On behalf of the National Health Law Program (NHeLP), we submit this statement for the record for the U.S. Special Committee on Aging hearing entitled “An Economy That Cares: The Importance of Home-Based Services.”

NHeLP is a public interest law firm working to protect and advance the health rights of low income and underserved individuals. Founded in 1969, NHeLP advocates, litigates, and educates at the federal and state levels. Consistent with its mission, NHeLP works to ensure that all people in the United States have access to affordable, quality health care, including home and community based services (HCBS) for people with disabilities.

HCBS allows people with disabilities and older adults to remain at home and active in their communities, while improving their health and quality of life outcomes. Additionally, HCBS typically costs less per-person than institutional services. HCBS is a key component of Medicaid, which is the nation’s primary payor of HCBS services such as personal assistance, supported employment, peer support, and other services older adults and people with disabilities need to remain at home. While all State Medicaid programs can cover these critical services, the extent to which they do often depends on geography or political context – not need. Some states choose to cover expansive HCBS, but others do not. This means that two people with the exact same needs living in different states may get vastly
different services. Worse yet, because states can “cap” the number of enrollees or the costs associated with these services, many people end up waiting years, even decades, for Medicaid HCBS services. These same barriers do not exist for mandatory nursing facility care services. It is often easier for someone who needs assistance to enter institutional care than to receive HCBS in their communities. Those who do access HCBS often have to forgo basic life opportunities that others take for granted, like being able to move states for school or a job, or marry and form a family. Those actions can endanger their access to HCBS.

Additionally, the currently underfunded HCBS system is unsustainable. People with disabilities and older adults languish on waiting lists, experience gaps in coverage, or are forced into institutional settings when they are unable to access care due to inadequate coverage. People approved to receive HCBS often struggle to find staff to support them, largely because low Medicaid rates lead to systemic staffing shortages, high turnover rates, and inadequate training. The essential workers who provide HCBS services—primarily women and people of color—are among the lowest paid health care workers in the United States, which perpetuates more racial and economic injustices. Quite simply, we cannot improve access to Medicaid-funded HCBS without also raising the rates for these services, and ensuring those rate increases go to increased wages and benefits for HCBS direct care workers.

As Congress moves forward, legislators must prioritize expanding access to HCBS services by addressing structural barriers, by providing robust funding, and by increasing support for caregivers and direct service providers to ensure these services remain available.

Medicaid has always been the primary driver of innovation in HCBS, and much progress has been made over the past two decades to improve access to HCBS for older adults and people with disabilities. For example, the Money Follows the Person (MFP) demonstration program

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has helped over 150,000 people transition from institutional settings, to receive care and services in their own homes. Additional funding via the American Rescue Plan Act helped states fund HCBS has been critical in helping states provide HCBS through the worst of the pandemic, but the funding is temporary.

Congress now has the opportunity to take another huge step forward towards improving the lives of people with disabilities and older adults. The Better Care Better Jobs Act would give states a much-needed infusion of federal funds for HCBS via a permanent increase in states’ federal medical assistance percentage (FMAP) for these services, and would turn current short-term investments in HCBS into more meaningful, long-term opportunities to build and sustain a responsive, comprehensive HCBS system. The Act would also Invest in the direct care workforce by addressing insufficient payment rates and requiring that rate increases are passed on to direct care workers. We call on Congress to build a sustainable HCBS infrastructure and fix structural biases that make it easier to access institutional care than community-based services by passing the Better Care Better Jobs Act.

Thank you for your consideration of our comments. If you have questions about these comments, please contact Dania Douglas (douglas@healthlaw.org)