

April 28, 2025

The Honorable Brett Guthrie Chair, House Energy and Commerce Committee Washington, DC 20510 The Honorable Frank Pallone Ranking Member, House Energy and Commerce Committee Washington, DC 20510

Dear Chair Guthrie and Ranking Member Pallone:

The American Network of Community Options and Resources (ANCOR) writes to urge your support for Medicaid-funded services for people with intellectual and developmental disabilities (I/DD) by rejecting broad cuts to Medicaid as contemplated by the FY 2025 budget resolution. The instructions to this committee, which would require cuts of at least \$880 billion—predominantly targeting the federal Medicaid program<sup>1</sup>— would harm people with disabilities and the provider networks that support them. As you consider legislation to respond to the instructions included in the budget resolution, we urge you to reject harmful Medicaid cuts.

Founded more than 50 years ago, ANCOR is a national, nonprofit association representing more than 2,500 private community providers of long-term supports and services to people with intellectual and developmental disabilities (I/DD), as well as more than 60 state provider associations. Combined, our members support more than one million individuals with I/DD in all 50 states across their lifespan and are funded almost exclusively by Medicaid. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

Community providers offer a broad range of supports to help people with I/DD live full and independent lives in their homes and communities. These services vary widely to meet the needs of people with I/DD, from assistance with intimate activities of daily living, including support with personal hygiene and managing medications, to supporting community integration and employment opportunities. Medicaid is the funding source that makes these supports possible, ensuring community providers can help people with disabilities to live, work, and thrive in their communities.

<sup>&</sup>lt;sup>1</sup> Letter to Representative Boyle and Representative Pallone from the Congressional Budget Office (Mar. 5, 2025), <a href="https://www.cbo.gov/system/files/2025-03/61235-Boyle-Pallone.pdf">https://www.cbo.gov/system/files/2025-03/61235-Boyle-Pallone.pdf</a> (noting that Medicaid outlays account for 93 percent of the projections of mandatory spending for the 2025–2034 period for the list of programs under the jurisdiction of the House Committee on Energy and Commerce).

## **Reductions to Medicaid Funding Will Harm People with Disabilities**

ANCOR appreciates the emphasis placed on preserving Medicaid for those who are most vulnerable. We understand it is not the intention of many members on this Committee to reduce access to community-based services for people with I/DD. However, significant reductions in Medicaid funding to states, no matter the policy mechanism, will do just that. State budgets must prioritize mandatory Medicaid services, leaving optional services, including community-based services for older adults and people with disabilities, vulnerable to reductions. When states are forced to make difficult decisions to cover funding shortfalls in state budgets, they will have to make cuts to services supporting vulnerable populations.

If community-based services are cut or reduced, people with disabilities will remain on waiting lists without access to the support they need to live in their homes and communities. Across the country, more than 500,000 people with I/DD are already on states' waiting lists for home and community-based services (HCBS). Wait times are often several years to decades long, forcing people with disabilities to either go without the support they need or be forced into hospital emergency rooms, nursing homes, and large high-cost state-run institutions. Service reductions will only grow these years-long waiting lists, putting community supports for people with disabilities out of reach for thousands of families.

If Congress truly intends to protect Medicaid services for people with disabilities, it cannot support reductions in Medicaid funding.

## **Reductions to Medicaid Funding Will Negatively Impact Disability Services**

Medicaid is a unique funding source that is supported through both federal and state expenditures. While Medicaid is the largest source of federal funding for states,<sup>2</sup> it is also the largest share of state budgets. Data from 2023 reveals that on average, states' total Medicaid expenditures, including federal matching funds, made up 30 percent of total state budgets; when including only nonfederal general fund expenditures, Medicaid spending comprised 18 percent of overall state spending.<sup>3</sup> Reforms to Medicaid financing, such as those contemplated by the instruction to this committee, will have a significant negative impact on state budgets and states' ability to continue offering crucial community-based services.

Restructuring federal funding will reduce access to Medicaid funding for community-based services for people with disabilities.

Any type of funding restructuring that requires a fixed amount of funding for states, rather than ensuring states receive a matching share of the total expense, will leave states exclusively responsible for funding all remaining costs. Proposals to reduce Medicaid funding such as per

<sup>&</sup>lt;sup>2</sup> National Association of State Budget Offices, *2024 State Expenditure Report Fiscal Years 2022-2024*, <a href="https://higherlogicdownload.s3.amazonaws.com/NASBO/9d2d2db1-c943-4f1b-b750-0fca152d64c2/UploadedImages/SER%20Archive/2024\_SER/2024\_State\_Expenditure\_Report\_S.pdf">https://higherlogicdownload.s3.amazonaws.com/NASBO/9d2d2db1-c943-4f1b-b750-0fca152d64c2/UploadedImages/SER%20Archive/2024\_SER/2024\_State\_Expenditure\_Report\_S.pdf</a>.

