

The Disability and Aging Collaborative

December 5, 2022

President Joe Biden
Vice President Kamala Harris
1600 Pennsylvania Avenue, N.W.
Washington, DC 20500

Re: Medicaid Home & Community-Based Services in FY 2024 Budget Request

Dear President Biden and Vice President Harris:

The Disability and Aging Collaborative (DAC) is a coalition of approximately 40 national organizations that work together to advance long-term services and support policy at the federal level. Formed in 2009, the DAC was one of the first coordinated efforts to bring together disability and aging organizations. **The undersigned DAC members recommend that the President's FY 2024 budget request include at least \$300 billion to support Medicaid Home and Community-Based Services (HCBS).** This budget request reflects the CBO's preliminary estimate associated with the Better Care Better Jobs Act (S. 2210/H.R. 4131).

We deeply appreciate all you have done to elevate the need to invest in the care infrastructure, including expressing your support in your 2022 State of the Union Address and economic recovery plans for investing in Medicaid HCBS. Medicaid HCBS is the only program covering the full range of support older adults and people with disabilities need to remain safely in their homes and connected to their communities. However, due to an institutional bias in federal Medicaid law, states are required to cover more costly care in nursing facilities and other institutions but not the full range of HCBS that individuals need to remain in their communities. This institutional bias, combined with persistent underfunding of HCBS, results in a lack of available community-based services and the unnecessary institutionalization of older adults and people with disabilities.

Although the 10% federal medical assistance percentage (FMAP) increase from the American Rescue Plan Act provided critical emergency support to states to minimize service cuts and shore up their Medicaid HCBS workforce, this one-time funding does not address the systemic issues that contribute to insufficient access. A sustainable solution is needed to provide states with resources to build an HCBS infrastructure that can meet the needs of older adults and people with disabilities, attract and retain a well-paid workforce, and allow family caregivers to return to their jobs.

Workforce

The HCBS workforce, comprised of personal care aides, home health aides, community support workers, and direct support professionals, provides critical care to older adults and people with disabilities. Despite the tremendous demand for these workers, their wages remain low—with a median hourly wage of approximately \$14 in 2021.¹ As a result of low wages and limited annual earnings, direct care workers experience tremendous economic instability; approximately 40% of all direct care workers live in or near poverty and rely on public assistance to survive. Insufficient Medicaid reimbursement rates restrict the ability of providers to offer industry-competitive wages. Inadequate wages contribute to workers leaving the long-term care field for higher-paying and/or more stable opportunities in entry-level industries, including retail, convenience, and fast-food. The resulting direct support workforce crisis threatens access to community-based services with 63% of community providers discontinuing

¹ PHI, "Workforce Data Center," (September 2022), available at <https://phinational.org/policy-research/workforce-data-center/>.

programs and services, a staggering 85.3% increase since the beginning of the pandemic.² A transformative investment into HCBS will provide this workforce, which is comprised predominantly of women and people of color, with family-sustaining wages, workplace supports, and recognition of their critical contributions, all of which are needed to reduce turnover and maintain sufficient staffing to meet the needs of older adults and people with disabilities.

Waitlists & Unmet Need

In addition to workforce shortages, the current HCBS infrastructure is insufficient to meet the needs of older adults and people with disabilities. Insufficient capacity is demonstrated in part by wait lists. More than 800,000 people are on waiting lists for HCBS, a number that likely underestimates the total number of individuals waiting for benefits, as wait list design differs by state.³ Waiting lists leave people with disabilities, older adults, and their families waiting years for services.⁴ Moreover, millions more people have unmet needs because they are not able to receive the full scope of services they need or do not have access to the HCBS system at all.

Family Caregivers

When older adults and people with disabilities cannot access the services they need, the responsibility of care and support often falls on unpaid family caregivers. Nearly 53 million family members currently provide unpaid care to their loved ones.⁵ As a result of providing care, many family caregivers incur financial insecurity, as they may experience lost income from having to cut back hours or leave the workforce altogether. Investments that increase access to HCBS would reduce strain on family caregivers, allowing this group of people to rejoin the workforce, which in turn will stimulate economic growth and job creation.

Recommendations

We ask that the President's FY 2024 Budget Request include at least \$300 billion to implement the following recommendations:

- **Dedicated, Permanent FMAP Increase for Medicaid HCBS to Build on the One Year of Funding Included in the American Rescue Plan.** An ongoing stream of additional federal funding, as outlined in the Better Care Better Jobs Act, is necessary to ensure that states have the fiscal certainty to actually expand access to and eligibility for services to support older adults and people with disabilities, including people currently on waiting lists for these services. This funding must focus on the equitable distribution of services and begin to ensure parity across states regarding what people with disabilities and aging adults can access. Extra effort and attention should be given to assistance for marginalized groups. Communities of color, tribal nations and indigenous communities, LGBTQ+ communities, and others should be supported in responding to the needs they identify.

