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CASE FOR INCLUSION

DATA SNAPSHOT

The Looming Impact of Funding Cuts on Access to Community Services

JANUARY 2026

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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.

In 2024, we began a new series of *Case for Inclusion* reports, referred to as Data Snapshots, that are designed to give you more targeted insights in a timelier manner. Data Snapshots are meant to offer a clearer sense of the challenges facing community-based IDD services and are supplemented by our annual Policy Blueprint, wherein we offer recommendations for what regulators and legislators at all levels of government can do to strengthen community services.

Highlighted within each Data Snapshot are key findings on select indicators chosen from the nearly 80 measures that comprise the *Case for Inclusion's* seven issue areas. These issue areas include:

- Addressing a Workforce in Crisis
- Promoting Independence
- Promoting Productivity
- Reaching Those in Need
- Serving at a Reasonable Cost
- Keeping Families Together
- Tracking Health, Safety & Quality of Life

This latest *Case for Inclusion* Data Snapshot finds that:

94%
The proportion of Medicaid-funded long-term supports and services (LTSS) for people with IDD provided in home and community-based settings.[1]

$17.20
The median hourly wage for direct support professionals (DSPs) in 2023.[2]

39.7%
The average turnover ratio in 2023—the first time this measure fell below 40% since data collection began—while average vacancy rates for DSPs decreased to 12.2% and 14.6% for full- and part-time positions, respectively.[3]

23.5%
The percentage of people with IDD accessing employment supports and working in integrated settings in 2022.[4]

552,339
The number of people with IDD were on their state's waiting list or interest list for home and community-based services in 2025, which represents an increase of 8% over the previous year.[5]

ACCESS TO SERVICES THREATENED BY CUTS TO MEDICAID

On July 4, 2025, President Trump signed budget legislation into law (Public Law 119-21). This sweeping legislation included nearly $1 trillion in cuts to federal Medicaid funding that have the potential to further weaken and risk access to a fragile network of community-based services for people with IDD.

Community-based services—already inaccessible to far too many people with disabilities in this country—are funded almost exclusively through Medicaid, a program which operates as a partnership between states and the federal government to fund certain health care services.

In this system, states determine which services to offer and how, while the federal government provides matching funds at rates that differ by state and service. The combined funding is then used by states to reimburse community providers for the services they deliver.

Even if federal Medicaid funding cuts in Public Law 119-21 were not designed specifically to restrict access to community-based IDD services, the law will place immense pressure on state budgets, which will increase the likelihood that states will look to optional programs like the Home and Community Based Services (HCBS) program to offset budget shortfalls.

The Impact of Public Law 119-21 on Provider Taxes

Public Law 119-21 prevents states from initiating new provider taxes or raising the rates for existing provider taxes. Additionally, states that expanded their Medicaid programs under the Affordable Care Act will be required to gradually reduce provider taxes to adhere to a new 3.5% cap. These new statutory provisions will limit a valuable source of Medicaid financing for states.

State taxes on providers are vetted through federal statute and regulation, allowed only under specific conditions, and serve as a crucial source of Medicaid funding for states. Freezing provider taxes at current rates, prohibiting the implementation of new provider taxes, and reducing provider tax rates will curtail the flexibility states currently have to finance their Medicaid programs, leaving states without mechanisms to maintain services in the face of rising costs of care. The reduction in available Medicaid funding means that states will face budget shortfalls that will squeeze state budgets, likely leading to cuts and reduced access to optional services, like community-based services for people with disabilities.

Underlying these challenges is the fact that although the HCBS program is optional for states, the **percentage of people with IDD receiving Medicaid-funded long-term supports and services (LTSS) in home- and community-based settings** reached 94% in 2020. Limiting available funding for the program that supports the vast majority of people with IDD risks significant program closures, which will in turn leave many turning to services that are costlier and more restrictive such as nursing homes and hospitals—while leaving others with no options whatsoever.

Even without federal funding cuts, states can and regularly do set limits on the number of people who can be supported through HCBS programs. After meeting the established cap of funded openings, many states maintain various lists to manage which people can be approved to seek which services, but only after an opening becomes available. These lists are most commonly referred to as waiting lists, but may also be called interest lists or planning lists.

