerated the denial of access to the quality and availability of services for people with IDD. In last year's *Case for Inclusion*, we began reporting on the widening cracks in the system wrought by the pandemic and illustrated by the drastic growth in job vacancies.²

More recent data from ANCOR's 2022 *State of America's Direct Support Workforce Crisis* report finds that the crisis is only getting worse.³ As of the third quarter of 2022, more than six in 10 community providers had discontinued programs or services in response to ongoing challenges related to high turnover and vacancy rates. This represents a staggering 85.3% increase since the early days of the pandemic.

The direct support workforce crisis is now damaging the structural integrity of the community-based services system. Providers are turning away new referrals at alarming rates

due to staffing shortages that leave people with significant or complex disability support needs forced to travel long distances outside of their local communities to receive services. With providers unable to hire sufficient staff, people with IDD are growing increasingly dependent on family members to deliver care (when they're fortunate enough to have family members who are positioned to deliver such care) or, in the worst cases, on large-scale congregate care settings. For most people with IDD, these options hamper people's ability to meaningfully engage in their communities and lead self-determined lives.

Of course, this isn't just a crisis for people with disabilities. Given that the nation's direct care workforce is composed primarily of women, people of color and, to a growing extent, immigrants, continuing to underinvest is a decision to perpetuate inequities. As just one example, consider that the median DSP wage in Illinois is \$13.52, just slightly above the national

COMMUNITY INCLUSION: A NATIONAL PROMISE

median of \$13.36 per hour.⁴ That means that a mid-career DSP working in Illinois—who is likelier than not to be a woman of color—earned \$1.48 per hour less than a person with no work experience at all on their first day at any number of big-box stores that have committed to a \$15 hourly minimum wage.

We know that just as in most other contexts, there are marked disparities in wages, job security and benefits between white workers and workers of color. However, limited data exists to fully assess the extent of these disparities. As we detailed in a supplemental article in the 2022 edition of the *Case for Inclusion*, data about people with disabilities and the workers who are key to their inclusion in the community too often fail to disaggregate on dimensions such as race, gender and citizenship status, in turn creating blind spots that hinder our ability to fully understand and address long-standing inequities and develop appropriate policy responses. Policymakers and researchers must work to collect better data capable of identifying these historically disparate outcomes.

Ironically, the failure of federal and state governments to adequately invest in Medicaid-funded services will soon trigger most states to seek additional time to comply with federal regulations due to the workforce crisis. The Home and Community Based Services Settings Rule, which established criteria in 2014 to ensure people accepting Medicaid-funded Home and Community Based Services (HCBS) receive those services in the most integrated settings possible, has a compliance deadline for states of March 2023. However, in acknowledging the exacerbating impact of the worker shortage on access to services, the federal Centers for Medicare & Medicaid Services (CMS) has authorized the use of corrective action plans to give states more time to comply with the staffing-dependent provisions of the Settings Rule.⁵

The impending HCBS Settings Rule compliance deadline brings into sharp focus that the moment for decisive action is now—not only so states can comply with federal regulations, but also because we know our problems, if left unattended, will only continue to get worse. By 2030, demand for workers to deliver home- and community-based services is projected to increase by 37% over 2020 levels, with an estimated 7.9 million new job openings in direct care industry.⁶ Without meaningful investment in community-based programs, the community-based service infrastructure is at risk of collapsing and leaving an even greater share of the estimated 2.5 million people nationwide with IDD facing the prospect of long-term institutionalization.

These and an array of other challenges command the focus of this report, but with these challenges we offer a range of plausible, meaningful policy solutions. It's worth noting that there is much cause for optimism on the horizon. In 2021, the White House issued a proposal to invest \$400 billion in the Medicaid HCBS program. Although that proposal didn't pass Congress, it set in motion an 18-month period of perhaps the most sustained advocacy in the history of our field. Disability advocates fought tirelessly to make legislators and regulators aware of the growing crisis in the direct support workforce. And, if there was one positive outcome from the COVID-19 pandemic, it might be that it gave providers and government the opportunity to test out long-term solutions in the form of temporary funding enhancements and regulatory flexibilities. The key now will be to make these temporary fixes permanent.

PART 1: THE CRISIS IMPACTING COMMUNITY-BASED SERVICES



FROM THE FIELD

Mosaic, an IDD service provider that supports people with IDD in several states across the country, found itself needing to limit the number of participants in its popular day program in Omaha due to staffing challenges. Typically, people in the program participate in different activities in and around Omaha each day, meeting at different hubs to decide on the day's activities.

"There was no good way to tell people there's not room for them in the program anymore," recalls Linda Timmons, Mosaic's President and CEO. "Our local leadership had to make difficult decisions, and unfortunately, it meant ending some connections with a few people we had served for years."

The move cut the number of participants in the program by nearly half. The criteria for who could remain in the program considered other services people were accepting from Mosaic, as well as transportation concerns, which were contributing to the staffing challenges.

"Belonging is one of Mosaic's values," Timmons said. "For us, part of that is fostering a climate of honesty and openness. Although we knew we could not make everybody happy, we made sure people understood why it was needed and offered them other options."

The data in this report illustrates the ways in which challenges facing IDD providers have stagnated or become worse in the nearly quarter-century since the *Olmstead* decision was handed down. However, long before we had the comprehensive data offered by the *Case for Inclusion*, speaking with any professional who has spent time in the provider community would reveal the ways these challenges are experienced.

Those with experience in this field would tell you that a decade or two ago, they had relatively few options to choose from when deciding which candidate to hire. Though they may not have realized it at the time, that felt like a walk in the park compared to the current situation: now, providers have little to no choice when deciding who to interview, let alone who to hire. Likewise, providers in the field 25 years ago could rattle off the many factors they screen for when identifying someone who could excel in the DSP role. But now? Although they still consider those factors, there are few applicants that meet minimum job requirements.

The direct support workforce crisis has drastically accelerated, increasing turnover rates and decreasing the ability of DSPs to develop the types of skills necessary to offer high-quality, individualized supports. The exodus of DSPs from the field is attributable to stagnant reimbursement rates that have left providers unable to offer wages competitive with hourly industries, such as a fast food and retail.

Without sufficient staffing, community providers are left with few good options for how to sustain the supports on which members of their communities have come to rely. More recently, these challenges have been amplified by the COVID-19 pandemic, and recent research is now beginning to capture the devastating effect of the COVID-19 pandemic on the direct support workforce.

