Case for Inclusion 2025

Policy Blueprint for Sustainable Services

ANCOR

UCP United Cerebral Palsy™

Life without limits for people with disabilities™

Acknowledgments

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Introduction

For almost two decades, the *Case for Inclusion* has offered comprehensive data across dozens of measures to assess how effectively states serve people with cerebral palsy and intellectual and developmental disabilities (IDD). Starting with the 2021 edition, the *Case for Inclusion* has paired those key findings with a policy blueprint for how federal and state government officials, lawmakers, providers and advocates can strengthen community-based services for people with IDD. These policy blueprints have offered concrete, actionable recommendations for policymakers at all levels of government, both in Washington, DC, and in statehouses across the country and serve as a supplement to the *Case for Inclusion* Data Snapshots and other reports and information provided on the *Case for Inclusion* website.

It's never been more important for policymakers to invest time, focus, and funding into community-based services. As the nation transitions to a new administration and Congress, new opportunities arise for policymakers to bolster the direct support workforce and enhance access to community-based services for people with IDD. Building on the policy recommendations that came before, 2025 marks the inaugural edition of the *Case for Inclusion Policy Blueprint*, offering recommendations for policies that power more sustainable services for people with IDD.

Our communities are at their best when all people—including people with disabilities—can develop skills, seek greater independence, and achieve their personal goals. Community providers contribute to a stronger, more inclusive America by supporting people with IDD to live, work, and thrive in their communities through a broad array of habilitation services. These services range from in-home and community integration supports to career planning and employment supports.

Yet, long-term underinvestment in home- and community-based services, together with stagnant and insufficient reimbursement rates, have hampered the ability of community providers to offer direct support professionals (DSPs) competitive wages and benefits, which has led to an exodus of qualified workers from the field and, in turn, declining access to quality services. With staffing shortages of the magnitude described in previous editions of the *Case for Inclusion*, community providers are forced to reject referrals and discontinue programs and services at an alarming rate. For example, *The State of America's Direct Support Workforce Crisis 2024* revealed that: 90% of providers experienced moderate or severe staffing challenges in the past year, resulting in 69% of providers turning away new referrals and 39% discontinuing programs and services. This degree of turnover and vacancy has adversely impacted the ability of people with IDD to find and access community-based services, evidence for which can be found among the 57% of case managers that reported difficulty connecting people with services.

IDD DEFINED

The term "IDD," short for intellectual and developmental disabilities, is used throughout this report to describe a diverse group of diagnoses that make people eligible to receive certain community-based disability services. IDD can refer to a number of conditions, some of which you are probably familiar with and others of which may be unfamiliar.

Examples of IDD include Cerebral Palsy, intellectual disability, Autism spectrum disorders, Fragile X Syndrome and Prader-Willi Syndrome.

The Value of Investing in Community IDD Services

For many Americans with cerebral palsy and IDD, Medicaid-funded Home- and Community-Based Services (HCBS) provide critical supports necessary to live, work, and thrive within their homes and communities. These services are delivered by community providers and the DSPs they employ, who together support people with a broad spectrum of services, including activities of daily living (e.g., meal preparation, medication management, communication), as well as employment support and assistance in pursuing personal goals. These supports are person-centered and designed to promote community inclusion.

Community providers support their local economies by employing professionals known as direct support professionals, or DSPs—an occupation projected to grow 21% from 2023 to 2033, outpacing the average for all other occupations.[1] A recent study of disability services in New York found that the economic impact of those services was double the investment made by the state into those services. Researchers in that study found that an investment of $6.7 billion by the state into disability service providers led to $14.3 billion in economic activity.[2]

Medicaid HCBS programs afford people with IDD the choice to receive support from direct support professionals, rather than from family members. As a result, community support options enable family members of people with disabilities to remain as economically productive members of the U.S. labor force by continuing to earn wages. Without the option to maintain employment, family members lose potentially hundreds of thousands of dollars annually in unearned wages.[3]

Furthermore, absent DSPs, families face mounting out-of-pocket expenses, as well as the physical and emotional strain of caregiving, leading family caregivers of people with disabilities to be at greater risk of adverse health consequences. These factors increase the likelihood that people with disabilities and their family members will need to rely on public assistance. A recent study assessing Maine's direct care workforce challenges, for instance, found that Maine is losing more than $1 billion per year in additional economic activity as a result of people leaving the labor force due to a lack of professional direct care workers.[4]

