



2024 THE CASE FOR INCLUSION

*Transforming Temporary
Progress into Long-Term
Sustainability*



2024 THE CASE FOR INCLUSION

*Transforming Temporary
Progress into Long-Term
Sustainability*

ACKNOWLEDGMENTS

The production of this report and its accompanying data and advocacy resources would not be possible without the meaningful contributions of so many. UCP and ANCOR owe a debt of gratitude to the lead author of this report, Lydia Dawson, as well as several of our respective organizations' team members, including Armando Contreras and James Garcia from UCP, and Elise Aguilar, Sean Luechtefeld and Barbara Merrill from ANCOR.

We are deeply grateful for the professionals who comprise the *Case for Inclusion 2024* Steering Committee, including Colleen Crispino, UCP of Long Island; Angela Easter, UCP of Georgia; Lori Opiela, UCP Seguin of Greater Chicago; Grey Persons, Hope House Foundation; Katie Slade, Exceptional Persons, Inc.; and Jared Weekly, Sunny Oaks, Inc. We also deeply appreciate the thought leadership of our external reviewers, Dorothy Hiersteiner and Laura Vegas from National Core Indicators.

Finally, we don't know where we'd be without the creativity and expertise of several consultants and partners who contributed to this report and its accompanying resources. Special thanks to Erin Dennis, Jadel Munguia and Nina Wheeler from BerlinRosen for supporting communications and outreach; to Karyn Baskette of Yondee Designs for her beautiful graphic design work seen in this report; and to Michael Walker and Jason Melancon of Data Made Useful for developing many of the helpful tools found at caseforinclusion.org.



TABLE OF CONTENTS

- A Letter to the Advocacy Community 5
- Executive Summary..... 6
- Temporary Measures Foster Hope for Permanent Solutions..... 9
- Data Snapshot: Home and Community-Based Services & The Workforce..... 12
- Data Snapshot: Access to Quality Services 16
- Data Snapshot: Equity & Innovation in Service Delivery 19
- A Policy Blueprint for Sustainable Services 21
- Conclusion..... 24
- Glossary of Terms 25
- Endnotes..... 26

“ WHAT WON’T CHANGE IS OUR COMMITMENT TO OUTLINING THE POLICIES NEEDED AT ALL LEVELS OF GOVERNMENT TO FURTHER STRENGTHEN THE SERVICES ON WHICH PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES RELY. ”

—
Armando Contreras & Barbara Merrill



A LETTER TO THE ADVOCACY COMMUNITY

Dear advocate,

This year's *Case for Inclusion* charts a new course for how we publish data throughout the year.

Whereas our current publication schedule enables you to access new data once per year, typically toward the beginning of the year, there are some drawbacks to this approach. Sometimes, new data becomes available right after we go to print, meaning this publication isn't current even when it is first made available. This can become a challenge for advocates seeking to plan their strategies for their states' upcoming legislative sessions.

Having heard feedback from readers like you, our new path forward will involve periodic data snapshots throughout the year on key issues. Having shorter, more targeted data snapshots released every several months when they're most timely will allow us to identify and analyze timely trends to better support your advocacy. What we ultimately envision is a *Case for Inclusion* that fuels a year-round advocacy strategy, rather than a concerted push at one time of the year.

What won't change is our commitment to outlining the policies needed at all levels of government to further strengthen the services on which people with intellectual and developmental disabilities (IDD) rely. This year's report includes the latest data and our annual policy blueprint for sustainable services. Moving forward, we'll start each year by sharing the policy blueprint and a summary of the data released in the previous year. That document will remain relevant across the span of the year when we release the data snapshots that shed light on the scope of the challenges we face.

These enhancements are designed to maximize your ability to leverage the *Case for Inclusion*, and we continue to welcome feedback on how you put this resource to work in service of your advocacy. In the meantime, we hope this 2024 edition helps you in your quest to ensure your state is doing all it can to support people with IDD to live a life without limits, in their homes and communities.

Sincerely,



Armando A. Contreras

Armando Contreras
President & CEO
United Cerebral Palsy



Barbara Merrill

Barbara Merrill
Chief Executive Officer
ANCOR

EXECUTIVE SUMMARY

Since 2006, the annual *Case for Inclusion* built on its foundation of reporting comprehensive data and policy recommendations regarding the effectiveness of state programs in supporting life without limits for people with intellectual and developmental disabilities (IDD) and their families.

The *Case for Inclusion* 2024 summarizes outcomes related to community inclusion across three data snapshots. Highlighted within each data snapshot are key findings derived from nearly 80 measures spanning six of the *Case for Inclusion*'s seven issue areas: Addressing a Workforce in Crisis, Promoting Independence, Reaching Those in Need, Serving at a Reasonable Cost, Keeping Families Together and Tracking Health, Safety & Quality of Life.¹

Following these data snapshots, our policy blueprint for sustainable services summarizes the current legislative and administrative environment, offering specific policy solutions tailored to the 118th Congress, the Biden administration, state governments, providers and other community partners.

Key Findings

This key findings report summarizes the most pressing issues from the *Case for Inclusion* 2024. Among the top findings in the *Case for Inclusion* 2024:

- **Hourly wages for direct support professionals (DSP) wages increased from \$13.61 in 2020 to \$14.41 in 2021.** This marks the second consecutive year of wage increases made possible, at least in part, to temporary emergency funding authorized in response to the COVID-19 pandemic.
- **Vacancy rates for both full- and part-time DSP positions increased substantially, with full-time vacancy rates increasing to 16.5% and part-time vacancy rates increasing to 20.3%.** Meanwhile, turnover among DSPs remained virtually unchanged, from 43.6% in 2020 to 43.3% in 2021.
- **Nationally, there were 497,354 people on state waiting lists for home- and community-based services (HCBS) waivers.** More than 4 in 5 (80.5%) people with IDD waiting for home- and community-based services lived in one of just five states: Texas, South Carolina, Florida, Illinois and North Carolina.
- **Seventeen states and the District of Columbia have closed all of their state-run institutions.** This is an increase from 16 states in last year's *Case for Inclusion*, as Kentucky became the latest state to fully deinstitutionalize. Additionally, there were 1,357 fewer people with IDD living in a large, state-run institution in 2019 than in 2018.
- **Thirty-eight states participated in the federal Money Follows the Person program, earmarked to support older adults and people with disabilities to transition from institutions into home- and community-based settings.** This represents an increase after multiple years of modest declines, with Kansas and New Hampshire rejoining the ranks of states offering this valuable program.
- **Eighteen demonstration waivers that include initiatives to address social determinants of health have been approved, while 17 more are pending.** Primary social determinants of health impacting people with IDD include food security and affordable, accessible housing.