As of 2025, there were 41 **states maintaining waiting or interest lists for their HCBS programs**. Over 600,000 people appear on these lists, 552,339 of whom are people with IDD. This represents an 8% increase between 2024 and 2025. On average, people with IDD spent 37 months waiting to receive services in 2025.[6]

Unfortunately, optional services like community-based services for people with IDD are often first to be cut when states face budget shortfalls. For example, data shows that when federal Medicaid funding dropped significantly between 2010-2012, every state and the District of Columbia reduced funding for one or more of their HCBS programs in response.[7]

FROM THE FIELD: A Mother Reflects on Long Wait Time, Uncertainty Regarding Son's Services

Joshua attends a day program several days a week, but transportation to and from the day program has been a significant challenge. He has been on a waiting list for additional Medicaid-funded services through an HCBS program for the past four years. The good news is that his mother, Maria, has finally been notified that Joshua has been pulled from his state's waiting list and may soon begin receiving HCBS.

But that's not where the story ends.

Maria is scrambling to gather the required documentation and facing a few hurdles along the way. For example, Joshua received his disability diagnosis nearly 20 years ago—records Maria is now scrambling to find and that the doctor may not even have. "I feel bad," Maria says, "because they might think, 'Okay, it's your son. How come you don't remember?' But they have no idea all the things I've been through with my son."

Despite these hurdles, Maria and Joshua are both looking forward to the additional support for their family. Maria knows Joshua will thrive in a more consistent and supportive environment, and Joshua is looking forward to more time with his friends.

All of these challenges come on the heels of a long-standing crisis when it comes to the recruitment and retention of direct support professionals (DSPs), the frontline workers that deliver critically important community-based services. Because of inadequate Medicaid reimbursement rates, providers struggle to pay wages that enable them to compete for talent against hourly wage industries such as fast food and retail. With too few DSPs to deliver the supports on which people rely, people with IDD are forced to either forgo services altogether or turn to more expensive and restrictive services until a provider is available to support them.

Furthermore, in many states, when a person who was on a waiting list is approved to access services, they must do so within a specified amount of time. Failure to do so, even if due to a dearth of available providers, often leads the person right back to the waiting list they were previously on—and sometimes at a much lower priority level.

The Impact of Public Law 119-21 on Eligibility Redeterminations

Provisions included in Public Law 119-21 that go into effect in 2027 will require states to conduct eligibility redeterminations at least once every six months for all adults made eligible through Medicaid expansion, a group that may include individuals with disabilities.

At the same time, the law also delayed implementation and enforcement of several key provisions of a Biden-era Medicaid enrollment and eligibility rule that included protections for people with disabilities, including prohibiting redetermination more frequently than every 12 months for Medicaid recipients with disabilities. Pausing this regulation would give states the option of extending the six-month eligibility redetermination requirement to all Medicaid populations, including people with IDD.

Eligibility redetermination processes can be especially onerous for people with IDD. Barriers for people with IDD may include difficulty comprehending complex instructions or navigating multiple systems, physical and communication limitations that create barriers to timely responses, and a lack of transportation and other supports required for in-person appointments. If someone with IDD is unable to successfully navigate the eligibility redetermination process, they will lose access to the Medicaid-funded supports that allow them to remain in their homes and communities.

