Case for Inclusion Data Snapshot

How a Workforce in Crisis is Jeopardizing Community Access

October 2024

ANCOR

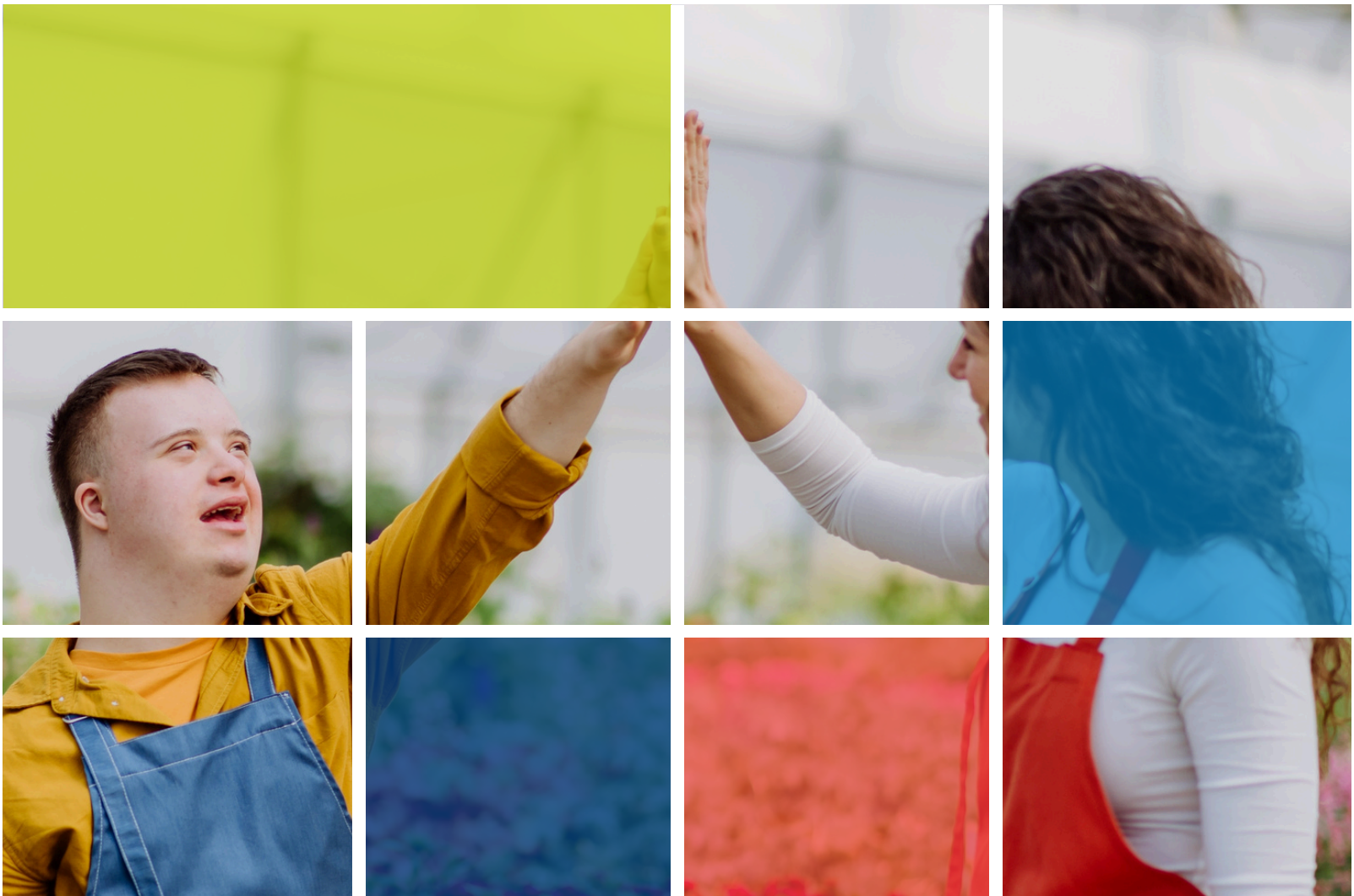
UCP UNITED 75 YEARS

Acknowledgements

UCP and ANCOR extend their gratitude to members of their respective teams for their contributions to this Data Snapshot. From ANCOR, we extend our gratitude to Lydia Dawson, the lead author of this publication; Alli Strong-Martin, the publication's lead designer; and Elise Aguilar, Noah Block, Sean Luechtefeld and Tom Rice, all of whom provided helpful feedback on the Data Snapshot. From UCP, we are grateful for Armando Contreras and James Garcia, whose leadership and contributions have been invaluable to this publication.