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One source of such data is ANCOR's 2022 *State of America's Direct Support Workforce Crisis*, which found that:

- More than six in 10 community providers have discontinued programs or services in response to job turnover and vacancy rates—an **85.3%** increase since the start of the pandemic.
- Nearly two-thirds of providers, **63%**, had discontinued programs or service offerings due to insufficient staffing.
- More than half, **55%**, of all respondents were considering new or additional discontinuations of programs and service offerings due to high turnover and vacancy rates.
- Among existing services, **92%** of providers indicated struggling to achieve quality standards.
- **83%** of providers had turned away or stopped accepting new referrals due to insufficient staffing.
- **71%** of respondents found it difficult or very difficult to connect families with case management services, including long-term services and supports, due to lack of available providers.⁷

Despite the gravity of the direct support workforce crisis, there is limited data quantifying and analyzing the social determinants impacting this workforce, which we know is primarily composed of women, people of color and, in growing percentages, immigrants. For example, National Core Indicators has found that 71.3% of DSPs identify as women, while only 38% identify as white.⁸ As such, many DSPs face heightened incidences of discrimination over the course of their professional lives, to say nothing about other areas where discrimination is common, such as housing, education and health care.

Adding to the challenges for this workforce, “direct support professional” is not an occupation formally recognized by the federal government, as there is not currently a Standard Occupational Classification for DSPs recognized within the U.S. Bureau of Labor Statistics’ Standard Occupational Code. This makes it even more difficult to collect basic demographic and related employment and economic data that could be used to better position providers to offer more competitive wages.⁹

IN FOCUS: WORKFORCE DEMOGRAPHICS

Data from PHI, a national nonprofit that provides research on the direct care workforce, reveals that approximately 61% of direct care workers are people of color, mainly Black or African American and Hispanic or Latino, while 86% are women. PHI also found that in 2020, the home care workforce—which includes DSPs supporting people in their homes as well as other professional caregivers—was 27% Black or African American, 23% Hispanic or Latino, and nine percent Asian American or Pacific Islander. Notably, the percentage of white, non-Latino DSPs in the workforce declined by 10% from 2009 to 2019.

“I often get asked 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 [...] this workforce is primarily 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.”

PART 1: THE CRISIS IMPACTING COMMUNITY-BASED SERVICES

Even with the emergence of COVID-19 vaccines, the pressures and trauma of providing close-contact direct support through the pandemic has lingered among the direct support workforce and the people they serve. A recent national survey conducted by the University of Minnesota and the National Alliance for Direct Support Professionals found that:

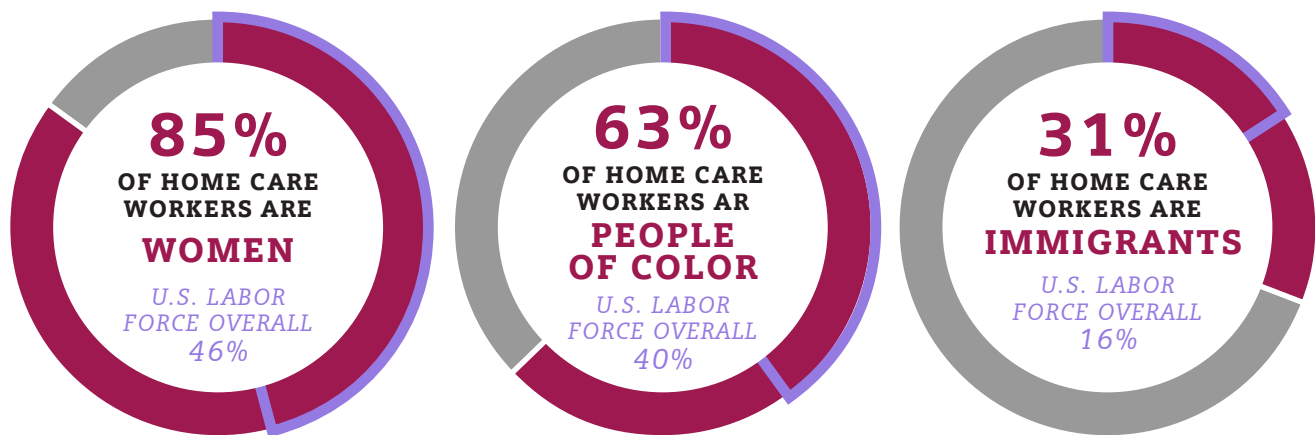
- ◆ **55%** of DSPs reported physical and/or emotional burnout as a result of the pandemic.
- ◆ **56%** experienced anxiety, 43% experienced sleep difficulties and 40% expressed depression.
- ◆ Among respondents that experienced a negative impact to their mental and physical health, a combined **77%** saw their daily work life affected “some” or “a lot.”¹⁰

Because there is no federal requirement for states to collect and report regional workforce data, the Centers for Medicare & Medicaid

Services (CMS) has little information to assess the adequacy of state payment rates to attract and maintain a sufficient and equitable workforce. Furthermore, there is limited guidance to states on measuring access to long-term services and supports. In turn, states routinely do not include home- and community-based services in their access monitoring review plans, leaving policymakers and other stakeholders without a means to collect critical data to demonstrate the lack of provider capacity and inadequacy of reimbursement rates.

Due to a lack of federal guardrails, the workforce crisis has eroded the system of care and is putting millions of people at risk of unnecessary institutionalization. The information highlighted in the following data snapshot captures what we know about the current state of the community-based services infrastructure and areas for further development based on the most recent national data.

WORKFORCE DEMOGRAPHICS



Source: PHI, *Direct Care Workers in the United States, 2022*



PART 1: THE CRISIS IMPACTING COMMUNITY-BASED SERVICES



DATA SNAPSHOT

REACHING THOSE IN NEED

While Medicaid requires coverage of long-term care in institutional settings, home- and community-based services are an optional benefit that states are not required to offer. As such, states can set hard limits on funding and create waiting lists to manage budgetary restraints. There are currently no federal requirements or standards regulating how states manage or prioritize those waiting lists, resulting in inconsistencies from state to state in terms of who ends up on these lists.

Although routinely cited, waiting lists are often poor indicators of overall unmet need in a given state. Inadequate staffing and service closures inhibit the ability of providers to accept referrals and support the full number of people eligible and authorized for home- and community-based services. In turn, when community providers have inadequate staffing to support those being cleared from waiting lists, people are forced to either forgo services altogether or live in hospitals and institutions—often at higher costs to state and federal governments—until a community-based provider is able to support them.

To make matters worse, most states require that people begin utilizing home- and community-based services within an impractically short timetable or risk losing their funding once they are approved to seek services. While a person with IDD may make it off a waiting list, there is no assurance that a provider is available to offer the full or even partial spectrum of supports that person needs. Moreover, because of growing program and service closures, people with IDD may need to move out of their communities or travel long distances to find an available and qualified provider.

As of the end of 2021, there were 481,601 people with IDD on state HCBS waiting lists nationwide.¹¹ When we last reported on this figure, the latest data available at that time captured the number of people waiting at the end of 2018; by comparison, there were roughly

108,000 fewer people waiting as of the end of 2021. However, we now have data capturing the situation as of the end of 2020, and examining that data, we learn that there were roughly 17,000 more people added to states' waiting lists over the course of 2021.