The Medicaid HCBS program is funded through a partnership between the federal government and state governments, with payment rates set by states and matching funds contributed by the federal government. States then use the combined funding to pay community providers for delivering services to people with IDD. In accepting federal Medicaid funding, states are expected to ensure that their provider reimbursement rates are consistent with efficiency, economy, and quality of care, and sufficient to enlist an ample provider base.[5]

The Economic Impact of Investing in Disability Services

States can see huge economic gains when they invest in community-based IDD services. But the corollary is also true: a failure to invest can cost millions due to diminished participation in the labor force.

2:1
IN NEW YORK

The economic return on the state's investment in IDD services. Researchers found $6.7 billion in investments resulted in $14.3 billion in positive economic activity.

$1 BILLION+
IN MAINE

The amount economic activity diminished in that state as the result of people leaving the workforce to care for disabled loved ones due to a lack of DSPs.

In Focus: The Payment Adequacy Challenge

Underinvestment in Medicaid has been the result of a range of factors, one of which is inadequate reimbursements from state Medicaid programs. This payment inadequacy may partly be the result of how states decide the rates at which they will reimburse providers for services.

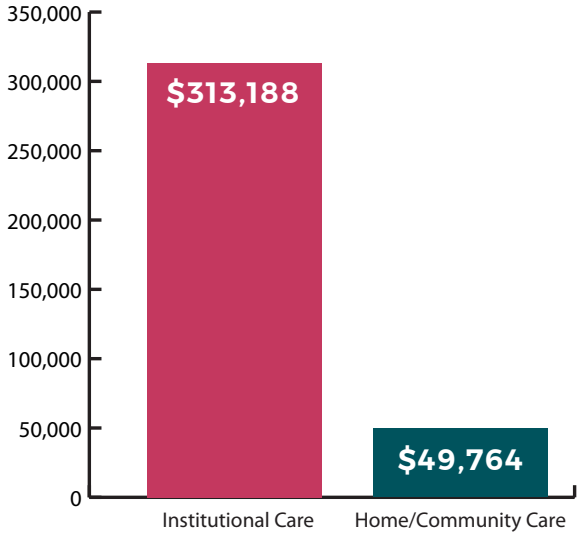
States determine how much they think it costs to support people with IDD by making a list of expenses and making assumptions about how much they believe each of those expenses cost. For example, because there is no standard occupational classification (SOC) for DSPs, most states use a blend of other SOC codes to determine an appropriate wage for DSPs.

This list may include DSP wages and benefits, training, clinical and quality oversight personnel, durable medical equipment, transportation, etc.

The combined total of these assumptions becomes the reimbursement rate. If the initial rate setting is too low, does not include all necessary expenses, or goes too long without review and adjustment for increased costs, providers are forced to close programs and shutter services without sufficient payment to support people with IDD.

Medicaid HCBS is far less costly for states compared to the alternative: long-term isolation of people in large, state-funded residential institutions. In 2020, the average annual cost to serve a person with IDD in their community through an HCBS waiver was $49,764, whereas the average cost to deliver those same services in a state-operated institution was $313,188.6 In other words, an investment in HCBS produces long-term savings by enabling more people to be supported in more affordable settings.

Cost of supporting people in large, state-run institutions vs. supporting people through home- and community-based services.[7]



Community-based services yield positive social and economic outcomes compared to the antiquated and costly state-run institutions, which ultimately limit choice for people with IDD and reduce valuable returns on our nation's investment.

Therefore, we must commit to effectively meeting the needs of Americans with IDD in the community today, tomorrow, and beyond. Specific actions policymakers can take to meet these needs are provided in the following sections.

How the Trump Administration Should Invest in Community IDD Services

Although Medicaid is funded through a partnership between state and federal governments, it is ultimately the role and responsibility of the federal government to ensure states are establishing sufficient payment rates for IDD services. To that end, the Centers for Medicare and Medicaid Services (CMS) requires states to review their rate-setting methodologies at least once every five years to ensure that HCBS rates are adequate to maintain an ample array of providers.[8] However, without clearer and more direct requirements to ensure rates can keep up with wages, inflation, and rising costs, reimbursement rates have stagnated.