Policy Recommendations

The report's accompanying policy blueprint recommends opportunities for federal and state legislative and executive branches, along with providers and other advocates, to build on progress seen within community-based services. The following is a brief overview of the recommendations that are detailed more fully in the policy blueprint section of this publication.

The *Case for Inclusion 2024* recommends that the Biden administration:

- **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.
- **Encourage interagency collaboration between the U.S. Department of Health & Human Services, U.S. Department of Labor, and other federal agencies** to ensure that policies that will result in and direct appropriate funding for community providers are in place prior to any significant increase in expense to service delivery.
- **Require state and federal agencies to collect and publicly report on measures related to direct support workforce volume, stability and compensation**, as well as measures which address systemic barriers to equity, support for underserved communities, and the delivery of culturally competent services within the direct support workforce.
- **Examine existing programs that support health-related social needs for people with IDD** and the direct support workforce to ensure better access to health care and promote economic independence.
- **Enact legislation to significantly increase the federal share of Medicaid funding for home- and community-based services** to stabilize the direct support workforce and require states to regularly review Medicaid reimbursement rates to ensure payments keep pace with increasing cost of service delivery.
- **Continue investing in HCBS through the American Rescue Plan Act** and extend the increased Federal Medical Assistance Percentage (FMAP) for states with existing maintenance of effort provisions that prevent states from restricting eligibility, limiting services, and reducing payment rates.
- **Enact legislation to provide increased funding** for community providers to offset the increased expense of regulatory compliance.
- **Urge the U.S. Office of Management & Budget to establish a Standard Occupational Classification for direct support professionals** within the federal Standard Occupational Classification system.
- **Enact legislation that would fund federal grant programs** to support the training, recruitment, retention and advancement of the direct support workforce.
- **Examine current policies and expand opportunities to provide immigrants living in the United States with work authorizations** and create pathways for aspiring Americans interested in joining the direct support workforce.

The *Case for Inclusion 2024* recommends that the 118th Congress:

EXECUTIVE SUMMARY

The *Case for Inclusion 2024* recommends that states:

- **Support and leverage as many opportunities as possible to secure additional funding from the federal government** to strengthen the direct support workforce, while also considering policies that expand access to services.
- **Establish systems that 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 the National Core Indicators' annual State of the Workforce Survey** and other data collection efforts assessing the direct support workforce.
- **Collect and publicly report on measures related to direct support workforce volume, stability and compensation**, as well as measures that address systemic barriers to equity, support for underserved communities, and the delivery of culturally competent services within the direct support workforce.

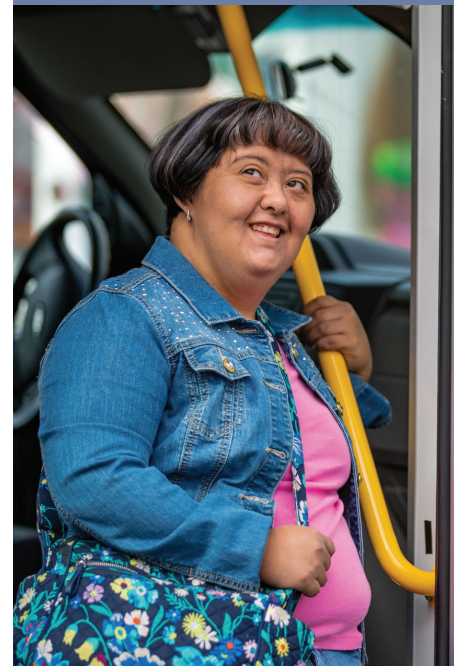
The *Case for Inclusion 2024* recommends that providers and advocates:

- **Engage proactively in opportunities for community partner 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 direct support workforce volume, stability and compensation**, as well as systemic barriers to equity, support for underserved communities, and the delivery of culturally competent services within the direct support workforce.
- **Encourage the federal government to expand opportunities for aspiring Americans interested in joining 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 to support more inclusive opportunities for direct support workers and people with disabilities by 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.



TEMPORARY MEASURES FOSTER HOPE FOR PERMANENT SOLUTIONS

In our 2023 report, the *Case for Inclusion* examined the impact of the direct support workforce crisis on community inclusion and the nation's ability to carry out the promises of the Americans with Disabilities Act (ADA). The data was demonstrative of a direct correlation between the ADA's promise of access and inclusivity against the ability of community providers to attract and retain a sizable and qualified workforce of direct support professionals (DSPs). The reality of the dramatic worsening in the direct support workforce crisis through the COVID-19 pandemic painted a dismal outlook for community inclusion.

By comparison, this edition of the *Case for Inclusion* finds glimmers of hope in recent positive data trends. However, underlying these encouraging gains are temporary COVID-19 relief policies and funding measures, which have been or are being phased out, portending new fiscal cliffs for community providers supporting people with IDD. Moreover, while some measures have improved, many services were devastated by the COVID-19 pandemic and by most measures, the system is a long way from returning to where it was prior to the pandemic.

This is not to say that the pre-pandemic state of the system is what we should strive for. The workforce shortage has limited access to services for at least a quarter of a century before COVID-19 entered our vocabulary. The direct support workforce crisis continues to represent the single greatest risk to community access and inclusion for people with IDD who need home- and community-based services to avoid the kind of unnecessary institutionalization outlawed by the United States Supreme Court in its 1999 landmark decision of *Olmstead v. L.C.*²

Although the workforce crisis was amplified dramatically by the pandemic, it is primarily attributable to long-standing insufficient reimbursement rates—now a reality for decades—



that inhibit the ability of providers to offer wages competitive with those of other hourly wage industries, such as fast food, retail and convenience stores.