Further raining on an otherwise sunny parade is an important contextual note. Although there were fewer people on states' waiting lists, that does not necessarily mean that more people were receiving services or that fewer people in need were finally receiving supports. Rather, some of those shifts are the result of updated methodologies used by states.

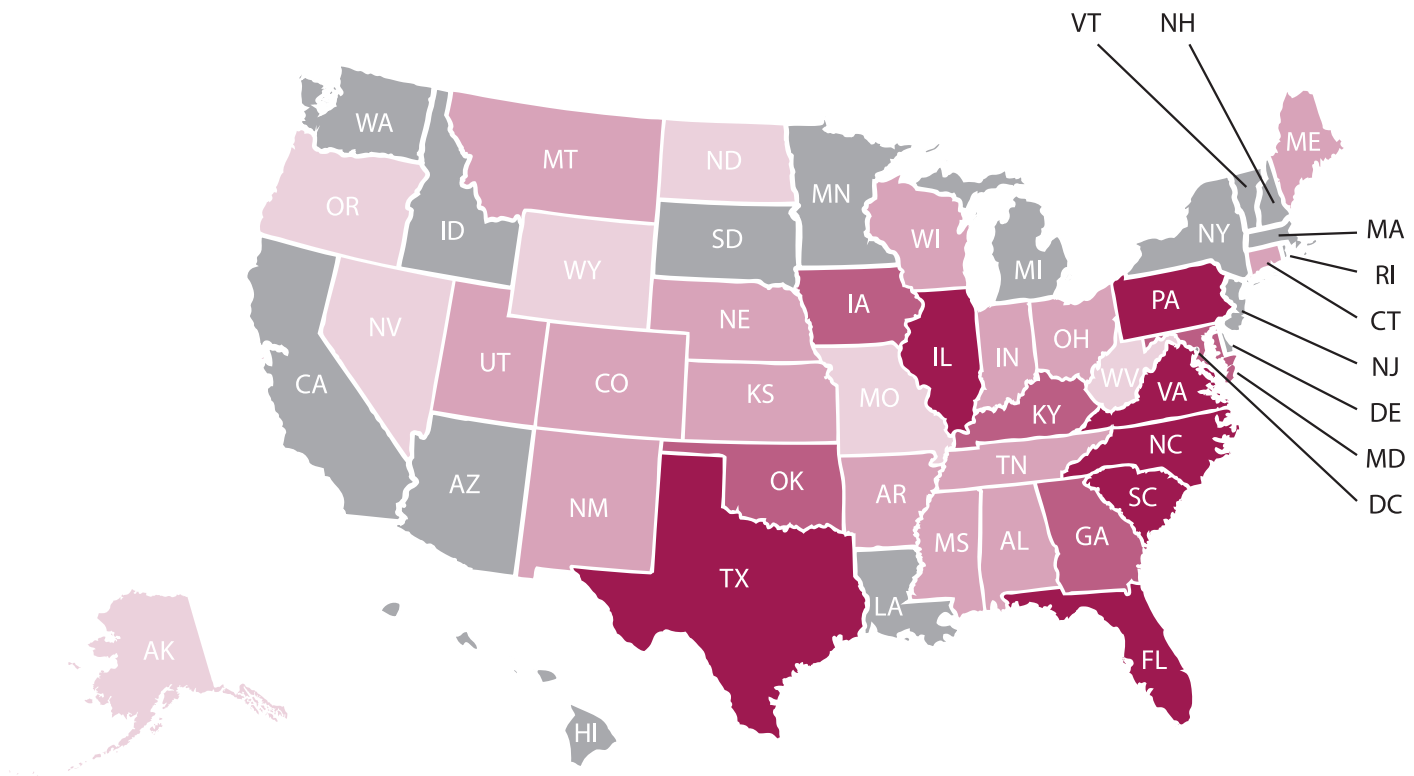
In fact, just two states—Louisiana and Ohio—account for about 85% of the decrease seen between the end of 2018 and the end of 2021. However, both of those states adjusted their methodologies in the interim without substantive new investments in services. That certainly does not mean those states haven't made significant strides, but at the very least, these methodological changes mean it's hard to make apples-to-apples comparisons between the waiting list data reported in the 2022 and 2023 editions of the *Case for Inclusion*.

Of course, Ohio and Louisiana aren't alone—the management of states' HCBS waiting lists varies widely across the country, both in terms of the criteria for being placed on a waiting list and the order in which people are removed. For example, some states add people to their waiting lists before determining whether the person is eligible for those services. Other states may require both evidence that the person is eligible and that support cannot be met with unpaid family caregivers prior to being added to the waiting list. Who comes off the list is equally varied: some states use a first-come, first-served approach, while others prioritize funding at higher risk for abuse, neglect or exploitation.

PART 1: THE CRISIS IMPACTING COMMUNITY-BASED SERVICES

NUMBER OF PEOPLE WITH IDD ON STATES' WAITING LISTS FOR HOME & COMMUNITY BASED SERVICES

Nationally, there are 481,601 people with IDD on states' waiting lists for Medicaid-funded Home & Community Based Services. The map below depicts states' share of that national number; the darkest states have the largest waiting lists, while lighter states have relatively smaller waiting lists. States without waiting lists are indicated in grey, but the reader should note that this does not necessarily mean there is no unmet need in these states.



KEY

Number of people with IDD on states' HCBS waiting lists

- No waiting list
- <1,000 people waiting
- 1,000-4,999 people waiting
- 5,000-9,000 people waiting
- 10,000+ people waiting

PART 1: THE CRISIS IMPACTING COMMUNITY-BASED SERVICES



DATA
SNAPSHOT

TRACKING HEALTH, SAFETY & QUALITY OF LIFE



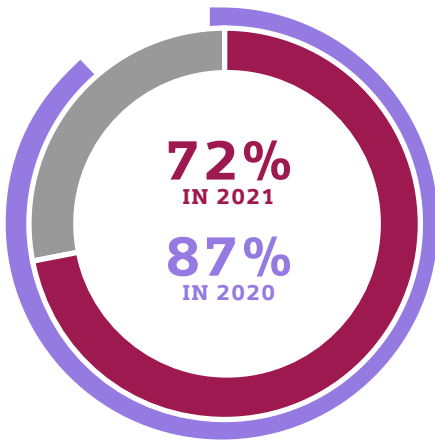
Money Follows the Person (MFP) is a federal grant-funded demonstration program that helps people with disabilities voluntarily move out of institutional care and into the community. While Medicaid funding for HCBS services is limited to medically necessary supports, MFP has flexibility to focus on the global needs of the person in transition, enabling a truly person-centered approach to community care. Funding, for example, can be used to cover upfront expenses, such as environmental modifications and moving expenses. MFP resources can also be used to provide additional services and supports to make the transition successful for the first 365 days before the person must shift back to traditional Medicaid-funded care.