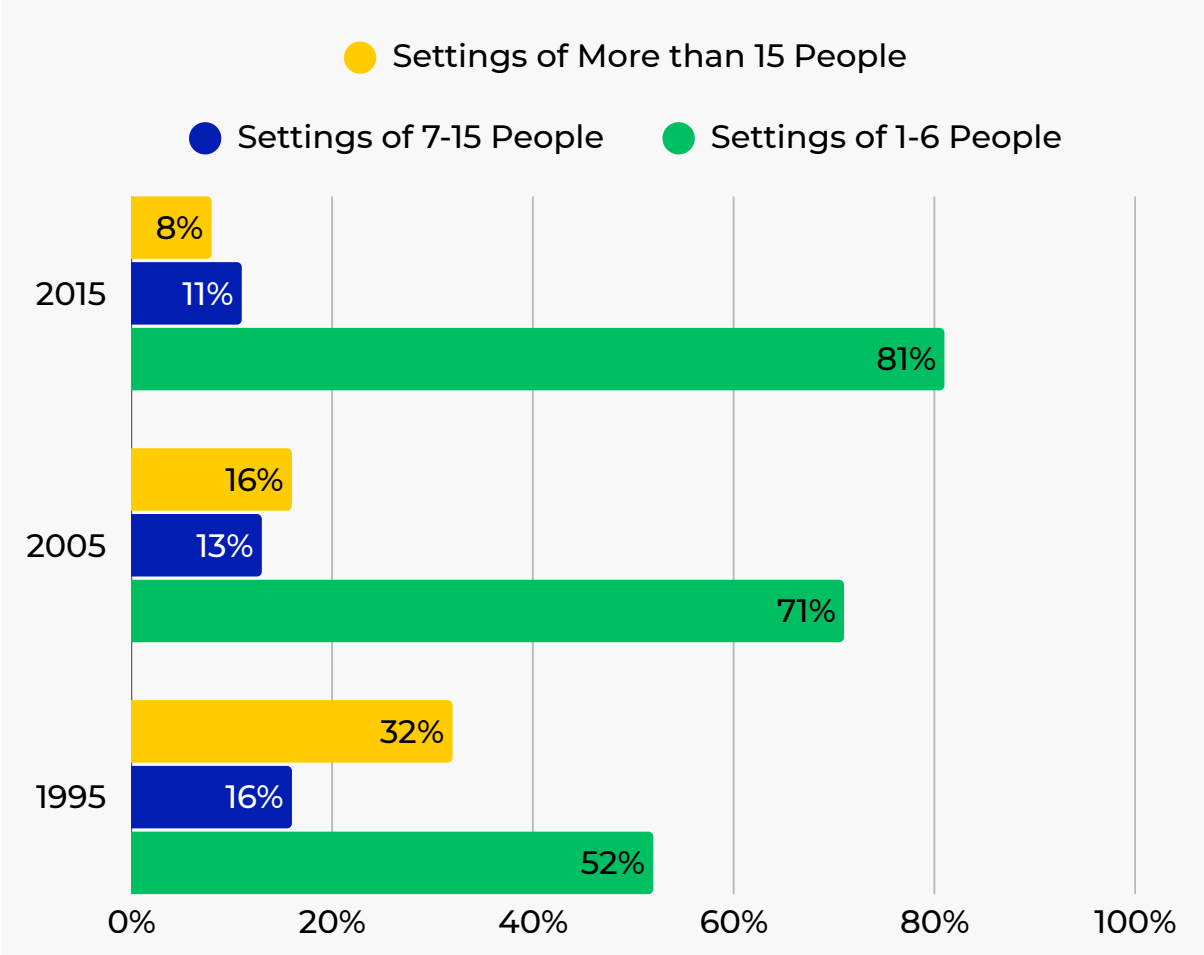
COMMUNITY-BASED SUPPORTS IN SMALLER LIVING SETTINGS YIELDS SIGNIFICANT COST SAVINGS

In 2020, 94% of people with IDD accessing Medicaid-funded LTSS did so in community-based settings. Within that group:

- 61% lived with family members
- 15% lived in group homes of six or fewer people
- 11% lived in their own homes
- 8% lived in institutional settings with seven or more individuals
- 5% participated in shared living (i.e., lived in a host home or with an adult foster family)

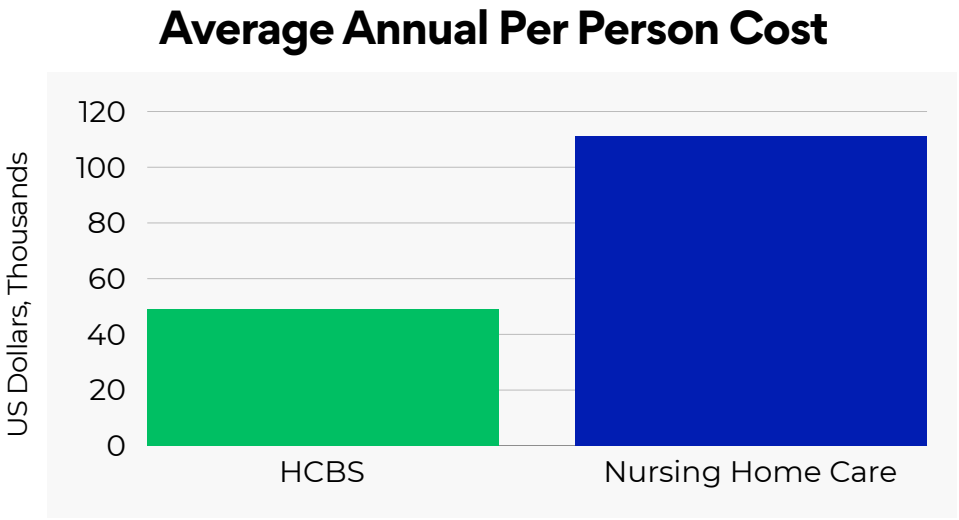
Overall, the number of people with IDD receiving LTSS in smaller, more integrated settings (i.e., in their own homes, a family home, or a group home with three or fewer people) has continued to increase over the past decade. At the same time, the percentage of smaller provider-operated settings utilized by people with IDD has continued to grow exponentially.[8]

Percentage of People with IDD in Different Living Settings



Source: Institute on Community Integration, In-Home and Residential Long-Term Supports and Services.