With the COVID-19 pandemic, however, came new acknowledgment of the importance and need to invest in the Medicaid Home and Community Based Services (HCBS) program. On March 11, 2021, President Biden signed the American Rescue Plan Act of 2021 (ARPA) into law with targeted funding for the HCBS program. Section 9817 of ARPA invited states to apply for a 10 percentage-point increase to the federal matching rate (known as FMAP) to be used to enhance, expand or strengthen state-based HCBS programs. Unfortunately, enhanced funding was only authorized for a one-year period and the spending deadline for these funds is March 31, 2025.

Broader initiatives to support Medicaid programs and regulatory flexibilities expired at the end of 2023. The Families First Coronavirus Response Act (FFCRA), which provided a 6.2% FMAP increase for Medicaid-funded services, began a gradual phase-out in April 2023 and was fully terminated on December 31, 2023.

TEMPORARY MEASURES FOSTER HOPE FOR PERMANENT SOLUTIONS



Similarly, when the federal public health emergency ended, the Centers for Medicare and Medicaid Services (CMS) began phasing out approval for regulatory flexibilities in 1915(c) waivers, including the ability to temporarily include retainer payments, increase payment rates and expand settings where services may be provided.

Meanwhile, with community providers facing a fiscal shortfall, the demand for home-based care services is expected to increase by 35% in the next decade, adding more than 1 million new jobs for direct care workers and creating more than 9.3 million job openings between now and 2031—more new jobs and job openings than any other single occupation in the country.³

Furthermore, the number of people with IDD waiting for HCBS services continues to grow, with 15,753 added in the last year alone.⁴ While we have seen growth in starting and average hourly DSP wages, vacancy rates for both full-time and part-time DSP positions increased

substantially, while turnover rates remained steady at around 43%.⁵ Despite two consecutive years of increases in starting wages, providers continue to struggle to remain competitive for workers with hourly wage industries offering higher pay and better benefits with less demanding work and training requirements.

The uncertainty of the future is underscored and reflected in recent data from the 2023 edition of ANCOR's *State of America's Direct Support Workforce Crisis* report.⁶ Now in its fourth year of publication, findings reveal community providers overwhelmingly struggle with recruitment and retention, with 95% reporting "moderate" or "severe" staffing shortages in the past year.

Insufficient staffing, in turn, remains a barrier to the ability of community providers to continue offering services, with 44% of respondents indicating they had discontinued programs or services due to the workforce shortage. Though this finding represents an improvement compared to the previous year's report, there was a notable increase in the number of respondents indicating they were likely to pursue additional discontinuations of programs and services at current rates of vacancy and turnover.

These challenges have wreaked havoc on the ability of providers to deliver quality services to those in need. March 2023 was the deadline for compliance with the HCBS Settings Rule, but the majority of states remain under a corrective action plan due to their inability to comply with the new standards nearly a decade after the rule's finalization.⁷

The HCBS Settings Rule established criteria in 2014 for the settings in which home- and community-based services should be delivered, emphasizing the critical importance of autonomy, self-determination and service quality.

TEMPORARY MEASURES FOSTER HOPE FOR PERMANENT SOLUTIONS

However, many of the provisions of the HCBS Settings Rule require a robust workforce and other investments in services that providers struggled to shoulder without increases in reimbursement. Following several delays of the implementation deadline and with the deadline now firmly behind us, CMS is working with states on procedures to correct deficiencies and to delay penalties for noncompliance given challenges due to insufficient staffing.

In the past year, the federal government has introduced new initiatives and regulatory proposals that could, if finalized, trigger significant new expenses for community providers. With the release of the Fall 2023 Unified Agenda of Regulatory and Deregulatory Actions, the Biden administration signaled new regulatory activity that would introduce significant new expenses, including finalization of rules that would increase overtime expenses for community providers by an estimated \$1.05 billion in the first year.⁸ This financial impact is



due to the nature of Medicaid as a state-federal partnership, with reimbursement rates set by states and matching funds contributed by the federal government, meaning states must meet federal mandates with commensurate increases in funding—something that often lacks the financial resources or political will to happen.

Fortunately, the challenges and barriers to creating a stable and sustainable system of services are not without reasonable and appropriate policy solutions. This year's *Case for Inclusion* emphasizes how coming together as a nation to withstand the COVID-19 pandemic brought to light the meaningful gains that can be achieved toward community inclusion through investments in community-based services. As we look to the future, we must acknowledge the ongoing crisis in community-based services. In short, we must remain vigilant in our advocacy to uphold America's promise of community inclusion for all.



DATA SNAPSHOT: HCBS AND THE WORKFORCE



FROM THE FIELD IF NOT HERE, THEN WHERE?

Along with their families, people with IDD who spend extensive time on their state's waiting list breathe a huge sigh of relief when they finally start receiving the services they have lacked for so long. But it is increasingly rare that families can depend on their service provider to remain in operation after they begin receiving services, causing new and sometimes unpredictable gaps and delays in access to services—even after coming off of the waiting list.

That experience hit close to home for a large group of Louisianans with IDD when an experienced provider closed its doors. Luckily for the group that had been supported by that provider, they were able to begin accepting services from Lafayette-based CADENCE of Acadiana, a provider of community supports and case

management services in 21 parishes across the southern part of the state.

The previous provider ultimately closed its doors because it couldn't recruit and retain enough qualified workers due to low reimbursement rates. Although CADENCE of Acadiana has significant staffing challenges of its own, Executive Director Erica Buchanan had hoped that the previous provider's employees would apply to come work at her agency to offer continuity in the transition for those relying on their support. Unfortunately, "none of the staff that worked with the previous agency have applied to continue supporting the individuals we are now serving," says Buchanan. "It is our privilege to support these individuals, but we are facing the same challenges [as the previous provider]."