Despite the successes of MFP, instability in the program's federal funding has negatively impacted state participation and the overall reach of the program. By the end of FY 2022, state participation in MFP had decreased to a new low of 36 states, down from 44 states in FY 2016.¹² Additionally, the number of transitions in the total program declined by 50% from 2017 to 2019.¹³ Since funding for the original MFP pilot program expired in 2016, the program has been funded by a series of short-term renewals, leaving states hesitant to continue investing over the fear that funds may eventually dry up. The most recent four-year congressional reauthorization will make program funds available through 2027.

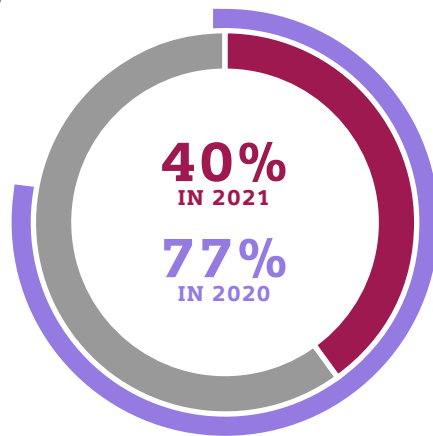
The good news is that in March 2022, CMS increased the reimbursement rate to 100% federal funding for supplemental services covered under MFP and expanded the definition of eligible services to include additional services that support individuals' transitions, including short-term housing and food assistance.¹⁴ This is a step in the right direction and may incentivize more states to participate, but permanent reauthorization remains necessary to ensure states continue to participate and support access from institutions into the community.

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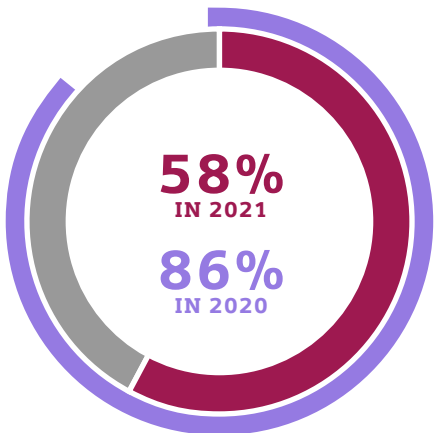
Programs like MFP are essential to the ability of people with IDD to be safe and healthy and enjoy a high quality of life. Unfortunately, however, the *Case for Inclusion 2023* finds that community engagement for people with IDD has declined sharply from FY 2019 to FY 2021. According to latest available data from National Core Indicators:



The percentage of people with IDD who reported having run errands in the past month fell from **87%** to **72%**.



The percentage of people with IDD who reported having gone out for entertainment in the past month fell from **77%** to **40%**.



The percentage of people with IDD who reported having gone out to eat in the past month fell from **86%** to **58%**.¹⁵

While a decrease in community activities in 2020 may have been reflective of emergency health precautions, such as government-mandated stay-at-home orders or fears of getting COVID-19, the fact that these trends have lasted at least into 2021 suggest a more fundamental problem: people with IDD have less access to their communities now than they did before the pandemic. This can be attributed in part to inequities in how quickly certain populations have emerged from the public health emergency compared to others, and in part to the lasting impact of program closures necessitated by high turnover and vacancy rates.



KEEPING FAMILIES TOGETHER

Faced with the instability of the direct support workforce and the resulting lack of access to providers in their communities, more people with IDD are choosing to live in a family home and receive support from family members. However, many families lack the means to serve in full-time caregiving roles, and even those that do can find their loved ones with IDD lacking options for community inclusion. These challenges grow as family members age and themselves become reliant on caregivers.

In other words, dependable and available access to community providers gives people with IDD choices beyond a family caregiving model or turning to institutions to receive support. In the absence of community-based providers, family support resources can help pay for services delivered to people with IDD living in their own home or in a family home. Though each state manages its family support programs differently, these programs commonly cover the costs of respite care, education and training, cash subsidies and environmental adaptations. Government spending for family support ranges widely across the country with a high of \$1.19 billion in California to as little as \$0 in states like Idaho, which does not have resources allocated for family support.

In 2022, the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregiver Advisory Council collaborated with the Advisory Council to Support Grandparents Raising Grandchildren to publish the National Strategy to Support Family Caregivers to measure the challenges faced by family caregivers and to recommend a strategic response.¹⁶ The report found that while the estimated per-family spending on family caregiving in 2016 was roughly \$7,000, the actual caregiving costs families incur when accounting for lost wages amounts to an estimated \$522 billion annually. Meanwhile, employers lose an estimated \$33 billion each year due to their employees needing to step into caregiving roles.

Although the National Strategy report centered on family caregiving, it identified the direct support workforce crisis as a one of the four essential issues intrinsically linked to the diminishing options for and quality of caregiving, adding that only “through the development of a robust, well-trained direct care workforce can we ensure family caregivers and the individuals they support have access to reliable, trusted, and affordable paid supports and assistance when and where they need it.” In its recommendations for federal action, the National Strategy supported policies to ensure an “agile, flexible and well-trained direct care workforce is available to partner with and support family caregivers.”¹⁷

The *Case for Inclusion 2023* concurs with this view, and in turn assesses states’ investments in family support by analyzing two key metrics: the number of families receiving home-based support and the total dollars spent by states on home-based family support.¹⁸

As one of this year’s relative bright spots, the *Case for Inclusion 2023* found a significant increase in family support funding. According to data published by *The State of the States in Intellectual and Developmental Disabilities*:

- ◆ Nationally, state funding for family support increased by approximately \$978 million between 2017 and 2019.
- ◆ 571,374 families received some form of family support in FY 2019, an increase of 25,980 families.
- ◆ The average state spending per family in FY 2019 increased to \$13,545.




PART 1: THE CRISIS IMPACTING COMMUNITY-BASED SERVICES



Readers should note that this data does not include the period from 2020 through 2022 and thus does not capture the extent to which the COVID-19 pandemic has affected the ability of families to receive funding or provide home care.

This is notable for several reasons, such as the fact that prior to the pandemic, many states maintained restrictions on the types of family members who could be hired to provide paid support in the home. With the declaration

of a public health emergency beginning in 2020, states were offered the opportunity to receive temporary emergency approval to make regulatory changes. Forty-eight states now allow legally responsible relatives to be paid family caregivers, an increase of 12 states since 2020.¹⁹ However, if those states do not take steps to permanently adopt these changes, these special authorizations will end with the expiration of the public health emergency.

MEASURE	FY 2017	FY 2019 *
 Overall State Funding for Family Support	\$6,812,800,000	\$7,752,500,000
 Number of Families Receiving Support	544,075	572,384
 Average State Spending Per Family	\$12,418	\$13,545

* Data current as of January 15, 2023.