Investments in HCBS have produced long-term savings by enabling more people to access person-centered services in less costly settings. The average annual per capita cost to serve someone with IDD through an HCBS waiver is $49,723,[9] while the average per capita cost to support someone with a mandatory service, such as in a nursing facility, is $111,325.[10]



The Impact of Public Law 119-21 on State-Directed Payments

State-directed payments (SDPs) allow states to provide additional funding to Managed Care Organizations (MCOs) above and beyond their capitation rates to allow for uniform rate increases for specific services, including HCBS for people with IDD. SDPs allow MCOs to pay their network providers for services rendered to Medicaid beneficiaries at the same level as their commercial clients. In doing so, SDPs improve access to care by eliminating the financial disincentives that providers encounter when serving Medicaid beneficiaries.

But Public Law 119-21 lowers the payment limit for SDPs, requiring states to cap the total payment rate at 100% of the Medicare payment rates for states that expanded Medicaid and at 110% of the Medicare payment rates in states that did not expand Medicaid. Capping SDPs as proposed is likely to diminish access to care for Medicaid beneficiaries because the lower reimbursement rates that result from the cap will leave some providers unable to continue delivering those services.

Medicaid-funded community-based services also enable people with IDD to receive support from people other than their family members. Providing additional support options for people with disabilities allows unpaid family caregivers to remain in the workforce and continue earning wages. Without this option, family members of people with disabilities lose thousands of dollars annually in unearned wages, with consequences for their long-term financial security as well. Moreover, as unpaid family caregivers experience mounting out-of-pocket expenses and the physical and emotional strain of caregiving, they are more likely to need additional support through public assistance.

Community providers also support a robust economy not only because they are employers of one of the fastest-growing segments of the labor force, but also because they empower people with disabilities to enter the workforce by providing supported employment services. The direct impact of employing DSPs, combined with the indirect impact of those workers' economic activity in their local communities, translates into positive outcomes at the state level.

For example, a recent study of the disability services sector in New York found that the economic impact of investing in community-based IDD services was double the cost. Researchers in that study found that the state's $6.7 billion investment in disability services produced $14.3 billion in economic activity.[11] Similarly, a study in Maine found that every dollar spent on DSPs results in between $1.17 and $1.80 in economic activity.[12]

The Impact of Public Law 119-21 on Medicaid Work Requirements

Despite an intention to exempt people with disabilities from Public Law 119-21's new Medicaid work requirements, beneficiaries with disabilities may inadvertently lose benefits due to an inability to navigate complex compliance processes. When this happens, they may not be able to successfully navigate the exemption process and stand to lose their Medicaid coverage as a result.

People with IDD may face substantial obstacles that make participating in the workforce or completing the required exemption paperwork in a timely manner difficult. These challenges may include an inability to adequately respond to forms and document requests without support and accommodation, a lack of access to the internet, mobile devices, and transportation.

Requiring people with disabilities to document and verify that they are employed or participating in community engagement activities for numerous hours each month or qualify for an exemption may result in terminated coverage for those who do not precisely adhere to these requirements, jeopardizing their access to the very employment supports that enable them to secure and maintain employment.

WITH INCREASED WAGES COME IMPROVEMENTS IN TURNOVER, VACANCY RATES

Community providers support people with IDD to build the necessary skills to live and participate in their communities by employing DSPs to deliver a broad spectrum of individualized, person-centered services. These services are complex and range from assistance with activities of daily living—such as support with eating, managing medications and personal hygiene—to facilitating the establishment of meaningful relationships and career planning for long-term integrated employment. As a result of community-based services, states across the country can significantly reduce their reliance on large, expensive, state-run institutions in favor of supporting people in their homes and communities.

Sadly, this foundation is crumbling, with high rates of turnover and vacancy plaguing the IDD services system. This decades-long workforce crisis has pervaded community-based services due to long-term underinvestment in Medicaid and the subsequent inability of community providers to offer wages to compete with employers in other hourly wage industries, such as fast food and retail. The resulting workforce crisis has had a profound impact on the ability of community providers to deliver essential programs and support people with disabilities in their homes and communities.