ANCOR and UCP also extend their gratitude to our colleagues, Laura Vegas and Dorothy Heiersteiner from National Core Indicators, for their feedback on earlier drafts of this publication, as well as for their advocacy in service of better data on the direct support workforce. Additionally, we appreciate KFF for furnishing annual data on the state of HCBS waiting lists.

Finally, we appreciate the work of Michael Walker and Jason Melancon from DataMadeUseful for developing the data apps that house the treasure trove of data accessible at caseforinclusion.org.



Executive Summary

Since 2006, the *Case for Inclusion* has been a leading source for data and policy recommendations regarding the effectiveness of state programs in serving people with intellectual and developmental disabilities (IDD) and their families.

Building on the value of the *Case for Inclusion*, 2024 marks the start of a new series of reports designed to give you more targeted insights in a timelier manner. Known as *Case for Inclusion* Data Snapshots, this new series of data resources kicks off with the publication of this Snapshot on the state of access to home- and community-based services. We believe having shorter, more targeted briefs analyzing the most recent available data will allow us to identify and analyze timely trends to better support your advocacy.

Highlighted within each Data Snapshot are key findings selected from the nearly 80 measures that comprise 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. These Snapshots are supplemented by our annual Policy Blueprint, typically released in the first quarter of the year to offer recommendations for policies that empower more sustainable services.

This inaugural *Case for Inclusion* Data Snapshot highlights that:

- Average **hourly wages** for direct support professionals (DSPs) increased from $14.41 in 2021 to $15.79 in 2022.[1]

- Nationally in 2022, the average **turnover ratio** was 40.9%, while average **vacancy rates** for DSPs were 15.3% and 17.9% for full- and part-time positions, respectively.

- Nearly a half-million people in the US were on their state's **waiting list** for IDD services in 2023.[2] However, until recently that number did not include the number of people on states' **interest lists**, giving us a more complete picture of unmet need. States that used the term interest list for people with IDD waiting for home- and community-based services included Michigan, Missouri, Texas and Wisconsin.

- On average, people with IDD spent 50 **months waiting to receive services** in 2023. This was the longest average wait time compared to other populations.

With Increased Wages Comes Meaningful Improvements in Turnover, Vacancy

Direct support professionals (DSPs) specialize in supporting people with intellectual and developmental disabilities (IDD) to build the necessary skills to live and participate in their communities. The broad spectrum of habilitation services delivered by DSPs are individualized to the person being supported and can range from skill-building to support for intimate activities of daily living to career planning for long-term competitive integrated employment.

In other words, enough qualified DSPs must be available to support a wide range of needs for the 7.4 million people with IDD in the United States, with the ability to both guide and empower the people they support while respecting their autonomy and self-determination.

Unfortunately, a decades-long workforce crisis has pervaded community-based settings, due to insufficient reimbursement rates and the inability of providers to offer wages competitive with employers in other hourly wage industries like fast-food restaurants or retail and convenience stores. Because of the nature of Medicaid as a state-federal partnership, with reimbursement rates set by states and financed with federal matching funds, community-based providers cannot meaningfully increase direct support wages absent state and federal action.

Inadequate wages have been reinforced by a lack of mechanism to compel most states to engage in regular reimbursement rate reviews and increases. In turn, reimbursement rates stagnate, sometimes for a decade or more, preventing community-based providers from raising wages while the cost of care skyrockets. Even if providers cut spending on other critical components of service delivery (e.g., training, supervision, quality oversight, transportation, etc.) to redirect limited resources toward DSP wages, they find themselves losing the recruitment war against other private sector businesses.

For example, in 2016, the state of Georgia assessed an appropriate hourly wage for DSPs delivering residential habilitation services at $10.63.[3] This wage was then incorporated into Georgia's rate calculations, which make assumptions about the necessary costs of delivering services and determine reimbursement for providers. Over the following years, this wage remained virtually unchanged in Georgia's funding model despite rising expenses and changes in the private market that significantly increased the hourly wage for entry-level jobs in retail and service industries.[4]

By 2022, providers were paying an average DSP wage of $13.24 per hour, and as high as $19.83 per hour in certain areas, in order to attract and retain DSPs while only being reimbursed for $10.63. This meant a loss of at least $3.24-$9.47 for every single hour of service delivered. That same year, 50.3% of community-based providers in Georgia stopped accepting new referrals due to staffing issues.