PROMOTING PRODUCTIVITY

The opportunity to work and contribute to a community of friends and colleagues remains an important component of inclusion for people with disabilities. In addition to tangible financial benefits, work creates connections forged through interest and circumstance that would not otherwise have been formed.

Unfortunately, without access to support, many people with IDD are barred from the same 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 opportunities in so-called integrated settings—those in which people with disabilities work alongside their non-disabled peers. Career planning and employment supports offer opportunities to explore potential work goals and assistance preparing for, getting to and sustaining jobs. Unfortunately, the direct support workforce crisis means fewer people can access the support they need to consider and pursue employment opportunities.

According to data from the Institute for Community Inclusion at the University of Massachusetts Boston, 22% of people who received any employment or day service were participating in integrated employment.²⁰ In FY 2020 an estimated 650,057 individuals received employment or day supports funded by state IDD agencies. This number grew from 455,824 in FY 1999. Likewise, the number of people participating in integrated employment services increased from 108,227 in FY 1999 to 140,871 in FY 2020. Within the 36 states that report data on the number of people working, 19% of individuals who receive an employment or day service were working for pay.

The success of job seekers depends in large part on the knowledge, skills, and abilities of employment specialists.²¹ Employment

support professionals experience high turnover, low salaries, and limited opportunities for both formal and informal professional development.²² Research has demonstrated that when employment specialists receive appropriate training combined with mentorship and performance feedback, they improve the number and quality of the jobs they develop, suggesting the importance of both formal learning and effective supervision and coaching.²³

The ongoing shortage of qualified DSPs means providers are focused on prioritizing basic essential needs over those activities that enhance life in the community. Without consistent access to staff to provide transportation and individualized support, people with IDD relying on that support have less ability to consider career paths and market themselves to employers. Similarly, lacking consistent staffing, community and employment support programs closed as the result of the COVID-19 pandemic, which in turn has amounted to fewer opportunities to prepare for and explore employment. As a result, prospects to work in the community remain extremely limited for people with IDD.

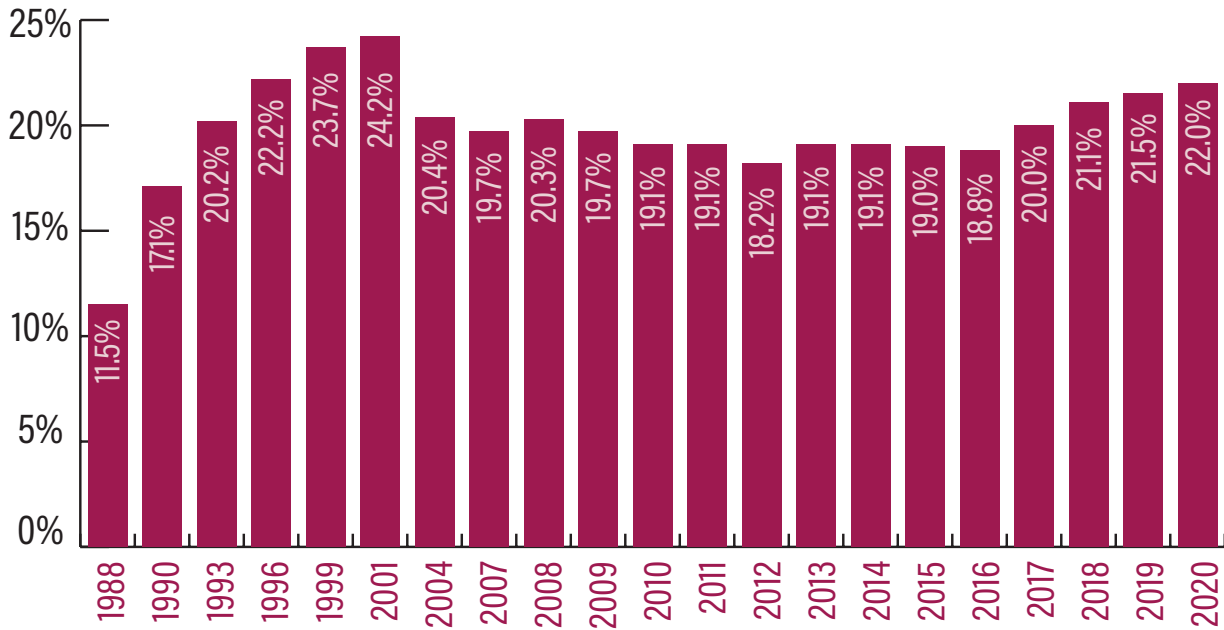
Of the opportunities to work that do exist, many are facilitated through states Vocational Rehabilitation (VR) programs. Within these programs, slightly more than a quarter (26%) became employed within one year of when they began receiving supports. Although this figure was unchanged from last year's *Case for Inclusion*, the average number of hours worked each week by workers receiving support through their state's VR program rose by one hour to 22—just over half of what most industries consider a full-time work week and well below the threshold at which most employers provide health and other employee benefits.