<sup>&</sup>lt;sup>3</sup> Peter G. Peterson Foundation, *How Do States Pay for Medicaid?* (Feb. 5, 2024) <a href="https://www.pgpf.org/article/budget-explainer-how-do-states-pay-for-medicaid/">https://www.pgpf.org/article/budget-explainer-how-do-states-pay-for-medicaid/</a>.

capita caps, which limit funding based on the number of individuals enrolled, and other spending cuts like block grants or reductions to the federal match rate, will all negatively impact state budgets on a massive scale. Such proposals will force states to make impossible choices, ones that will have a real impact on the health of their residents and their economies.

Reductions in federal Medicaid funding will have a devastating impact on access to services for people with disabilities. Because community-based services are not federally mandated, they are especially vulnerable to Medicaid funding reductions. Even if a proposal for Medicaid reform is not intended to target disability services, any broad funding cuts or structural changes will force states to make difficult budget decisions. Historically, when states face Medicaid funding shortfalls, non-mandatory services like home- and community-based services (HCBS) are among the first to be scaled back, restricting access to essential supports for people with disabilities. In fact, data shows that between 2010 and 2012, in response to the great recession, every single state and the District of Columbia cut spending to one or more of its HCBS programs, either by reducing inflation-adjusted, per-beneficiary spending, or by reducing the number of beneficiaries.<sup>4</sup>

Reducing permissible health care-related taxes, such as provider taxes, will cut available Medicaid funding for disability services.

Similarly, proposals like eliminating or reducing the use of health care-related taxes (i.e. provider taxes)—which account for an average of 17% of the state share of the cost of Medicaid—would have a significant impact on Medicaid funding.<sup>5</sup> 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. Every state, with the exception of Alaska, utilizes at least one provider tax for services to support beneficiaries of the Medicaid program, including people with disabilities.<sup>6</sup> Thirty-nine states have at least three provider taxes.<sup>7</sup>

Reducing or eliminating the use of provider taxes would result in devastating financial losses for states, deep damage to state health care infrastructure, and most importantly, harmful impacts on access to health care for children, families, seniors, and people with disabilities. The most common providers subject to provider taxes are nursing facilities, hospitals, and intermediate care facilities for individuals with intellectual disabilities. Yet, even if provider taxes are not levied against community-based services, the reduction in federal funding implicates these services. The reduction in funding means that states will face budget shortfalls that will likely impact the delivery of community-based services.

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<sup>&</sup>lt;sup>4</sup> Jessica Schubel et al., Health Affairs, *History Repeats? Faced With Medicaid Cuts, States Reduced Support For Older Adults And Disabled People* (Apr. 16, 2025), https://www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled.

<sup>&</sup>lt;sup>5</sup>See Medicaid & CHIP Payment & Access Comm'n, Health Care-Related Taxes in Medicaid (May 2021), https://www.macpac.gov/wp-content/uploads/2020/01/Health-Care-Related-Taxes-in-Medicaid.pdf.

<sup>&</sup>lt;sup>6</sup> Georgetown Univ. McCourt School of Pub. Policy, *Medicaid Provider Taxes: A Critical Source of Medicaid Funding for States* (Feb. 4, 2025), <a href="https://ccf.georgetown.edu/2025/02/04/medicaid-provider-taxes-a-critical-source-of-medicaid-funding-for-states/#:~:text=While%20there%20is%20no%20more,states%20have%20more%20at%20risk.">https://ccf.georgetown.edu/2025/02/04/medicaid-provider-taxes-a-critical-source-of-medicaid-funding-for-states/#:~:text=While%20there%20is%20no%20more,states%20have%20more%20at%20risk.</a>

<sup>&</sup>lt;sup>7</sup> Alice Burns et al, Kaiser Family Foundation, *5 Key Facts About Medicaid and Provider Taxes* (Mar. 26, 2025), https://www.kff.org/medicaid/issue-brief/5-key-facts-about-medicaid-and-provider-taxes/. 
<sup>8</sup> 42 C.F.R. 433.56.

Adding additional red tape to the eligibility and renewal process risks further reductions in coverage and services for people with disabilities.