When assessing DSP wages for rate calculations, states overwhelming utilize wage data from the U.S. Bureau of Labor Statistics' standard occupational classification (SOC) codes.[5] SOC codes are used to collect data and help local, state and federal governments identify employment trends. However, despite the unique and critical services performed by DSPs, the federal occupational classification and data collection system does not include a distinct SOC code for DSPs. Instead, DSPs are often inaccurately and inconsistently incorporated into a variety of classifications that do not capture their full scope of work activities.

In other words, without a SOC specifically for DSPs, states often use blended percentages from a variety of different SOCs to create an assumed wage for DSPs in underlying reimbursement rates.

Georgia's 2016 DSP Wage Assumption Using Weighted Bureau of Labor Statistics Occupations[6]

OCCUPATION / RESPONSIBILITY	WEIGHT
Personal Care Aide	60%
Home Health Aide	10%
Recreation Worker	10%
Social and Human Services Assistant	10%
Rehabilitation Counselor	10%

From the Field

Karla Greene knows first-hand how hard it can be for Spanish-speaking, immigrant parents to find services for children with intellectual and developmental disabilities.

As an immigrant herself and the parent of 9-year-old twins on the Autism spectrum, Greene works as an interpreter and community outreach specialist at United Cerebral Palsy of Huntsville and Tennessee Valley.

A former industrial engineer and pre-school music teacher, Greene helps dozens of families, mostly from Mexico and Central America, to access her agency's many services.

"My job is to educate them about why it's important to get support for their children and to get it early," said Greene, who is originally from Ciudad Juarez, Mexico, just across the border from El Paso, Texas.

Most of the families she helps are recent immigrants from poorer, rural regions of central and southern Mexico, though others come from Puerto Rico or as far away as Venezuela and Ecuador.

"The [parents] who truly blow my mind are the ones from places like Oaxaca (in Mexico) who speak indigenous languages and know little Spanish. The places they come from have no services for people with disabilities or even regular health care. Sometimes they're discovering for the first time about the kind of services we offer."

Most of the families she works with come to Alabama to work in construction, the hospitality industry, or as farm laborers.

"I go to their houses with early intervention developmental specialists and therapists," Greene said, "and sometimes they have almost nothing, but they're so grateful somebody wants to help them, somebody who looks like me, and it gives them hope that there's light at the end of the tunnel."

Due to the dearth of standardized federal data on the direct support workforce, the *Case for Inclusion* looks to data from National Core Indicators State of the Workforce for IDD (NCI-IDD-SoTW). The latest NCI-IDD-SoTW data, published in February 2024 and reflective of the direct support workforce in 2022, illustrates that even with wages steadily climbing, rates of turnover and vacancy remain high.

- Average hourly wages for DSPs increased from $14.41 in 2021 to $15.79 in 2022. This meaningful progress was made possible in large part due to $26.3 billion in spending on recruitment and retention initiatives from the American Rescue Plan Act (ARPA). Unfortunately, ARPA funding was only authorized over a limited time and the spending deadline for these funds is March 31, 2025.[7]

- A state's 2022 turnover ratio represents the number of DSPs who left their positions in 2022 divided by the number of DSPs employed at the end of that year. Among the 29 states (including the District of Columbia) participating in the 2022 NCI-IDD-SoTW survey, the turnover ratio was 40.9%, a slight improvement compared to the 2021 turnover ratio. The state with the highest turnover ratio was Nebraska, clocking in at a whopping 59.1%.

STATE	TURNOVER RATIO
Alabama	46.8%
Arizona	34.6%
Colorado	42.6%
Connecticut	44.8%
District of Columbia	**21.3%**
Delaware	40.5%
Georgia	37.5%
Hawaii	30.1%
Illinois	41.6%
Indiana	45.4%
Louisiana	39.0%
Maryland	33.2%
Missouri	46.6%
Montana	41.6%
Nebraska	**59.1%**
New Jersey	34.4%
New Mexico	49.7%
New York	33.8%
North Carolina	30.4%
North Dakota	53.6%
Oklahoma	40.0%
Oregon	45.4%
Pennsylvania	36.0%
South Carolina	42.4%
South Dakota	51.1%
Tennessee	44.5%
Utah	49.1%
Virginia	43.7%
Wyoming	50.0%

Mean turnover ratio among states participating in National Core Indicators' *State of the Workforce for IDD* survey.

