



U.S. Senate Committee on Health, Education, Labor, and Pensions
Making Health Care Affordable: Solutions to Lower Costs and Empower Patients
Thursday, July 31, 2025

The American Network of Community Options and Resources (ANCOR) appreciates the opportunity to submit a statement for the hearing, *Making Health Care Affordable: Solutions to Lower Costs and Empower Patients*. Given the focus of this committee in ensuring better, more sustainable health care solutions to support patients, ANCOR urges the committee to support policies to invest in Medicaid-funded services for people with intellectual and developmental disabilities (I/DD).

Founded 55 years ago, ANCOR is a national, nonprofit association representing more than 2,500 private, mostly non-profit community providers of long-term supports and services to people with 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.

People with I/DD Benefit from Community-Based Services

Medicaid is a lifeline for people with disabilities—not only does Medicaid provide health care, but it is the largest payer of long-term supports and services. ANCOR's members offer a broad range of supports to help people with I/DD live full and independent lives in their homes and communities. Through Medicaid-funded community-based services, people with I/DD have access to a spectrum of person-centered supports, including assistance with activities of daily living, skill-building supports, community integration, and employment opportunities. These supports enable people with I/DD to develop a greater level of independence and autonomy.

Federal Investments in Medicaid Are Necessary to Support Community-Based I/DD Services

To ensure a sustainable system and keep the promise of community living for people with I/DD a reality, Congress must support and invest in the Medicaid program. The data is clear: increased federal investments strengthen and sustain community-based services, while reductions in Medicaid funding have led to cuts and reduced access to community-based services programs.

Recently, temporary federal investments into the Medicaid Home and Community-Based Services (HCBS) program were authorized through the American Rescue Plan Act (ARPA). This funding was instrumental for states in strengthening their community-based services. Every state and the District of Columbia used ARPA funding to invest in strengthening their direct support workforce. Data from ANCOR's research demonstrates that, during this time period, even though community-based providers continued to experience workforce staffing shortfalls, fewer providers indicated they were closing programs or services.¹ For example, in 2022, 63% of survey respondents reported closing programs or services. After the release of additional federal funding through ARPA, that figure dropped to 44% in 2023 and 39% in 2024.²

Yet, Medicaid I/DD services remain in a fragile state. ANCOR's 2024 survey found that 90% of providers experienced moderate or severe staffing challenges in the past year, resulting in 69% of providers turning away new referrals.³ However, rather than invest in Medicaid HCBS, Congress recently passed legislation that places limitations on state and federal funding for Medicaid. The impact of this legislation will be to further exacerbate the already fragile state of Medicaid community-based services and will likely lead to a reduction in access and an increase in individuals' reliance on institutional or hospital settings to receive care.

Even if not targeted specifically at cuts to Medicaid HCBS, reductions in Medicaid funding authorized through the fiscal year 2025 budget reconciliation bill may 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. Historically, when states face Medicaid funding shortfalls, non-mandatory services like 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 a reduction in federal funding in the wake of 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.⁴

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 HCBS.⁵ 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

¹ American Network of Community Options and Resources, *The State of America's Direct Support Workforce Crisis 2024*, <https://www.ancor.org/wp-content/uploads/2024/12/The-State-of-Americas-Direct-Support-Workforce-Crisis-2024.pdf>.

² *Id.*

³ *Id.*

⁴ 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>.

⁵ Kaiser Family Foundation, *Number of People Waiting for Medicaid Home Care (HCBS), by Target Population and Whether States Screen for Eligibility* (2024), <https://www.kff.org/medicaid/state-indicator/number-of-people-waiting-for-hcbs-by-target-population-and-whether-states-screen-for-eligibility/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.

community supports for people with disabilities out of reach for thousands of families, and raising unnecessary costs for states to cover health care in more expensive settings.

Community-Based I/DD Services Are Less Costly than Other Long-Term Services and Supports

Medicaid home and community-based services not only support people with I/DD to live, work, and thrive in their communities, but they are also a cost-efficient solution as compared to the alternative: providing long-term supports in large state-run institutional settings. Medicaid HCBS is far less costly for states than long-term services and supports rendered in public institutional settings. The average annual per capita cost to serve someone with I/DD through a home and community-based waiver program is \$49,764 while the projected cost to serve that individual within large state-run institution, would be \$325,580.⁶

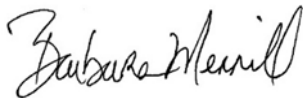
Moreover, Medicaid-funded long-term services and supports enable individuals with I/DD to receive support outside of family caregivers. Providing support options for people with disabilities enables family caregivers to remain in the workforce and continue to earn wages. Community-based services are also essential in upholding individuals' and their families' choices for those who choose to remain in their communities, rather than institutional settings. Thus, investing in community-based services benefits people with disabilities, their families, and state budgets.

Conclusion

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. Sufficient Medicaid funding and a robust community provider network are foundational to building a stronger America for everyone. The best way to keep health care sustainable and available for the individuals with I/DD who depend on it is to invest in home and community-based services.

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

Sincerely,



Barbara Merrill
Chief Executive Officer
ANCOR

⁶ Residential Information Systems Project, In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities (June 30, 2020), https://ici-s.umn.edu/files/a6fkEiad6J/2020_risp_report?preferredLocale=en-US.