As CADENCE of Acadiana continues accepting new referrals, the agency is seeing longer and longer delays in getting people approved for and receiving services. These delays translate into further gaps in required supports at a time when people's lives have already been upended.

Still, Buchanan persists, because she knows from the case management services her agency offers that there are no other providers to step in. Buchanan added that her agency "shares the state's goal of 'getting individuals served,' but there is simply not enough direct support staff, support coordination staff or specialty providers who can deliver the service at the rate and requirements that come along with the task."

Home- and community-based services (HCBS) supporting people with IDD are primarily funded by Medicaid and cover a wide range of habilitation services, including support for skill-building across activities of daily living, employment, transportation, and other necessary supports that promote independence and community inclusion.

DSPs deliver individualized services to millions of people with IDD, meeting the differing needs necessary to help people achieve community integration and avoid unnecessary and expensive institutionalization. DSPs must be qualified, available and culturally competent to support a wide range of needs, with the ability to both guide

and empower the person they are supporting while respecting their autonomy and self-determination. This level of complexity takes a skilled professional deserving of competitive, livable wages.

Unfortunately, there has been a workforce crisis for many decades in community-based settings, due to insufficient reimbursement rates and the inability of providers to offer wages that enable them to compete with industries offering hourly wage positions, such as fast-food restaurants or retail and convenience stores. This crisis continues to be the greatest barrier to accessing community-based support and services for people with IDD.

DATA SNAPSHOT: HCBS AND THE WORKFORCE

Without sufficient staffing, community providers have been forced to reject referrals and close services, increasing the risk of hospitalization and institutionalization for people with IDD.

The direct support workforce crisis was exacerbated by the COVID-19 pandemic, causing devastating impacts to access and community inclusion as poignantly demonstrated in last year's *Case for Inclusion* report. As the public health emergency came to a close, we saw the emergence of new research on the lasting impacts of the direct support workforce crisis. One source of such data is ANCOR's 2023 *State of America's Direct Support Workforce Crisis*, which found that:

- **95%** of community providers experienced moderate to severe staffing shortages in the past year.
- More than half (**54%**) of community providers indicated they deliver services in an area where few or no other providers deliver similar services.
- More than three-fourths (**77%**) of community providers reported turning away new referrals in the past year due to ongoing staffing shortages.
- **72%** of respondents reported that they had experienced difficulties adhering to established quality standards due to ongoing staffing challenges.
- Of those community providers that reported offering case management services, fully **three-fourths** indicated they had experienced difficulties connecting people with services due to a lack of available providers.

It is not surprising that community providers are continuing to suspend services, especially as the effects of underinvestment in the direct support workforce can be seen in substantial increases to vacancy rates through the COVID-19 pandemic. Vacancy rates for both full- and part-time direct support positions increased drastically in 2020

and 2021. Full-time vacancy rates grew to 16.5% in 2021—a 94% increase from pre-pandemic levels.⁹ Meanwhile, part-time vacancy rates increased from 16.4% in 2020 to 20.3% in 2021.¹⁰

Although vacancy rates continued to rise between 2020 and 2021, so too did starting and average wages for DSPs. Data from 2021 marked the second consecutive year in which average hourly DSP wages increased by a statistically significant amount (5.9%), from \$13.61 in 2020 to \$14.41 in 2021. This was the first time since the *Case for Inclusion* began reporting on this data that we saw significant increases in the average DSP wage two years in a row. Starting wages also grew by a promising 6.2%, from \$12.72 per hour on average in 2020 to \$13.61 per hour on average in 2021.

Unfortunately, these increases tie directly to investments made pursuant to pandemic relief funding, much of which has terminated or faces impending sunset provisions. Moreover, despite the positive trends in increased funding, direct support wages continue to be insufficient to attract and sustain a sufficient and qualified workforce to prevent closures.

While the direct support workforce crisis continues to suffer lasting impacts from the COVID-19 pandemic, many of the measures related to community access and relationships appear to show signs of reversion to pre-pandemic levels. For example, the number of people with IDD reporting they had gone out for entertainment at least once in the past month has climbed back from 40% in 2021 to 62% just one year later. Moreover, the number of people with IDD reporting that they had a dental visit within the past year actually exceeded pre-pandemic levels, rising from 70% in 2019 to 75% in 2021.¹¹

Emerging from the pandemic and seeking community engagement outside of the home puts more pressure on community providers to ensure the direct support workforce is available to deliver personalized and individualized supports.

DATA SNAPSHOT: HCBS AND THE WORKFORCE



DATA OF NOTE

ADDRESSING A WORKFORCE IN CRISIS

Promisingly, the gap between average DSP wages and states' minimum wages grew nationally and in nearly every state for which data were available. This measure matters because a more significant gap suggests a better ability to compete for hourly wage workers.

In 2021, Pennsylvania and Utah—both of which have minimum wages that match the national minimum of \$7.25—became the first two states to see their average hourly DSP wage exceed 200% of the state minimum wage.



Indeed, the ability to control one's schedule and access to the broader community are enumerated rights guaranteed by the HCBS Settings Rule.

However, with limited staffing, it is much more difficult to allocate human capital when balancing the needs of multiple people with differing interests and activities outside of the home.

In recognition of how the direct support workforce crisis impacts the ability of states to comply with the requirements of the Settings Rule, CMS authorized corrective action plans (CAP) to provide states with additional time to come into compliance.¹² Of the 45 states using approved CAPs for any HCBS program, 29 were in use for services delivered to people with IDD.¹³ Unfortunately, without a clear path of redress to the workforce crisis, it is uncertain how these states will transition out of the use of CAPs and successfully meet the terms of compliance.