- Average full-time vacancy rates also declined slightly in 2022 after experiencing a dramatic 94% increase over pre-pandemic levels in 2021.
    - The average full-time vacancy rate, which measures the percentage of full-time direct support positions that were vacant as of the end of 2022, decreased by about one percentage point to 15% nationally. The state with the worst performance on this measure was Montana, which saw 21.1% of its full-time direct support positions vacant at the end of 2022.
    - The average part-time vacancy rate, which measures the percentage of part-time direct support positions that were vacant, decreased approximately two percentage points to 17.9% nationally. In Tennessee, the part-time vacancy rate was an astounding 30.5%.

IN FOCUS: WHY TURNOVER MATTERS

Successfully delivering individualized person-centered supports to an individual with I/DD requires a thorough understanding of the person accepting the service, including their unique backgrounds, goals, and likes/dislikes, as well as their behavioral, medical, and social needs. This type of comprehensive knowledge about a person is not acquired overnight; it requires DSPs to spend a significant amount of time working with that person. High staff turnover takes away those natural on-the-job learning opportunities for DSPs which, in turn, limits their ability to successfully and safely meet the needs of the people they are supporting.

From the Field

A New York native, Colleen Crispino is president and CEO of United Cerebral Palsy of Long Island. She's worked in disability services for more than 30 years. We asked her about the workforce challenges her agency has faced since the end of the global pandemic.

"Post-covid, my day program is operating at about 60 percent capacity. We have people who used to be able to come to us every day for active, productive programming who now sit at home because I can't bring in enough staff."

Because state and federal funding has not kept pace with the costs of rising wages and inflation in New York overall, Crispino said many of her employees "essentially earn minimum wage."

Years ago, Crispino said her agency paid 20 percent above minimum wage, with paid time off and benefits. "Now we can't keep pace."

"People do this work because they love it, but they could work a cash register in the retail industry for better hourly wages. It's a big responsibility to care for human beings as opposed to stocking shelves."

Access to Services Remains at Grave Risk

Home- and community-based services (HCBS) are an optional Medicaid benefit, meaning states can and regularly do set limits to 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 be considered for referral to services only when an opening becomes available.

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 and undercounting of people with IDD experiencing unmet needs for community-based services.

As discussed in prior editions of the *Case for Inclusion*, although routinely cited, waiting lists are often incomplete indicators of overall unmet need as they often represent only a fraction of people with IDD waiting for services. States' management of HCBS waiting lists varies widely across the country, with some employing a first-come, first-served approach and others making eligibility based on a set of state-determined assessments of the significance of people's needs. This means that a state's waiting list can change drastically with changes in methodology, even if there hasn't been any change in the circumstances of the people waiting for services.

For example, the *Case for Inclusion 2023* examined a marked decrease in the waiting list between 2018 and 2021, which resulted in 108,000 fewer people counted toward the national total. However, just two states—Louisiana and Ohio—accounted for about 85% of the overall decrease. On further examination, both of those states had adjusted their counting methodologies in the intervening years; there hadn't necessarily been substantive changes in the circumstances of those individuals removed from Ohio and Louisiana's waiting lists. As we noted then, this does not mean those states haven't made significant progress, but it demonstrates the difficulties in making apples-to-apples comparisons from state to state or year to year.

While some states have systems of priority for who comes *off* a waiting list, others create systems of priority for who may be placed *onto* a waiting list. This approach sometimes prompts states to create two types of lists: an official "waiting" list and unofficial lists of people with unmet needs whose needs don't meet the state's criteria to be added to the waiting list. For these reasons, KFF now reports the total number of people who were on a state's "waiting list, referral list, interest list, or another term" to estimate the number of people waiting for HCBS.[8]

With this change alone, KFF was able to identify that among all populations waiting for HCBS, there were more people on interest lists (361,000) in 2023 than on official waiting lists (331,000). Given the widespread use of waiting lists as an indicator of access to services, this inability to federally track unmet needs has the potential to underestimate needed investments by more than half. This is especially true for people with IDD waiting for services, who experience the longest average wait time of all target populations at just over four years.