ANCOR's *State of America's Direct Support Workforce Crisis 2025* survey reveals that 88% of providers experienced moderate or severe staffing challenges in the past year, resulting in 62% of providers turning away new referrals. This degree of turnover and vacancy has had a profound impact on the ability of people with IDD to find and access services. For instance, 29% of providers reported discontinuing programs and services due to their inability to meet required levels of staffing. These survey results are corroborated by the fact that 59% of respondents delivering case management services reported that they were struggling to connect people with services.

These findings are especially alarming considering that 56% of respondents also reported that they deliver services in areas where there are few or no other providers delivering those services. Without an adequate network of community providers, the safety and well-being of the people relying on those services is jeopardized without the availability of those services to meet their needs.

The Impact of Public Law 119-21 on HCBS Eligibility Pathways

Public Law 119-21 establishes a new, optional pathways that states may pursue to expand HCBS eligibility. Beginning July 1, 2028, states can apply for what's known as a standalone 1915(c) waiver—in essence, permission from the federal government to provide home- and community-based services to people who do not qualify for an institutional level of care. This would allow states to access Medicaid funding to offer these supports for an initial term of three years, which could then be extended for additional five-year periods.

This provision in the law represents an opportunity for people with IDD who may not have been otherwise eligible for HCBS waivers. However, with community-based providers struggling to hire and retain staff due to insufficient reimbursement rates, access to care may still be challenging for some individuals, even if they are approved for one of these waivers.

Further complicating the fight to provide better wages to DSPs is the fact that currently, "Direct Support Professional" is not a profession recognized by the federal government. Lacking a standard occupational classification (SOC) for DSPs, these workers either do not get counted as part of our labor force at all, or state policymakers lump DSPs into other categories such as home health aides or personal care attendants.

This challenge comes to bear on wages because it is the federal government's occupational code which states most often look to when determining reimbursement rates. Without a SOC for DSPs, states are left to decide how similar or different a DSP's job is to other seemingly related occupations. In turn, state rate models vary widely, which in many cases suppresses DSP wages.

Beyond defining DSPs with their own SOC in the federal occupational code, the direct support workforce can be strengthened by stronger federal and state investments in community-based services. Since 2020, wage data has—for the first time since National Core Indicators (NCI) began tracking DSP wages in 2014—shown multiple consecutive years of statistically significant improvements.

For example, in just one year, the median hourly DSP wage increased from $15.79 in 2022 to $17.20 in 2023.[13] By comparison, wages only increased by less than one dollar over the first five years NCI reported data from its annual survey, from $11.11 per hour in 2014 to $12 per hour in 2019.

These wage improvements are correlated with decreases in both the average national turnover ratio and average national vacancy rates. The annual turnover ratio—which identifies the proportion of DSPs who were employed by a provider agency at the beginning of the year who are still employed there by the end of the year—decreased from 43.3% nationally in 2022 to 39.7% nationally in 2023.[14]

In fact, 2023 marked the first time the national turnover ratio dropped below 40% since data collection began in 2014. Meanwhile, average vacancy rates among full-time direct support positions dropped from 15% in 2022 to 12.2% in 2023, while average vacancy rates among part-time positions fell from 17.9% in 2022 to 14.6% in 2023.[15]

The Impact of Public Law 119-21 on Funding for Rural Health Initiatives

While Public Law 119-21 institutes a significant overall reduction in Medicaid spending, it also provides some new sources of funding, one of which is the Rural Health Transformation Program (RHTP). Public Law 119-21 includes a $50 billion appropriation over five years ($10 billion per year beginning in Fiscal Year 2026) to the Centers for Medicare & Medicaid Services (CMS) for states to invest in improving rural health. Community-based services are an important means of supporting rural communities by supporting family caregivers to remain in the workforce and reducing reliance on hospitals by supporting people in their homes. By the end of 2025, CMS will have approved or denied all applications submitted by states for an RHTP allotment; if approved, state will be eligible for an allotment each year from through Fiscal Year 2030.