Meanwhile, the demand for direct care workers continues to grow at an exponential rate, adding nearly 1.6 million new jobs in the last decade.¹⁴ Direct care continues to be the fastest growing occupation in the country with another 1 million new jobs expected to open in the field between 2021 to 2031 because of the growing demand for HCBS services.¹⁵ Given the shortages, made worse by turnover and vacancy rates, it is expected that there will be 9.3 million total job openings for direct care workers in the next decade.¹⁶

While the overall home care workforce is projected to grow by 35 percent in the next decade, it is difficult to capture the specific impact of the DSP workforce. Despite the unique and skilled dedication of DSPs, the direct support workforce continues to be left behind by federal data collection efforts. Currently, "Direct Support Professional" is not recognized as an occupation in the federal Standard Occupational Classification system. SOCs are used to collect data and help all levels of government identify employment trends. Without a SOC, DSPs are either excluded from data altogether or inaccurately and inconsistently incorporated into categories for other professions, undermining our ability to understand the full spectrum of professional activities carried out by DSPs.

DATA SNAPSHOT: HCBS AND THE WORKFORCE

The direct support workforce is integral in meeting the high rates of demand for HCBS due to the increasing population of people with IDD seeking and accessing services and the hundreds of thousands more on waiting lists. Although growth in average and starting wages is promising, absent additional funding, community providers are unable to offer higher wages without cutting programmatic costs, which has led to shuttering programs and services. And as COVID-19 relief funding begins to disappear, community providers will face a new reality of being forced to pay for more with less, or risk closing their doors entirely.



DATA OF NOTE

SPENDING ARPA FUNDS TO SHORE UP THE DIRECT SUPPORT WORKFORCE

According to the Centers for Medicare and Medicaid Services, the American Rescue Plan Act (ARPA) generated **\$36.8 billion** in new spending on home- and community-based services.



As if that amount isn't cause for celebration, consider this: more than two thirds of that spending (**\$24.6 billion**) went toward recruitment and retention initiatives, and all 50 states and the District of Columbia spent at least some of their ARPA resources on strengthening the DSP workforce. These initiatives included everything from raises to one-time bonuses to temporary rate increases and more.

The lesson?
Investing in the direct support workforce works for all of us.

DATA SNAPSHOT: ACCESS TO QUALITY SERVICES



FROM THE FIELD PITTING SERVICE QUALITY AGAINST SERVICE AVAILABILITY

ANCOR's 2023 finding that 77% of providers had turned away new referrals in the past year is especially troubling when you consider that more than half (54%) operate in areas where few or no other providers deliver similar services. This dynamic creates a gut-wrenching choice for leaders in our field: turn people away knowing they may have no other way of getting the support they need or agree to support them even though being understaffed has the potential to diminish the quality of available services.

Carrie Guida is the Executive Director of Minnesota-based Pine River Group Home, Inc. Guida admits that she once advocated for closing or consolidating some of Pine River's group homes because she worried she couldn't guarantee the quality of services in those homes due to the workforce crisis. However, it quickly became clear that closing or consolidating the homes wasn't an option without leaving people unsupported and without access to necessary services. Although continuing to operate means more people in Guida's community have access to the services they need, staffing shortages may also lead to "many fewer opportunities for community inclusion" and as a result "increased feelings of isolation."



Beyond delivering services that assist people to achieve independence and community inclusion, HCBS programs also traditionally offer a more cost-effective approach to supporting people with IDD who can benefit from living in the community. Although HCBS waiver programs are federally prohibited from exceeding the average institutional cost per person for each level of care, most states spend only a small fraction of the cost of institutional care on their HCBS programs. In 2019, states spent three times more on average per capita to support people with IDD in institutions (\$396,019 on the lowest end of the spectrum); by comparison, average spending on the low end of the spectrum in home- and community-based settings was just \$55,492.¹⁷

However, as an optional Medicaid benefit, states can and often do set limits on the number of people served in HCBS programs. After meeting the set cap of funded openings, many states maintain waiting lists where people with IDD can wait years for funding to be approved before they are approved to seek services. Because there are no federal requirements for when and how states manage their waiting lists, there are often inconsistencies in how states account for access to HCBS.

As discussed in the *Case for Inclusion 2023*, although routinely cited, waiting lists are often poor indicators of overall unmet needs and often represent only a fraction of people with IDD waiting for services that support community inclusion. The management of state HCBS waiting lists varies widely across the country from a first-come, first-served approach to eligibility based on a set of state-determined prioritized needs.

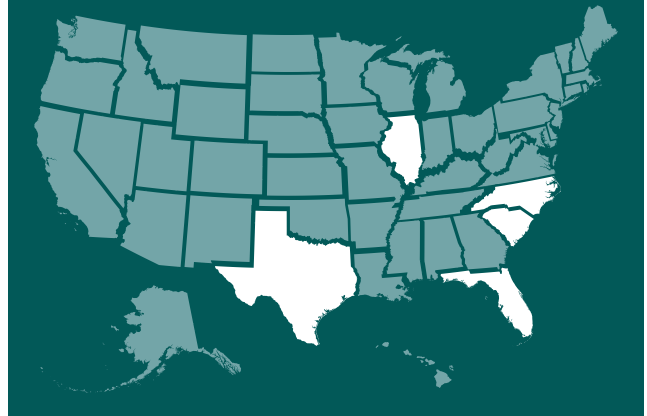
DATA SNAPSHOT: ACCESS TO QUALITY SERVICES

Moreover, inadequate staffing remains a significant barrier to accessing services even after being removed from waiting lists. When there are fewer people on state waiting lists, that does not always mean that more people are receiving services or that there are fewer people in need of services. Rather, reported shifts can be a result of updated methodologies used by states to transition away from waiting lists to “referral lists” or “registries” using the same criteria. It is for these reasons that researchers have started asking states to report people who are interested in, but not receiving, services—rather than simply asking for the number of people on the state’s “official” waiting list.¹⁸

Nonetheless, waiting lists can offer flags for further investigation where there is trending growth putting people with IDD at increased risk for hospitalization and institutionalization. Between 2022 and 2023, the number of people with IDD waiting for waiver services nationally grew by 3.3%, with 497,354 people now on state waiting lists.¹⁹

Among those waiting for HCBS services in 2023, more than 4 in 5 (80.5%) lived in one of just five states: Texas, South Carolina, Florida, Illinois and North Carolina.

In fact, if you’re a person on a state’s waiting list for IDD services, there’s a better than **50-50** chance that you live in Texas; **63%** of all who were waiting live in Texas.