The distinction between waiting lists and other kinds of lists is especially important as the Centers for Medicare and Medicaid Services (CMS) seeks to begin implementation of the recently finalized regulation, Ensuring Access to Medicaid Services, which includes requirements for states to report annually on waiting lists. Beginning July 9, 2027, states will be required to submit a description of how they maintain their waiting lists, the number of people on the waiting list, and the average amount of time new waiver enrollees waited to enroll.[9]

Although this data could increase transparency of waiting lists and waiting list methodologies, it also carries the potential to misconstrue the number of people waiting. Without a holistic accounting of all other interest, registry and similarly termed lists that are used to account for people in need of services, federal data collection efforts risk overlooking the nuances in how states determine the significance of the needs of those seeking services.

Inadequate staffing and the resulting inability of providers to accept referrals are also significant barriers to accessing services, even after being removed from waiting lists. When too few community-based providers have too few staff to deliver services to people newly cleared from waiting lists, people may be forced to either forgo services altogether or live in hospitals and institutions until a provider is available to support them.[10]

Furthermore, many states require people who are removed from waiting lists to begin accessing services within a specified amount of time. If the person can't locate an available provider within that timeframe, they are placed back on the waiting list, and sometimes at a much lower priority level.

With the rapid decline in providers accepting new referrals, finding new services may mean traveling great distances outside their communities or losing their funded opening for services. Even with the gains made between 2021 and 2022 in indicators such as turnover and vacancy, 60% of community-based providers indicated in 2023 that they were likely to pursue additional discontinuations of programs and services due to insufficient staffing.

Taken together, the *Case for Inclusion* points to evidence that even with modest gains in wages, community-based providers are quickly approaching a tipping point.

Approved for Services But Nowhere to Go

Even when a person is "cleared" from a state's waiting list and approved to seek services, a number of barriers routinely prevent families from accessing the services they require. These barriers include:

Lack of providers in the region

Lack of accessible, affordable housing

Providers in the region not accepting new referrals

Insufficient supply of qualified professionals to deliver individualized services

Conclusion

While the situation is dire, it is not without hope for a better and more sustainable future for community-based services supporting people with IDD. At the beginning of the year, the *Case for Inclusion 2024* Key Findings Report included a Policy Blueprint to address the impacts of the workforce crisis on access to services highlighted in the preceding pages of this Data Snapshot. Those recommendations stand today as we continue to advocate for policy progress, including:

- Increased federal funding to help states and community-based providers address stagnant reimbursement, the impacts of the COVID-19 pandemic, and fiscal demands of compliance with new federal requirements.
- Systems of access monitoring that compel regular review and necessary adjustments to Medicaid reimbursement rates to fully fund service delivery expenses.
- Interagency dialogue and collaboration among federal agencies and community stakeholders to address the direct support workforce crisis and align approaches that support access to community-based services.
- The creation of a Standard Occupational Classification code for DSPs.

Ready to join us in our advocacy? Here are four easy ways you can take action today!

- Access state-specific *Case for Inclusion* data to fuel your advocacy by visiting caseforinclusion.org.
- Stay informed about one-click opportunities to take action using the ANCOR Amplifier at amplifier.ancor.org.
- Utilize the Advocacy Toolkit at ancor.org/advocacy/toolkit for practical guidance and templates on how to connect with your elected officials in your district, write persuasive op-eds and letters to the editor, and more.
- Browse resources from UCP and ANCOR at their respective websites, ucp.org and ancor.org.

Endnotes

1. Except where noted, the direct support workforce data in this report is derived from *2022 State of the Workforce Survey Report* (Alexandria, VA: National Core Indicators, 2024).

2. Except where noted, the waiting list data in this report is derived from "Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility," State Health Facts, KFF, accessed September 4, 2024.

3. *Residential & Respite Cost Study: Final Rate Models* (Phoenix, AZ: Burns & Associates, 2015).

4. *Final Report of the Senate Study Committee on People with Intellectual and Developmental Disabilities and Waiver Plan Access (SR 770)* (Atlanta: Georgia State Senate Research Office, 2022).

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

6. Burns & Associates, "Final Rate Study," 13.

7. *Overview of State Spending Under American Rescue Plan Act of 2021 (ARP) Section 9817, as of the Quarter Ending December 31, 2023* (Baltimore, MD: Centers for Medicare & Medicaid Services, 2024).

8. Alice Burns, Maiss Mohamed & Molly O'Malley Watts, "A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2023," KFF, 2023, Nov. 29.

9. Final Rule, "Medicaid Program; Ensuring Access to Medicaid Services," 42 CFR 431, (May 10, 2024): 40542-40874.

10. *The State of America's Direct Support Workforce Crisis 2023* (Alexandria, VA: ANCOR, 2024).

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**.

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. Learn more at **UCP.org**.