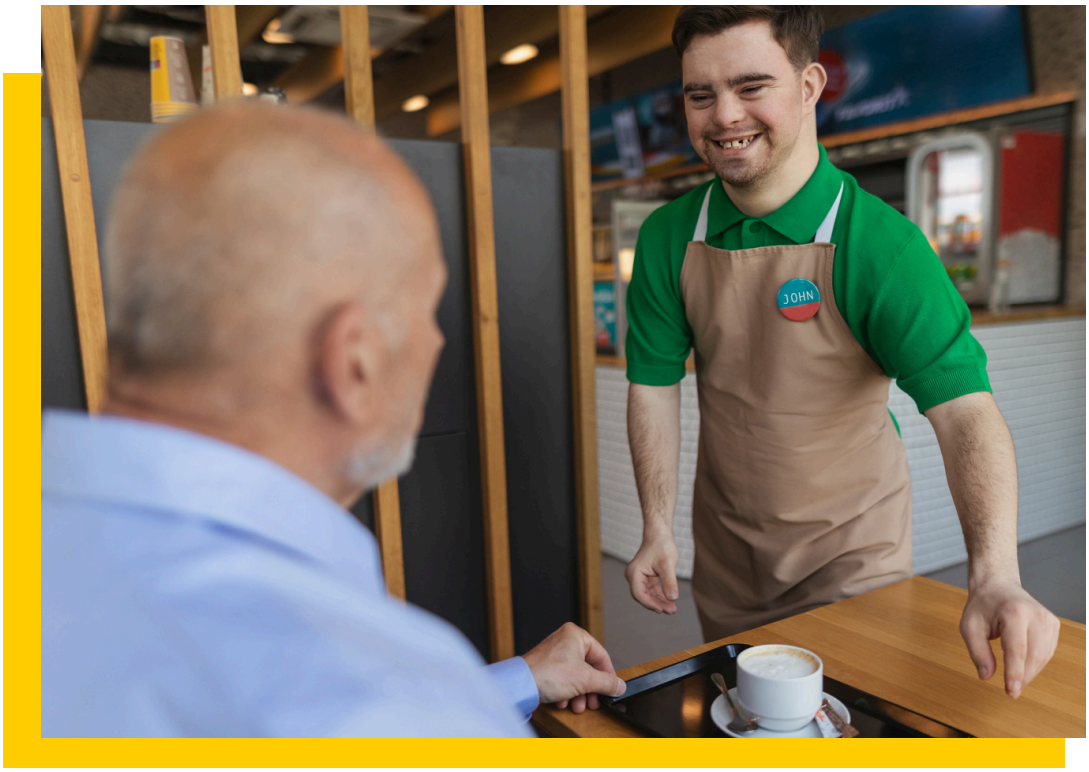
All of this progress has been meaningful, and it was made possible in large part due to $26.3 billion in spending on recruitment and retention initiatives via the American Rescue Plan Act (ARPA).[16] Unfortunately, ARPA funding was only authorized over a limited time and the spending deadline for those funds was March 31, 2025.

An ARPA Success Story: Georgia's Employee Assistance Program for DSPs

With the use of ARPA funds, Georgia created the Georgia Uplift Program to support its DSPs through three regional offices across the state. The Uplift Program is designed to empower and support DSPs in enhancing their stability and success in the field. Program services include:

- **Success Coaching:** Provides staff to work directly with DSPs to help them navigate challenges and access resources related to housing, transportation, healthcare, and childcare.
- **Resource Connections:** Links DSPs with a broad network of support to ensure they have the tools and resources necessary for their personal and professional development.