BARRIERS TO SERVICES AND COMMUNITY INCLUSION THAT SOMEONE FACES IF THEY'RE FORTUNATE ENOUGH TO MAKE IT OFF A WAITLIST:



DATA SNAPSHOT: ACCESS TO QUALITY SERVICES

As more states move away from large-scale, state-run institutions, we can expect a corresponding increase in people seeking HCBS and access to support in the community. Currently, 17 states and the District of Columbia have closed all their state-run institutions, with Kentucky joining the ranks of deinstitutionalized states since the publication of the *Case for Inclusion 2023*.²⁰ Further, there were 1,357 fewer people with IDD living in a state-run institution in 2019 than in 2018.²¹ Nationally, about 16,200 people remained living in and receiving services from state-run institutions.²²

This year's report also marks new participation in the Money Follows the Person (MFP) program, further emphasizing the shift from institutional care into the community. MFP is a federal, grant-funded demonstration program that provides resources to support people transitioning out of institutions and into the community. The MFP program offers flexibility in funding to cover some of the upfront expenses not traditionally offered through Medicaid. For example, MFP can be used to pay for environmental modifications, moving expenses, and necessary services for the first 365 days of the transition.

Unfortunately, since funding for the original MFP pilot program expired in 2016, the program has been funded by a series of short-term renewals, dissuading states from participating without certainty of funding. As a result, we saw multiple years of modest declines in the number of states participating in MFP. However, 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 people's transitions, including short-term housing and food assistance.²³

It is perhaps for this reason we are seeing a change in the trajectory of MFP participation



with participating states increasing from 36 in 2022 to 38 in 2023.²⁴ In the last year, Kansas and New Hampshire joined or rejoined the ranks of states offering this valuable program to people with IDD leaving institutions for community care. The most recent four-year congressional reauthorization will make program funds available through 2027.

While it is encouraging to see more interest from states in developing a pathway for people with IDD out of institutions and into the community, it is unsustainable without a network of quality supports and services for people to access in their communities. Nationally, 93% of people receiving IDD services in 2019 were receiving services through a waiver, yet the proportion of spending to meet rising service delivery expenses increased only slightly from 83% to 84%.²⁵ COVID-19 relief funding infused Medicaid-funded supports with an increased FMAP, but new funding was only available temporarily. Without permanent measures in place to stabilize the workforce and meet increased expenses, the growing demand will only result in more people waiting for services.

DATA SNAPSHOT: EQUITY & INNOVATION IN SERVICE DELIVERY

People with disabilities face significant and sometimes compounding barriers to community inclusion that extend far beyond access to services. As policymakers consider opportunities to strengthen the service delivery system, such initiatives must be coupled with action to improve social safety net services more broadly.

While the *Case for Inclusion* focuses on the effectiveness of state Medicaid programs in serving people with IDD and their families, those programs are only as effective as the person's ability to access the full benefits from them. Emerging research finds that health-related social needs (HRSN)—a person's unmet, adverse social conditions that contribute to poor health—can affect as much as 50% of county-level variance in health outcomes.²⁶ These needs result from underlying social determinants of health, such as housing, food security and transportation, and can profoundly hinder access to services for people with IDD.

For example, lack of affordable and accessible housing remains a significant barrier to receiving services in the community. Unlike institutional long-term care, Medicaid does not cover the cost of room and board for most community-based settings. In turn, people with IDD must separately secure housing to have a home in which to receive home-based services. Faced with the rising cost of housing and the intersectional impacts of disability discrimination, many people with IDD are unable to find housing and must turn to hospitals and institutions to receive support for basic needs.

Following President Biden's Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, we saw a renewed focus from the U.S. Department of Health and Human Services on advancing health equity.²⁷ Soon thereafter, CMS released the first pillar of its strategic plan to advance health equity by "designing, implementing, and operationalizing policies and programs that support health for all people served by [CMS] programs by incorporating the

perspective of lived experiences and integrate safety net providers and community-based organizations into [CMS] programs."²⁸

In November 2023, CMS released an informational bulletin and corresponding framework on how Medicaid and CHIP programs can help their enrollees stay connected to coverage and access needed supports and services by addressing health-related social needs. Across HCBS authorities, CMS encouraged states to seek housing and home environment supports including housing transition and navigation services, pretenancy navigation services, one-time transition and moving costs, and tenancy and individualized case management. CMS also encouraged states to address nutrition and food security through offering nutrition counseling and instruction, home delivered meals or pantry stocking, and grocery provisions to avoid unnecessary acute care admissions.²⁹

In turn, more states have started seeking approval for demonstration waivers with provisions that address social determinants of health. There are currently 18 states with approved demonstration waivers including provisions that address social determinants of health and 17 states with demonstration waivers submitted and pending approval.³⁰ Of the 18 approved waivers, nine include infrastructure funding, 17 include housing supports, seven include support with nutrition, and six include employment supports.

While this offers a positive outlook for people with IDD accessing Medicaid services, unmet HRSNs also deeply affect the workforce that supports people with IDD. Without access to affordable housing, DSPs also experience health inequities, which in turn affect their ability to deliver the highest-quality home- and community-based supports. Recent research finds that 39% of direct care workers live in low-income households and 46% rely on public assistance.³¹

DATA SNAPSHOT: EQUITY & INNOVATION IN SERVICE DELIVERY

Given that direct care workers are primarily women (approximately 80%) and people of color (approximately 65%), low wages and the resulting inability to meet their health-related social needs amplify the intersectional impacts of both racial and gender inequities.

Meaningfully ensuring community inclusion requires not only a stable and robust system of services, but also requires recognition of how social determinants of health can impact access to those services. This extends to the direct support workforce and can have a ripple effect that goes beyond the people relying on those services. Thus, ensuring sufficient funding for community-based services is crucial to ensuring a more equitable community.



**DATA
OF NOTE**

NEW JERSEY'S 1115 WAIVER

New Jersey recently received final approval for its Section 1115 demonstration waiver, which includes targeted initiatives to address health-related social needs.