Medicaid reform proposals that increase administrative burdens for people with disabilities can also jeopardize access to community-based services. For example, work reporting requirements are burdensome for beneficiaries to navigate and for states to administer. Requiring people with disabilities who are working to document and verify that they are working will harm those who do not successfully navigate these bureaucratic processes by causing them to lose coverage for the very supports that enable them to continue working. Even if people with disabilities are exempted from Medicaid work requirements, screening processes may not identify them correctly, and many will not be able to successfully navigate an exemption process. Accordingly, such requirements can be harmful to people with disabilities, potentially leading to a loss in critical health care and long-term services coverage.

Moreover, work reporting requirements are also likely to have unintended negative consequences for low-income workers, including direct support professionals who are the backbone of long-term services and supports for people with I/DD. Approximately one-third of direct support professionals (DSPs) work part time or with inconsistent schedules—two job features that are generally incompatible with work reporting requirements. If direct support professionals are unable to meet burdensome reporting requirements, they will lose the health care that enables them to engage in the workforce and further endanger the sustainability of community-based supports for people with I/DD.

## **Medicaid Reform Necessitates Greater Investment**

Medicaid I/DD services are already in a fragile state. Long-term underinvestment in community-based services, together with stagnant and insufficient reimbursement rates, has hampered the ability of community providers to offer DSPs competitive wages and benefits. This has led to an exodus of qualified workers from the field. In fact, ANCOR's *State of America's Direct Support Workforce Crisis 2024* survey reveals that 90% of providers experienced moderate or severe staffing challenges in the past year, resulting in 69% of providers turning away new referrals. <sup>10</sup> This degree of turnover and vacancy has had a profound impact on the ability of people with I/DD to find and access services. Cuts to Medicaid will exacerbate the current workforce shortages, putting critical community-based services further out of reach of those who need them.

It is important to underscore that proposals to reform the Medicaid system aimed at rooting out the misallocation or misuse of federal funds require additional investments, not reductions in funding. Any efforts to promote efficiency and improved quality in the Medicaid system must take into account the need for additional state and federal oversight, administration, and technological

<sup>&</sup>lt;sup>9</sup> Jessica King, PHI, *Medicaid Work Requirements Will Harm Direct Care Workers* (Aug. 17, 2023), <a href="https://www.phinational.org/medicaid-work-requirements-will-harm-direct-care-workers/">https://www.phinational.org/medicaid-work-requirements-will-harm-direct-care-workers/</a>.

<sup>&</sup>lt;sup>10</sup> American Network of Community Options and Resources, The State of America's Direct Support Workforce Crisis 2024, <a href="https://www.ancor.org/wp-content/uploads/2024/12/The-State-of-Americas-Direct-Support-Workforce-Crisis-2024.pdf">https://www.ancor.org/wp-content/uploads/2024/12/The-State-of-Americas-Direct-Support-Workforce-Crisis-2024.pdf</a>.

improvements. As noted by the advisory entities charged with overseeing the sufficiency of these systems, such as the Medicaid and CHIP Payment and Access Commission (MACPAC) and the U.S. Government Accountability Office (GAO), when recommendations are made for shoring up the oversight of waste, fraud, and abuse, they do not include significant cuts to Medicaid funding.<sup>11</sup>

Federal investments support individuals with I/DD in achieving independence, improving their quality of life, and reducing reliance on expensive institutional care. Recently, temporary federal investments into Medicaid HCBS were authorized through the American Resue Plan Act. This funding was utilized by every state and the District of Columbia to invest in strengthening their workforce. Data from ANCOR's research demonstrates that, during this time period, fewer providers indicated they were closing programs or services. In 2022, 63% of survey respondents reported closing programs or services but that figure dropped to 44% in 2023 and 39% in 2024.<sup>12</sup>

To keep the promise of community living for people with I/DD a reality, we must support and invest in the Medicaid program. Our communities are at their best when all people, including people with disabilities, have the opportunity to develop skills, achieve greater independence, and successfully reach their goals. Medicaid is foundational to building a stronger America for everyone. Please reject harmful cuts to Medicaid funding.

For questions or more information, please reach out to Elise Aguilar, Senior Director of Federal Relations, at eaguilar@ancor.org.

Sincerely,

Darbaro Meiril

Barbara Merrill, Chief, Executive Officer

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<sup>&</sup>lt;sup>11</sup> Gov't Accountability Office, *High Risk Series: Efforts Made to Achieve Progress Need to Be Maintained and Expanded to Fully Address All Areas* (Apr. 20, 2023), <a href="https://www.gao.gov/products/gao-23-106203">https://www.gao.gov/products/gao-23-106203</a>.

<sup>&</sup>lt;sup>12</sup> The State of America's Direct Support Workforce Crisis 2024, supra note 10.