The resulting insufficient payments preclude providers from offering compensation that enables them to compete against other hourly wage industries, such as fast-food restaurants or retail/convenience stores. This has led to an exodus of qualified workers from the field, which was deeply exacerbated by the COVID-19 pandemic. The resulting workforce crisis has had a profound impact on disability service providers' ability to deliver essential programs and support people with IDD with the level of quality care they deserve.

- ☐ The Trump administration should require states to establish systems of access monitoring that compel regular reviews of Medicaid reimbursement rates, ensuring payments stay current with increasing service delivery costs and safeguard access to quality home- and community-based services.

In addition to ensuring appropriate payment review and adjustment, the Trump administration should collect comprehensive data on the direct support workforce by creating 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 help all levels of

government identify employment trends and design policies, including those that govern states' rate-setting efforts within their HCBS programs. The absence of a SOC categorizing DSPs as distinct professionals also allows the use of adjacent or unrelated professions to justify assumptions that can suppress the wages included in states' underlying reimbursement rate methodologies.

- ☐ The Trump administration should revise the Standard Occupational Classification system to create a distinct classification for DSPs to help all levels of government identify employment trends and design appropriate policies to address the direct support workforce crisis.

- ☐ The Trump administration should require state and federal agencies to collect and publicly report on measures related to workforce volume, stability, and compensation and its resulting impact on access to services.

- ☐ The Trump administration should support and develop programs that meet the social needs of people with IDD and the direct support workforce, including housing and food security, to ensure better access to health care and promote economic independence.

Given the current fragility of the community-based services system, any new policy initiatives with a significant fiscal impact on service delivery must be approached cautiously and with adequate funding to preserve access to care. Without appropriate interagency collaboration, community providers are often confronted with new federal mandates that

pile on additional expenses to service delivery without recognizing or understanding the impact of these mandates on IDD services.

For example, whereas many private employers can increase the price of their products or services when expenses rise, community providers supporting people with IDD are beholden to the costs that reimbursement rates permit. When new federal policies increase the cost of service delivery without commensurate funding, it forces providers to close programs and limit expenditures beyond the bare minimum to remain in operation, thereby jeopardizing quality and service innovation.

- ☐ The Trump administration should require interagency collaboration between the U.S. Department of Health and Human Services, the U.S. Department of Labor, and other federal agencies to ensure appropriate funding is in place prior to issuing new regulations that increase the cost of service delivery.

How the 119th Congress Should Invest in Community IDD Services

With the termination of pandemic-era investments in the Medicaid HCBS program colliding with growing operating costs and an unrelenting workforce shortage, the most significant support Congress can provide is increased federal funding. After decades of starving the system of necessary funds, increased federal investments during the COVID-19 pandemic helped stem the tide of program closures. In 2024, 34% of providers reported considering further cuts to programs, a significant improvement from 60% in the previous year.

Furthermore, temporary funding authorized in response to the pandemic enabled all 50 states to invest in recruitment and retention initiatives, and these initiatives had a direct and positive impact on wages and, in turn, recruitment and retention of DSPs. Whereas the median hourly wage for DSPs until 2020 hovered around $12, three years of meaningful investment pushed hourly wages above $15 for the first time in 2023, providing a much-needed boost to the ability of IDD service providers to attract and retain workers.

- ☐ The 119th Congress should increase the federal share of funding for the Medicaid HCBS program to stabilize the direct support workforce and ensure access to services.

While direct federal investments in IDD services help stabilize the system, significant cuts to the federal Medicaid system place additional financial strain on state budgets. While reductions may not specifically target funding for IDD services, the resulting pressure on state budgets creates an elevated risk of further service cuts for people with IDD. Since programs like HCBS are optional services, they are more vulnerable to reductions.

- ☐ The 119th Congress should preserve existing community-based programs and current Medicaid funding for home- and community-based services for people with IDD.

Because of the nature of Medicaid as a state-federal partnership, with reimbursement rates set by states and matching funds contributed by the federal government, community providers do not have the ability to increase funding to meet increased operating costs. When federal agencies create new policies without ensuring commensurate Medicaid funding, it has the potential to completely collapse the system of community services for people with IDD. Adding new service delivery expenses through federal policy must be accompanied by increased funding to meet new costs that could not be accounted for during rate-setting processes.