Approved housing supports outlined in New Jersey's 1115 waiver include medically necessary air conditioners and air filtration devices, medically necessary home modifications and remediation services, pretenancy and tenancy-sustaining services, and housing transition navigation services.




A POLICY BLUEPRINT FOR SUSTAINABLE SERVICES


Whereas the preceding Data Snapshots highlight barriers and opportunities to build on positive momentum, this Policy Blueprint for Sustainable Services offers targeted solutions to stabilize the workforce and ensure meaningful access to sustainable services and community inclusion. This section is dedicated to exploring these policy solutions.

How the Biden Administration Should Invest in Community IDD Services


Reimbursement rates determine payment for services and thus the ability of providers to offer competitive wages. Unfortunately, reimbursement rates often go years without review or adjustment to account for inflation and the rising expense of service delivery. It is critical that states establish systems of regular reimbursement rate review to ensure payments reflect and address the increasing cost of living and support a qualified and well-trained workforce.


Further, it is crucial that there be increased interagency dialogue and collaboration across federal agencies proposing new policies that increase the cost-of-service delivery without providing commensurate funding. This type of dialogue is especially important in the coming months as both the U.S. Department of Health & Human Services and U.S. Department of Labor engage in substantial changes to the rules that impact the direct support workforce. Without alignment across agencies, future proposed rule changes have the potential to cause significant fiscal impacts to community providers, rendering them unable to mitigate the resulting negative impacts on access and forcing them to shutter programs and services.

 **The Biden administration should require states to establish systems of access monitoring that compel regular reviews of Medicaid reimbursement rates** to ensure payments reflect and address the increasing costs of service delivery and safeguard access to quality home- and community-based services.

 **The Biden administration should encourage interagency collaboration between the U.S. Department of Health and Human Services, U.S. Department of Labor, and other federal agencies** to ensure that policies are in place to guarantee appropriate funding for community providers prior to any significant increase in service delivery costs.

Currently, there is no comprehensive national data assessing the direct support workforce related to workforce volume, stability and compensation. 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, thus enabling them to 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 racial equity, support for underserved communities, and the delivery of culturally competent services within the workforce.

 **The Biden administration should examine existing programs that support health-related social needs** for people with IDD and the direct support workforce to ensure better access to health care and promote economic stability.

How the 118th Congress Should Invest in Community IDD Services

With the wind-down of pandemic-era investments in the Medicaid HCBS program colliding against growing operating costs and a persistent workforce shortage, the greatest support Congress can provide is increased federal funding.

A POLICY BLUEPRINT FOR SUSTAINABLE SERVICES

- ✓ **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 require states to regularly review Medicaid reimbursement rates to ensure payments reflect and address the increasing costs of service delivery and safeguard access to quality home and community-based services.

In particular, the Better Care Better Jobs Act (H.R. 547 / S. 100) would provide an increased FMAP for states to invest in their HCBS workforce and would require more frequent rate reviews. Meanwhile, the HCBS Access Act (H.R. 1493 / S. 762) would ensure greater funding by making HCBS a mandatory service.

- ✓ **Congress should continue the investment in HCBS authorized under ARPA** and extend the increased FMAP for states. The HCBS Relief Act (S. 3118 / H.R. 6296) would provide states with an additional 10 percentage-point FMAP increase for two years.

- ✓ **Congress should enact legislation to provide increased funding for community providers to offset the increased expense of regulatory compliance.** The Disability Community Act (H.R. 7267) would provide increased funding to IDD providers to enable them to meet compliance with new policy measures introduced by the U.S. Department of Labor and U.S. Department of Health & Human Services.

In addition to ensuring appropriate funding, Congress should do more to require comprehensive data collection on the direct support workforce by urging the U.S. Office of Management & Budget to create a Standard Occupational Classification (SOC) for DSPs. The highly specialized and diverse nature of DSP work requires a different set of skills when caring for people with IDD 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.³² The absence of a SOC categorizing DSPs as employed in a distinct profession also enables states to keep DSP wages low by using extant data about adjacent professions to justify depressed reimbursement rates.

- ✓ **Congress should urge the U.S. Office of Management & Budget to establish a Standard Occupational Classification for DSPs.** The Recognizing the Role of Direct Support Professionals Act (H.R. 2941 / S. 1332) supports the creation of a SOC for DSPs.

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 certify and 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.

- ✓ **Congress should enact legislation that would fund federal grant programs to support the training, recruitment, retention and advancement of the direct support workforce.** The Supporting Our Direct Care Workforce and Family Caregivers Act (S. 1298) and the Direct CARE Opportunity Act (H.R. 4720) are two bills that would authorize federal grant programs to support the training, recruitment, retention and advancement of the direct support workforce.

- ✓ **Congress should examine current policies and expand opportunities to provide immigrants living in the United States with work authorization** and create pathways for aspiring Americans interested in joining the direct support workforce.

How States Should Invest in Community IDD 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** to strengthen the direct support workforce, while also considering measures that expand access to services.
- ✓ **State governments should establish systems that provide regular review of Medicaid reimbursement rates** to ensure payments reflect and address the 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, through measures including but not limited to, encouraging the U.S. Office of Management & Budget to establish a SOC for DSPs and participating in National Core Indicators' annual State of the Workforce Survey.

States should also independently and publicly report on measures and metrics related to workforce volume, stability and compensation. Providing an accurate accounting of the current workforce will support state & federal response to target gaps in access before further damage to home- a community-based services infrastructure.

- ✓ **State governments should participate in National Core Indicators' annual State of the Workforce 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 measures that address systemic barriers to equity, support for underserved communities, and the delivery of culturally competent services within the workforce.

How Providers & Advocates Should Invest in Community IDD 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 IDD services 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 community partner 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



While the *Case for Inclusion 2024* continues to illustrate the devastated state of the direct support workforce and its impact on access to services, this year's edition also points to breakthroughs in which the vigilance of advocates working together made meaningful changes to the service delivery system. In short, it's imperative that we transform the glimmers of hope we see now—those signs of short-term progress—into the long-term sustainability of the service delivery system.