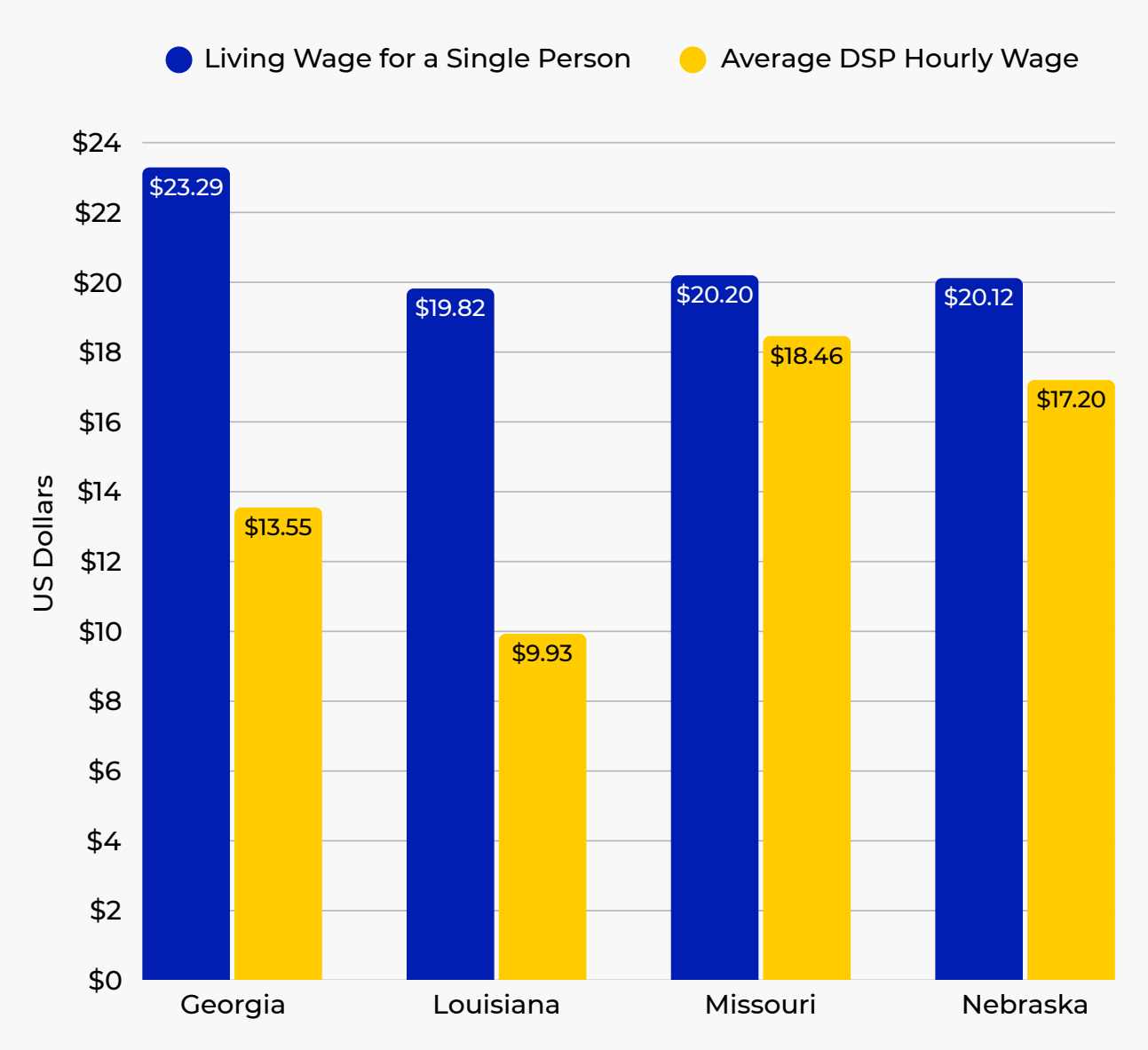
This program has been tremendously successful in reducing turnover and increasing retention among DSPs. Since its inception, Georgia Uplift has achieved a 91% retention rate among DSPs that have received assistance through the program.



Although it is certainly worth celebrating rising wages among DSPs, it should be made clear that no state's average DSP wage came close to what constitutes a living wage in that state. For example, among states participating in NCI's 2023 State of the Workforce Survey, the state with the lowest cost of living for a single person was Oklahoma, where the living wage was $19.33 per hour in 2023. However, that year, the average DSP in Oklahoma earned only $12.35 per hour.

In 2023, the average living wage (required for a single person to support themselves) was $22.08 per hour while the average hourly wage for a DSP during that period was just $17.34, with a wide variation across states.[17]

Living Hourly Wage vs. Average DSP Hourly Wage in Select States



Source: National Core Indicators, State of the Workforce for Intellectual and Developmental Disabilities 2023.

COMPETITIVE INTEGRATED EMPLOYMENT INCREASES AS THE USE OF FACILITY-BASED EMPLOYMENT SUPPORTS DECLINES

When it comes to employment opportunities for people with IDD, many individuals strive for jobs in what is known among community providers as competitive, integrated employment. In this context, "competitive" refers to the fact that compensation is competitive with market rates, while "integrated" refers to the fact that people with IDD are working alongside nondisabled co-workers.

The percentage of people with IDD engaged in employment services and working in integrated employment reached its highest level, 23.5%, in 2022—the latest year for which data is available—after hovering between 19-22% over most of the past decade. At the same time, participation in facility-based work services has declined steadily since 1999 and, in 2013, dropped below the participation rate for integrated employment. Overall, the number of people reported by states to have participated in a facility-based work setting dropped by approximately 112,232 individuals between 1999 and 2022.[18]

It is worth noting that although decreased utilization of facility-based work programs generally can be attributed to increased efforts to support people to work in integrated settings, some of the decrease that was realized between 2020 and 2022 may be attributable to the closure of supported employment programs during the COVID-19 pandemic or to people's decision not to participate in the workforce due to health risks wrought by the pandemic.

