February 6, 2026

Dr. Mehmet Oz
Administrator
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
Washington, DC

Dear Administrator Oz:

The undersigned organizations, as part of the Long-Term Services and Supports Taskforce of the Consortium for Constituents with Disabilities (CCD), write to ask for additional clarification and guidance on the implementation of Public Law No. 119-21, the fiscal year 2025 budget reconciliation legislation (H.R. 1).

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society, free from discrimination.

Section 71121 allows states to implement a new waiver to expand home and community-based services (HCBS) for those individuals who would otherwise not be eligible for services under a 1915(c) waiver because they do not require an institutional level of care. Section 71121 requires states implementing the new waiver to meet certain conditions, while also providing $50 million to the Administrator of the Centers for Medicare & Medicaid Services (CMS) for purposes of carrying out this provision in fiscal year (FY) 2026, and an additional $100 million to states in FY 2027 to support State systems to deliver HCBS independent of Section 71121.

We are appreciative of additional funding for states to invest in HCBS—especially as states and HCBS providers continue to grapple with a dire workforce shortage that limits access to services,[1] hundreds of thousands of individuals remain on state waiting lists

[1] American Network of Community Options and Resources, *The State of America's Direct Support Workforce Crisis 2025,* https://www.ancor.org/resources/the-state-of-americas-direct-support-workforce-crisis-2025/.

across the country,[2] and as states are contemplating reductions in Medicaid rates.[3] However, we are also concerned that without additional guidance from CMS, that even with the existing beneficiary protections in place that cover 1915(c) waivers and would extend to services authorized under section 71121, there could be uncertainty in how states implement the new waiver authority and potentially even unintended consequences that have the impact of limiting access to HCBS for certain individuals.

Below are our recommendations for technical guidance for states implementing the new waivers.

Waiting Lists

We are grateful for guardrails included in Section 71121 to help ensure that individuals who are eligible to receive HCBS through existing 1915(c) waivers are not forced to wait longer for services. However, the statutory language needs additional clarification on how states can track waiting lists and ensure there are no adverse impacts on individuals waiting for or already being supported through existing services.

CMS should further define "a material increase in the average amount of time" that currently eligible individuals will need to wait to receive HCBS, to include not only how waiting lists are traditionally conceptualized (e.g. the length of time an individual must wait to get a level of care determination or the time they must wait from receiving a level of care determination to approval to enroll in a waiver), but also, at a minimum, transparent annual reporting of existing provider network capacity and average wait times from when services are initially approved to when individuals begin receiving the full scope and hours of services authorized. We recommend aligning these tracking and reporting requirements with the access reporting requirements in 42 C.F.R. 441.311(d) to the extent practicable, so that beneficiaries and other interested parties can track the impact on access to waiver services consistently across waiver authorities. Similarly, waiting lists should be defined and measured the same way across all 1915(c) waivers within a state, and should measure waiting lists in a consistent manner over time, to allow better measurement of any material increases in wait time.

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[2] Kaiser Family Foundation, Number of People Waiting for Medicaid Home Care (HCBS), by Target Population and Whether States Screen for Eligibility (2025), 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.

[3] *See, e.g.*, Shaun Boyd, *Medicaid Spending in Colorado Is Unsustainable, Gov. Jared Polis Says*, CBS News (Oct. 31, 2025), https://www.cbsnews.com/colorado/news/medicaid-spending-colorado-unsustainable-gov-jared-polis/; Kyle Pfannenstiel, 'This Perfect Storm:' How Idaho Medicaid Cuts Could Affect Everyone's Health Care Access, Idaho Capital Sun (Nov. 4, 2025), https://idahocapitalsun.com/2025/11/04/this-perfect-storm-how-idaho-medicaid-cuts-could-affect-everyones-health-care-access/.

Establishing a New Needs-Based Criteria

The language in Section 71121 requires that states develop new needs-based criteria to determine who will be eligible for the new waiver and specifies which services those individuals will receive through the new waiver. CMS should provide additional guidance on how states should develop the needs-based criteria. For example, the requirements that apply to 1915(i) state plans—which similarly allow states to provide HCBS for individuals who do not meet an institutional level of care—include specific requirements regarding assessments of an individual's support needs and capabilities. We request that CMS expand on its expectations regarding state obligations when evaluating need, and thus eligibility, for these new 1915(c)(11) waivers.

Use of Funding

We appreciate the inclusion of additional HCBS funding in the statute. However, it is unclear how the funds may be used by states to support state systems to deliver home and community-based services, and what accountability measures will be included to ensure proper use of funding. We urge CMS to provide explicit guidance to states on the use of the $100 million appropriated in FY 27, how that funding may be used to invest in services, including:

- Permissible uses of funds to invest in services, such as investments into the direct care workforce (e.g., wages, training, supervision, and career ladders) and
- Improvements to assessment, eligibility, and data systems needed to administer the new waivers.

We also request that CMS clearly outline the reporting mechanisms that will be put into place to ensure transparency and accountability for how funds are used. We urge this guidance to be developed with stakeholder input to identify existing challenges and ensure states are prepared to use the funding once it is available.

Ongoing Stakeholder Input

Recognizing that the creation of new eligibility and scope of HCBS will necessitate additional discussion, we urge CMS to continue to consult this LTSS Taskforce and other stakeholders for feedback, resources, and support as you draft guidance on this provision.

Thank you for your consideration of these comments. We stand ready to provide additional information, including state-specific examples and data, as CMS implements Section 71121 in a manner that strengthens and expands access to HCBS for children and adults with disabilities.

Sincerely,

Allies for Independence
American Association on Health and Disability
American Network of Community Options and Resources (ANCOR)
American Therapeutic Recreation Association
The Arc of the United States
Autism Speaks
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Center for Public Representation
CSH
Disability Belongs
Disability Rights Education and Defense Fund (DREDF)
Easterseals, Inc.
Epilepsy Foundation of America
Justice in Aging
The Kelsey
Lakeshore Foundation
Muscular Dystrophy Association
National Academy of Elder Law Attorneys (NAELA)
National Alliance to End Homelessness
National Disability Institute
National Down Syndrome Congress
National Health Council
National Health Law Program
National PLAN Alliance (NPA)
National Respite Coalition