For example, we saw additional closures of state-run institutions and, in turn, increased utilization of community-based services. We also saw a record 28 states and the District of Columbia participate in National Core Indicators' 2021 State of the Workforce Survey, volunteering their time and data to better understand the direct support workforce. And, after multiple years of decline, the number of states participating in Money Follows the Person increased, offering new resources to support people transitioning from institutions into the community.

Where there is hope, there is also a long road ahead to stabilizing the direct support workforce and rebuilding the community-based services infrastructure devastated by years of underinvestment and compounded by the COVID-19 pandemic.

We simply cannot do this work alone. UCP and ANCOR once again call on state and federal leaders to work together and alongside community partners to build on the momentum we have in this moment to change the course of history for people with IDD relying on community-based services.

We can and must do more to safeguard the future of community inclusion for people with IDD relying on community-based services.

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

- 1 Visit the *Case for Inclusion 2024* website at caseforinclusion.org to access additional data, stories and other resources that can aid in your advocacy.
- 2 Use the ANCOR Amplifier at amplifier.ancor.org to lend your voice to calls on elected officials to take meaningful action in service of this shared vision.
- 3 Connect with United Cerebral Palsy at UCP.org and/or its network affiliates in the U.S. and Canada to see how you can get involved in these issues at a local, state or regional level.

GLOSSARY OF TERMS

ABBREVIATION	DEFINITION
ANCOR	American Network of Community Options and Resources; a nonprofit trade association representing nearly 2,500 private community IDD providers; partners with UCP to co-present the annual <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
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 federal Standard Occupational Classification system to formally identify and recognize a particular occupation
UCP	United Cerebral Palsy; a national nonprofit organization whose 55 affiliates in the U.S. and Canada support people with cerebral palsy and other intellectual and developmental disabilities; with ANCOR, which co-presents the annual Case for Inclusion report

ENDNOTES

- ¹ Readers should note that data in issue areas not covered in this report were excluded because they were not available as of the end of 2023. However, new data may have been published after the initial draft of this report was written. The full suite of data current as of the end of 2023 can be found at caseforinclusion.org.
- ² *Olmstead v. L.C.*, 527 U.S. 581, 600 (1999).
- ³ *Direct Care Workers in the United States: Key Facts* (New York: PHI, 2023).
- ⁴ "IDD Waiting List Enrollment for Medicaid Section 1915(c) Home and Community Based Services Waivers as of 2023," State Health Facts, Kaiser Family Foundation, accessed February 8, 2024
- ⁵ *2021 State of the Workforce Survey Report* (Alexandria, VA: National Core Indicators, 2023).
- ⁶ *The State of America's Direct Support Workforce Crisis 2023* (Alexandria, VA: ANCOR, 2023).
- ⁷ Maiss Mohamed, Alice Burns & Molly O'Malley Watts, "How are States Implementing New Requirements for Medicaid Home- and Community-Based Services?," Kaiser Family Foundation, December 13, 2023.
- ⁸ "Fall 2023 Unified Agenda of Regulatory and Deregulatory Actions," Office of Information & Regulatory Affairs, The White House, accessed February 8, 2024.
- ⁹ *2021 State of the Workforce*, 41.
- ¹⁰ Ibid.
- ¹¹ *2021-22 In-Person Survey: Community Inclusion, Participation and Leisure* (Alexandria, VA: National Core Indicators, 2023).
- ¹² *HCBS Settings Rule Implementation: Moving Forward Toward March 2023 & Beyond* (Baltimore, MD: Centers for Medicare & Medicaid Services, 2022).
- ¹³ "How are States Implementing New Requirements," 1.
- ¹⁴ *Direct Care Workers in the United States*, 11.
- ¹⁵ Ibid.
- ¹⁶ Ibid.
- ¹⁷ *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2019* (Minneapolis, MN: Residential Information Systems Project, Institute on Community Integration, University of Minnesota, 2022).
- ¹⁸ Alice Burns, Maiss Mohamed & Molly O'Malley Watts, "A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2023," Kaiser Family Foundation, November 29, 2023.
- ¹⁹ "IDD Waiting List Enrollment," 1.
- ²⁰ Ibid.
- ²¹ Ibid.
- ²² Ibid.
- ²³ "HHS to Provide \$110 Million to Strengthen Safety Net for Seniors and People with Disabilities," Centers for Medicare & Medicaid Services, March 31, 2022.
- ²⁴ "Money Follows the Person Recipient Contact Information," Centers for Medicare & Medicaid Services, accessed February 8, 2024.
- ²⁵ *In-Home and Residential Long-Term Supports*, 49.
- ²⁶ *Addressing Social Determinants of Health: Examples of Successful Evidence-Based Strategies and Current Federal Effort* (Washington, DC: Office of Health Policy, U.S. Department of Health & Human Services, 2022).
- ²⁷ Exec. Order No. 13985, 86 Fed. Reg. 7009 (2021).
- ²⁸ *CMS Strategic Plan Health Equity Fact Sheet* (Baltimore, MD: Centers for Medicare & Medicaid Services, 2023).
- ²⁹ *Coverage of Health-Related Social Needs Services in Medicaid and CHIP* (Baltimore, MD: Centers for Medicare & Medicaid Services, 2023).
- ³⁰ "Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State," Kaiser Family Foundation, accessed January 5, 2024.
- ³¹ *Direct Care Workers in the United States*, 10.
- ³² *Review of States' Approaches to Establishing Wage Assumptions for Direct Support Professionals When Setting IDD Provider Rates* (Alexandria, VA: ANCOR, 2022).



About ANCOR

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](https://www.ancor.org).



About UCP

United Cerebral Palsy (UCP) exists to promote the independence, productivity and full citizenship of people with cerebral palsy, intellectual and developmental disabilities, and other conditions, through its network of affiliates in the U.S. and Canada.

For 75 years, UCP has been a trusted resource for the people with disabilities supported by its affiliates and their family members. From homeownership to health care reform, inclusive education to competitive employment, UCP works closely with its affiliates to open doors for people with disabilities and has established itself as a leader in the disability community. Learn more at [UCP.org](https://www.ucp.org).