Despite the challenges born of the COVID-19 pandemic, employment outcomes have continued improving, which may be attributable to the adoption of Employment First policies and practices by numerous states.[19] Employment First is a national systems-change framework centered on the premise that all individuals, including those with the most significant disabilities, are capable of full participation in competitive, integrated employment and community life.

Under the Employment First approach, publicly financed systems are urged to align policies, regulatory guidance and reimbursement structures to commit to competitive, integrated employment as the priority goal of day and employment services for youth and adults with significant disabilities. Many states have formally committed to the Employment First framework through official executive proclamation or formal legislative action.[20]

In Fiscal Year 2022, an estimated 598,303 people received employment and day services from state IDD agencies, which represents a modest 0.2% increase over the previous year's total. By comparison, only 455,824 people received such supports in Fiscal Year 1999.[21]

Despite modest improvements, too few workers with disabilities are achieving the gold standard of competitive, integrated employment. This may be because disabled workers are employed but don't earn competitive wages, and/or because disabled workers earn competitive wages but do not work alongside nondisabled co-workers. And in some instances, disabled workers earn less than the federal minimum wage.

The practice of paying workers with disabilities wages below the required minimum is legally authorized by Section 14(c) of the Fair Labor Standards Act, which allows employers to receive a certificate from the U.S. Department of Labor that functionally waives the minimum wage requirement for employees with disabilities. The number of workers with disabilities earning subminimum wages has declined from an estimated 210,689 workers in 2013 to 59,537 workers in 2022, in part because several states have passed laws to phase out such programs.[22]

CONCLUSION

While the current state of community-based services for people with IDD has improved in some areas, access to community-based supports remains out of reach for hundreds of thousands of families as state waiting lists continue to grow. Additionally, the expiration of ARPA funding, coupled with the slashing of nearly $1 trillion in federal Medicaid funding passed through Public Law 119-21, threatens to undo the progress made in strengthening community-based services for people with IDD.

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.

Last year, *The Case for Inclusion 2025's* Policy Blueprint for Sustainable Services addressed the impacts of the workforce crisis on access to services. The recommendations contained therein stand today as we continue to advocate for policy progress, including:

- **Revising the federal occupational code to create a standard occupational classification for DSPs.** Doing so will help all levels of government identify employment trends and design appropriate policies to address the direct support workforce crisis.
- **Increasing the federal share of funding for the Medicaid HCBS program** to stabilize the direct support workforce and ensure access to services.
- **Investing in the training and professionalization of the direct support workforce** by establishing career pipeline programs for DSPs, which will support recruitment, retention and advancement efforts.
- **Establishing systems of access monitoring that provide regular review of IDD reimbursement rates.** This would ensure payments stay current with increasing service delivery costs and safeguard access to quality home- and community-based services.
- **Collecting and publicly reporting on measures and metrics related to workforce volume, stability and compensation** to identify and address gaps in access to care and avoid further harm to the HCBS infrastructure.

READY TO TAKE ACTION?

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.
- Use 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. In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through June 30, 2020 (Minneapolis: Institute on Community Integration at the University of Minnesota, 2024). See also: Alexandra Carpenter, Cara Stepanczuk, Caitlin Murray, and Andrea Wysocki; Trends in Users and Expenditures for HCBS as a Share of Total Medicaid Long-Term Services and Supports Users and Expenditures, 2023; October 17, 2025.
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13. National Core Indicators, "State of the Workforce."
14. Ibid.
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17. National Core Indicators, "State of the Workforce." Note that National Core Indicators uses data for living wages derived from MIT's Living Wage Calculator.
18. Winsor, et al., National Survey of State Intellectual and Developmental Disabilities Agencies. For the purposes of this data point, the term "facility-based work settings" includes all employment services that occur in a setting where the majority of employees have a disability. These activities occur in settings where continuous job-related supports and supervision are provided to all workers with disabilities. This service category is typically referred to as a sheltered workshop, work activity center, or extended employment program.
19. Ibid.
20. "Employment First," Office of Disability Employment Policy, U.S. Department of Labor, accessed October 19, 2025.
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22. Ibid.

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