PART 1: THE CRISIS IMPACTING COMMUNITY-BASED SERVICES

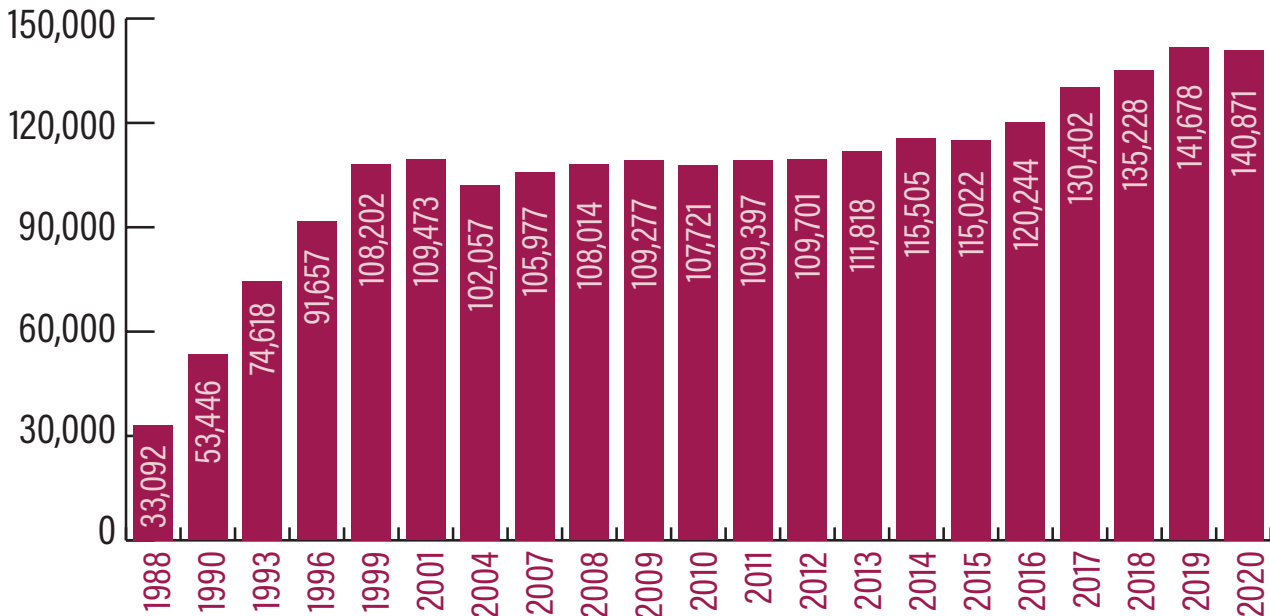
NUMBER VS. PERCENTAGE OF PEOPLE WORKING IN INTEGRATED EMPLOYMENT

The graphs below illustrate that although the number of people with IDD working in integrated employment has increased modestly in recent years, the percentage of the population working in integrated employment has remained largely stagnant. This is because the total number of people receiving employment services has remained stagnant, suggesting that services are effective, but access to those services remains limited.

U.S. Percentage of People in Integrated Employment



U.S. Number of People in Integrated Employment*



PART 2: SOLUTIONS TO STABILIZE THE DIRECT SUPPORT WORKFORCE

The previous section highlights the urgent need to address the direct support workforce crisis given its apparent impact in the community-based services infrastructure and our country's moral obligation to ensure everyone can access the benefits of community.

But as we shared in the introduction to this report, the significance of the challenges we face does not mean solutions are lacking. Indeed, there is a range of meaningful, manageable and moveable solutions lawmakers at all levels of government can take to invest in people with IDD and the workforce of professionals who support them. This section is dedicated to exploring these policy solutions.

UNWINDING FROM FUNDING & FLEXIBILITIES THAT HAVE BECOME A WAY OF LIFE

Though the COVID-19 pandemic drew new attention to disability supports and congregate group care settings, short-term investments were not enough to address the damage to the workforce caused by decades of stagnant reimbursement rates. As a result, states and providers leaned on emergency funding and regulatory flexibilities to slow program closures and an erosion of access. As the data in this report confirms, the home- and community-based services infrastructure will soon be unable to withstand the pressures imposed by a growing exodus of qualified professionals from the workforce.

Emergency Funding for HCBS

The Families First Coronavirus Response Act (FFCRA) was signed into law on March 18, 2020, as the pandemic surged. Among other critical provisions, the FFCRA included a 6.2 percentage-point increase to FMAP, the rate at which the federal government matches states' investments

in Medicaid-funded services, for all states and territories to meet continuous coverage requirements for enrollees.

However, as a result of the passage of Consolidated Appropriations Act of 2023, the 117th Congress announced that states could restart Medicaid eligibility redeterminations and renewals beginning April 1, 2023. Simultaneously, the FMAP begin a phased decrease to reach its pre-pandemic levels by the end of 2023 as follows:

- **A 5 percentage-point enhancement** will remain in effect from April 1, 2023, through June 30, 2023.
- **A 2.5 percent percentage-point enhancement** will remain in effect from July 1, 2023, through September 30, 2023.
- **A 1.5 percentage-point enhancement** will remain in effect from October 1, 2023, through December 31, 2023.

On March 11, 2021, President Biden signed the American Rescue Plan Act of 2021 (ARPA) into law. With its passage, the Medicaid HCBS program was acknowledged and targeted funding was appropriated for the first time. Section 9817 of ARPA invited states to apply for a 10 percentage-point increase to the FMAP rate to be used to enhance, expand or strengthen states' HCBS programs. Unfortunately, enhanced funding was only authorized over a one-year period starting April 1, 2021.

An analysis by the National Association of State Directors of Developmental Disabilities Services reported that 44 of the 49 state ARPA spending plans reviewed included one-time and time-limited initiatives aimed at addressing ongoing workforce issues.²⁴ Further, analysis by ADvancing States, which represents the nation's 56 state and territorial directors of agencies on aging, disabilities and long-term services and supports,

PART 2: SOLUTIONS TO STABILIZE THE DIRECT SUPPORT WORKFORCE

identified similarly time-limited and targeted rate increases in 28 spending plan narratives and intention to review at least one payment rate across 25 spending plan narratives.²⁵ However, much like the Provider Relief Fund established under the Coronavirus Aid, Relief and Economic Security Act (CARES Act), disbursement of ARPA funding was significantly delayed.

With only one year of funding distributed slowly across multiple years, CMS has extended the spending deadline for states through March 31, 2025. While this prevents the expiration of newly available funding, it also has the potential to further delay critical rate review initiatives and dilute the effectiveness of enhanced funding intended for a single year. For states that have already spent the funds, 2023 represents a fiscal cliff as providers attempt to revert to operating at reduced funding levels. For states that are delaying implementation with the extension, the direct support workforce may no longer be there to invest in.

Regulatory Flexibilities

With the declaration of the federal public health emergency, CMS authorized states to request temporary emergency authorization of regulatory waivers. States took advantage of these flexibilities by immediately submitting requests for Section 1135 waivers and Appendix K provisions of Section 1915(c) waivers. Appendix K provisions more specifically address flexibilities in the way HCBS services are delivered. While each state manages its Appendix K flexibilities differently, common examples include the ability to temporarily make retainer payments and increase payment rates, as well as to temporarily expand settings where services may be provided.²⁶

On January 30, 2023, the Biden administration announced its intent to end the public health emergency on May 11, 2023. Faced with the end of the public health emergency, states will have to transition out of the use of emergency authorizations of regulatory flexibilities.

For providers, this will mean facing yet another cliff, this one simultaneous with increased staffing needs to meet new administrative burdens and settings requirements. It also means that temporary regulatory flexibilities, such as expanded telehealth opportunities, new support for family caregivers, retainer payments to support short-term hospital stays and more will also end unless permanently instituted.

At a time when community providers are stretched to capacity with most in the process of discontinuing services, any negative administrative or fiscal impact without commensurate adjustment to reimbursement rates carries the risk of further reducing already diminished access to home- and community-based services by people with IDD.

KEEPING THE NATION'S PROMISE TO PEOPLE WITH IDD

Without a doubt, it will take state and federal governments, providers and advocates working together to address the deterioration of the community-based services network and create sustainable solutions to keep the court-mandated promise of *Olmstead*. To support advocates' efforts, the remainder of Part 2 of this report outlines actions that key actors should take to strengthen community IDD supports. These actions are broken down according to key actors, including the 118th Congress, the Biden administration, state governments, and providers and other stakeholders.