- ☐ The 119th Congress should provide increased funding for community providers to offset the increased expense of regulatory compliance.

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 job placement.

- ☐ The 119th Congress should invest in the training and professionalization of the workforce by establishing career pipeline programs for DSPs, which will support recruitment, retention, and advancement efforts.

How State Governments 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 any initiative to expand or enhance existing services because doing so ensures the availability and sustainability of existing supports.

- ☐ State governments should apply for federal funding opportunities focused on stabilizing the direct support workforce.

- ☐ State governments should establish systems of access monitoring that provide regular review of IDD reimbursement rates to ensure payments stay current with increasing service delivery costs 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 needs in their states through measures including, but not limited to, (1) encouraging the U.S. Office of Management and Budget to establish a SOC for DSPs and (2) 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 accurate

accounting of the current workforce will support state and federal response in a way that targets gaps in access before further damage can be done to the HCBS infrastructure.

- ☐ State governments should encourage the U.S. Office of Management and Budget to establish a SOC for DSPs.

- ☐ State governments should participate in the National Core Indicators' State of the Workforce survey.

- ☐ State governments should collect and publicly report on measures and metrics related to workforce volume, stability and compensation to identify and target gaps in access to care to avoid further harm to the HCBS infrastructure.

How Providers & Advocates Should Invest in Community IDD Services

Above all else, providers and advocates must remain vigilant. As we continue to fight together for a stronger, more sustainable system, it's imperative that you stay abreast of the latest developments regarding state and federal laws and proposals shaping the IDD services landscape.

- ☐ Providers and advocates should seek out and apply for state and federal funding opportunities to expand or strengthen community-based supports for people with IDD.
- ☐ Providers and advocates should urge their states to leverage federal funding opportunities to stabilize the direct support workforce crisis by increasing reimbursement rates and creating review systems that ensure DSP wages can keep pace with rising labor costs wrought by inflation and increased demand for services.
- ☐ Providers and advocates should seek out and take advantage of opportunities for stakeholder engagement and public comment on HCBS-related policies, laws, regulations, and funding decisions.
- ☐ Providers and advocates should access state-specific *Case for Inclusion* data to fuel your advocacy by visiting caseforinclusion.org.
- ☐ Providers and advocates should take advantage of available resources from UCP and ANCOR at their 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.

Conclusion

With the proper supports, many people with IDD go to school, get jobs, make friends, live independently, and become vital members of their communities. Sadly, the supports that are so vital in ensuring people with IDD can reach these milestones are neither readily available nor accessible for everyone due to long-term underinvestment in these supports and the resulting direct support workforce crisis.

While the present situation is dire, we have hope. We believe there is a viable path forward to preserve, protect, and expand opportunities for community inclusion. Ongoing communication and collaboration between the Trump administration, Congress, state governments, advocates, and community providers will be crucial over the coming days, months, and years to bringing about policy solutions to ensure that millions of Americans with IDD can continue to access supports that allow them to live, work, and thrive within their own homes and communities with dignity and respect.

Time is of the essence, and only by working together can we fulfill the promise of community inclusion for people with IDD.

Endnotes

[1] *Direct Care Workers in the United States: Key Facts 2024* (New York: PHI, 2024), 1.

[2] *The Role of Disability Service Providers in the New York State Economy* (Albany, NY: Rockefeller Institute of Government, 2021), 3-4.

[3] Richard Schultz, et al., "Economic Impact of Family Caregiving," in *Families Caring for an Aging America* (Washington, DC: National Academies Press, 2016), 123-158.

[4] Arthur Phillips & Josie Phillips, *The High Cost of Undervaluing Direct Care Work* (Augusta: Maine Center for Economic Policy, 2023).

[5] 42 U.S.C. Sec. 1396a(a)(30)(A)

[6] Sheryl Larson, Jonathan Neidorf, Brian Begin, Sandra Pettingell & Mary Sowers, *Long-Term Supports & Services for Persons with Intellectual or Developmental Disabilities: Status & Trends Through 2020* (Minneapolis: University of Minnesota, 2024).

[7] Ibid

[8] Application for a §1915(c) Home and Community-Based Waiver [Version 3.3] Instructions, Technical Guide and Review Criteria Release Date: November 2005.

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