How the Biden Administration Should Invest in Community IDD Services

The Biden administration should provide certainty to states on the availability of regulatory flexibilities through the conclusion of the COVID-19 public health emergency and issue guidance that specifically addresses the transition away from Section 1135 and Appendix

PART 2: SOLUTIONS TO STABILIZE THE DIRECT SUPPORT WORKFORCE

K flexibilities with respect to workforce. Without knowing what budgetary constraints they may face, states are reluctant to make investments in the direct support workforce for fear of impending fiscal shortfalls. Federal guidance would also clarify in instances where states have offered conflicting messages to advocates regarding which regulatory flexibilities can and should move to permanent standards.

- ✓ The Biden administration should issue clear guidance that specifically addresses workforce-related regulatory flexibilities, which will terminate with the conclusion of the public health emergency.

Reimbursement rates determine payment for services and thus the ability of providers to offer competitive wages. Unfortunately, reimbursement rates often go decades at a time without review or adjustment to account for inflation, increased costs and the changing labor market. During the COVID-19 pandemic, reimbursement rates were not assessed to account for changes in the private market, which offered increased wages, hiring incentives and hazard pay to overcome recruitment and retention challenges triggered by the pandemic. It is critical that states establish systems of regular reimbursement rate review to ensure payments stay current and support a qualified and well-trained workforce.

- ✓ The Biden administration should require states to establish systems of access monitoring which require regular review of Medicaid reimbursement rates to ensure payments stay current with increasing costs of service delivery and safeguard access to quality home and community-based services.

Currently, there is no comprehensive national data assessing the direct support workforce related to workforce volume, stability and compensation. As discussed earlier in the report, there is also a fundamental inability to identify issues of equity within the workforce due to a

lack of available data. States are in a unique position to collect and report on these measures and metrics which can then identify concerns and influence responsive policy.

- ✓ The Biden administration should require state and federal agencies to collect and publicly report on measures related to workforce volume, stability and compensation, as well as systemic barriers to equity and the delivery of culturally competent services within the workforce.
- ✓ The Biden administration should expedite existing visa processes to ensure opportunities for aspiring Americans interested in joining the direct support workforce.

How the 118th Congress Should Invest in Community IDD Services

With a new Congress, advocates have an opportunity to build on what we proved in 2022: that an engaged constituency, working together to amplify a common voice, can build the awareness and will required of lawmakers at all levels of government to act. Included in the President's American Jobs Plan, proposed in early 2021, was a \$400 billion investment in home- and community-based services. The investment could have offered a historic foundation of support for community-based services for people with IDD. With the failure of that proposal, however, it is time now for Congress and the White House to take decisive bipartisan action to stabilize the direct support workforce and offer hope to restabilize the home and community-based services infrastructure.

PART 2: SOLUTIONS TO STABILIZE THE DIRECT SUPPORT WORKFORCE

- ✔ The 118th Congress should pass legislation to increase the federal share of Medicaid funding for home- and community-based services to stabilize the direct support workforce and mandate that states must regularly review Medicaid reimbursement rates to ensure payments stay current with increasing costs of service delivery and safeguard access to quality home and community-based services.

In addition to ensuring appropriate funding, the 118th Congress should do more to require comprehensive data collection on the direct support workforce by compelling the U.S. Office of Management & Budget to create a Standard Occupational Classification (SOC) for DSPs. The highly specialized nature of DSPs' work makes their duties more diverse and requires different sets of skills than those held by their counterparts in adjacent professions. SOCs are used to help all levels of government identify employment trends and design policies, including state rate-setting for HCBS.²⁷ 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 118th Congress should pass legislation requiring the creation of a Standard Occupational Classification for Direct Support Professionals.

The 118th Congress should invest in the training and professionalization of the direct support workforce by supporting career pipeline programs for DSPs. Without career ladders or opportunities to professionalize the direct support workforce, DSPs are unable to specialize or leverage their skills to support career advancements. As providers discontinue services, well-trained and experienced DSPs are left with non-transferable qualifications which force them to start anew with each placement.



- ✔ The 118th Congress should enact legislation that would authorize federal grant programs to support the training, recruitment, retention and advancement of the direct support workforce.
- ✔ The 118th Congress should require state and federal agencies to collect and publicly report on measures related to workforce volume, stability and compensation, as well as systemic barriers to equity and the delivery of culturally competent services within the workforce.
- ✔ The 118th Congress should expand opportunities for people entering the United States to join 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. 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.

- ✔ State governments should seek to leverage as many opportunities as possible to secure additional funding from the federal government that strengthen the direct support workforce, while also considering measures that expand access to services.

PART 2: SOLUTIONS TO STABILIZE THE DIRECT SUPPORT WORKFORCE

- ✔ State governments should establish systems which provide regular review Medicaid reimbursement rates to ensure payments stay current with increasing costs of service delivery and safeguard access to quality home and community-based services.

States should develop and contribute to as deep an understanding as possible of the scope of unmet need in their states, including but not limited to, encouraging the U.S. Office of Management and Budget to establish and SOC for DSPs and participating in National Core Indicators' State of the Workforce survey (formerly known as the Staff Stability Survey). States should also independently publicly report on measures and metrics related to workforce volume, stability and compensation. Providing an accurate accounting of the current workforce will support state and federal response to target gaps in access before further damage to the home- and community-based services infrastructure.

- ✔ State governments should participate in National Core Indicators' State of the Workforce surveys (formerly known as the Staff Stability Survey) and other voluntary survey measures assessing the direct support workforce.
- ✔ State governments should collect and publicly report on measures related to workforce volume, stability and compensation, as well as systemic barriers to equity and the delivery of culturally competent services within the workforce.
- ✔ State governments should encourage the federal government to expand and expedite programs that provide opportunities for aspiring Americans interested in joining the direct support workforce.

How Providers & Advocates Should Invest in Community Services

Above all else, providers and advocates must stay vigilant. 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. 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.

- ✔ Providers and advocates should seek out and engage in opportunities for stakeholder engagement and public comment.
- ✔ Providers and advocates should access state-specific *Case for Inclusion* data to fuel your advocacy by visiting caseforinclusion.org.
- ✔ Providers and advocates should browse resources from UCP and ANCOR at their respective websites, ucp.org and ancor.org.
- ✔ Providers and advocates should stay informed about one-click opportunities to take action using the ANCOR Amplifier at amplifier.ancor.org.

Time is of the essence, and it will take every one of us fighting together to keep the promise of community inclusion for people with IDD.

CONCLUSION

Advocates have been reporting for decades on the threat posed by the direct support workforce crisis to the community-based services infrastructure. It is with heavy hearts that members of the UCP and ANCOR teams craft a *Case for Inclusion 2023* that illustrates how those threats have actualized to the point of blocking access altogether to community IDD services. Speaking frankly, we are well beyond the point where stopgap measures will make any difference in stemming the tide of a direct support workforce abandoning the profession in droves.

UCP and ANCOR call on state and federal leaders to keep the promise our nation made to people with disabilities through the ADA and, later, the *Olmstead* decision, by taking bold and decisive action to stabilize this critically important workforce and partner with us to rebuild the community-based services infrastructure.

We call on Congress to pass bipartisan legislation that invests and further professionalizes the direct support workforce by establishing methods and measures of data collection and reporting, training and developing pipelines for career advancement.

We call on the Biden administration to guide states through the unwinding of the pandemic-era policies by guaranteeing available resources and making permanent the regulatory flexibilities that enabled the direct care workforce to hang on by a thread through the COVID-19 pandemic and beyond.

We call on the governments of every state in our nation to develop and contribute to as deep an understanding as possible of the scope and capacity of the provider network to meet the unmet needs of direct care workers and the people they support in your communities.

Above all, we call on you, our fellow advocates, to remain vigilant with us in this fight not to lose further ground. The *Case for Inclusion 2023* is a tool for you to stay informed and access data that make the case for communities whose characters are defined by their exemplification of diversity, equity and inclusion.

Thank you for staying with us in this fight.



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 *Case for Inclusion*

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

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

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 56 affiliates across North America support people with cerebral palsy and other intellectual and developmental disabilities; with ANCOR, one of the co-presenters of the *Case for Inclusion*

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

ENDNOTES

¹ *Olmstead v. L.C.*, 527 U.S. 581, 600 (1999).

² As reported in the *Case for Inclusion 2022*, vacancy rates for full-time direct support positions increased from 8.5% in 2019 to 12.3% in 2020, representing an increase of roughly 45%.

³ *The State of America's Direct Support Workforce Crisis 2022*. Alexandria, VA: ANCOR, 2022.

⁴ National Core Indicators, *2020 Staff Stability Survey Report*. Alexandria, VA: National Core Indicators, 2020.

⁵ *HCBS Settings Rule Implementation: Moving Forward Toward March 2023 & Beyond* (PowerPoint presentation). Baltimore, MD: Centers for Medicare & Medicaid Services, 2022.

⁶ *Direct Care Workers in the United States: Key Facts*. New York: PHI, 2022.

⁷ *The State of America's Direct Support Workforce Crisis 2022*.

⁸ *2020 Staff Stability Survey Report*.

⁹ *Review of States' Approaches to Establishing Wage Assumptions for Direct Support Professionals When Setting I/DD Provider Rates*. Alexandria, VA: ANCOR, 2022.

¹⁰ *Providing Support During the COVID-19 Pandemic: Direct Support Workforce 24-Month Follow-Up Survey*. Minneapolis: Institute on Community Integration, University of Minnesota, 2022.

¹¹ "IDD Waiting List Enrollment for Medicaid Section 1915(c) Home and Community Based Services Waivers as of 2018," *State Health Facts*, Kaiser Family Foundation, accessed Jan. 26, 2023.

¹² Victoria Peebles & Johanna Dolle, "Money Follows the Person: Updated State Transitions as of December 31, 2020," *Mathematica*, 2022, Jul. 20.

¹³ *Ibid.*

¹⁴ "HHS to Provide \$110 Million to Strengthen Safety Net for Seniors and People with Disabilities," Centers for Medicare & Medicaid Services, 2022, Mar. 31.

¹⁵ *2020-21 In-Person Survey: Community Inclusion, Participation and Leisure*. Alexandria, VA: National Core Indicators, 2022.

¹⁶ *2022 National Strategy to Support Family Caregivers*. Washington, DC: Administration for Community Living, 2022.

¹⁷ *Ibid.*

¹⁸ *The State of the States in Intellectual and Developmental Disabilities 2022*. Lawrence: University of Kansas, 2022.

¹⁹ *Ongoing Impacts of the Pandemic on Medicaid Home & Community-Based Services (HCBS) Programs: Findings from a 50-State Survey*. Washington, DC: Kaiser Family Foundation, 2022.

²⁰ Individuals who receive an integrated employment service include those who are receiving services with an immediate goal of entering employment, such as job development, and those receiving long-term services to support maintaining employment.

²¹ Amy Hewitt & Sheryl Larson, "The Direct Support Workforce in Community Supports to Individuals with Developmental Disabilities: Issues, Implications & Promising Practices." *Mental Retardation [sic] and Developmental Disabilities Research Reviews*, 13(2), 178-187.

²² Oliver Lyons, Alberto Migliore, Kelly Nye-Lengerman, Derek Nord & John Butterworth, "Who are Employment Consultants? Characteristics of the Workforce that Connects Job Seekers with Intellectual and Developmental Disabilities to Employment," *Bringing Employment First to Scale*, 1(7). See also Allison Hall, Jennifer Bose, Jean Winsor & Alberto Migliore, "Knowledge Translation in Job Development: Strategies for Involving Families," *Journal of Applied Research in Intellectual Disabilities*, 27, 489-492.

²³ John Butterworth, Alberto Migliore, Derek Nord & Amy Gelb, "Improving the Employment Outcomes of Job Seekers with Intellectual and Developmental Disabilities: A Training and Mentoring Intervention for Employment Consultants," *Journal of Rehabilitation*, 78(2), 20-29.

²⁴ *ARPA Spending Plan Topical Analysis*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, 2021.

²⁵ *Analysis of State ARPA Plans*. Arlington, VA: Advancing States, 2021.

²⁶ "1915(c) HCBS Waiver Appendix K Modifications," Medicaid and CHIP Payment and Access Commission, accessed 2023, Jan. 26.

²⁷ *Review of States' Approaches to Establishing Wage Assumptions*.



About ANCOR & the ANCOR Foundation

For more than 50 years, the American Network of Community Options and Resources (ANCOR) has been a leading advocate for the critical role service providers play in enriching the lives of people with intellectual and developmental disabilities. Learn more at ancor.org.

As the 501(c)3 charitable arm of ANCOR, the ANCOR Foundation exists to expand the commitment and capacity of providers and communities dedicated to improving quality of life for people with disabilities. Learn more at ancorfoundation.org.



About UCP

The mission of United Cerebral Palsy is to be the indispensable resource for people with cerebral palsy, Down syndrome, autism spectrum disorder and other neurodevelopmental disabilities. Founded in 1949, UCP has 56 affiliates (54 in the US and two in Canada) that provide a wide range of services annually to more than 150,000 children and adults, including resources and referrals, advocacy, research, educational instruction, early intervention, physical therapy, job training, integrated employment, home and community based services, recreational opportunities and housing assistance. UCP also advocates for direct support professionals and other direct care workers. We believe all people with disabilities should be treated as equal members of an inclusive society so they can "live life without limits." Learn more at UCP.org.