² ANCOR, "The State of America's Direct Support Workforce Crisis 2022," (2022), available at <https://www.ancor.org/wp-content/uploads/2022/10/The-State-of-Americas-Direct-Support-Workforce-Crisis-2022.pdf>

³ MACPAC, "State Management of Home and Community-Based Services Waiver Waiting Lists," (August 2020), available at <https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf>

⁴ *Id.*

⁵ AARP & National Alliance for Caregiving, "Caregiving in the U.S.," (2020), available at <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>.

The FMAP increase must be tied to better workforce support, including initiatives to increase wages, recruitment, and retention. This funding is necessary to support adequate HCBS infrastructure, including building both the service infrastructure and the direct care workforce and to pay a family-sustaining wage to those who provide direct care to support individuals who need HCBS.

This funding must include a mechanism to ensure that states cannot cut services at a time when they should be expanding them and to ensure that workers' wages, benefits, and employment opportunities are adequate for the present and adjusted as necessary in the future to ensure a stable, fairly paid workforce.

- **Dedicated, Additional Funding for ACL to Continue its Recently Established National Direct Care Worker Resource Center, Beyond the Current Life of the 5-year Grants.** Per the Administration for Community Living (ACL), “[T]he Center will serve as a hub, providing tools, resources and training to assist state systems and service providers and to support the development and coordination of policies and programs that contribute to a stable, robust direct care workforce. The center’s website will share resources, model policies and best practices and will facilitate peer-to-peer sharing of lessons and promising practices. It will also support collaboration between state systems, including Medicaid, aging, disability, and workforce agencies; service providers; and aging, disability and labor stakeholders.”⁶
- **Create a Standard Occupational Classification for Direct Support Professionals.** This will enable comprehensive data collection on the direct support workforce, which is necessary to address the workforce crisis and inform wages for better retention and recruitment of direct support professionals.
- **Permanently Authorize the Money Follows the Person Program (MFP) and Protections from Spousal Impoverishment for Married Persons Receiving HCBS.** MFP, which helps transition people out of nursing facilities and into the community, and federal protections from spousal impoverishment, which help married persons live together in the community, are critical measures to prevent people from being institutionalized unnecessarily and help them access HCBS. There is strong bipartisan support for both policies, and Congress has voted to extend them multiple times. They are currently set to expire in 2023. Permanent authorization of these programs is needed to remove barriers, such as financial uncertainty, that discourage state uptake and expansion of programs.
- **Eliminate Medicaid Estate Recovery.** Medicaid Estate Recovery is a federal policy that requires states to recover certain Medicaid expenses from the heirs of a deceased Medicaid enrollee. We support eliminating this discriminatory policy. It stops families from escaping poverty, makes the racial wealth gap worse, and also keeps older adults and people with disabilities from getting the HCBS they need.
- **Establish Comprehensive HCBS Data Collection and Reporting.** Current HCBS data limitations inhibit a comprehensive understanding of who uses these benefits and whether services meet people’s needs. Establishing and implementing a uniform set of demographic data, utilization, and access measures, stratified by demographic characteristics, across HCBS and LTSS will enable states to deploy targeted strategies that better address people’s needs, including intersectional needs resulting in a heightened risk of nursing home placement. Funding,

⁶ ACL, “ACL Launches National Center to Strengthen the Direct Care Workforce,” (October 2022), available at <https://acl.gov/news-and-events/announcements/acl-launches-national-center-strengthen-direct-care-workforce>.

technical support, and oversight from the federal government are needed to ensure states accurately report this information and present it in an accessible format.

The undersigned organizations recommend that the President's FY 2024 budget request include at least \$300 billion to support Medicaid HCBS. This investment is critically needed to expand access to services for older adults and people with disabilities, attract and retain the direct care workers delivering these services, and allow family caregivers to rejoin the workforce. If you have questions regarding this request, please contact Natalie Kean, Director of Federal Health Advocacy at Justice In Aging, at nkean@justiceinaging.org, or Haeyoung Yoon, Senior Policy Director at the National Domestic Workers Alliance, at haeyoung@domesticworkers.org.

Respectfully,

ADAPT of Texas
Allies for Independence
American Association of People with Disabilities
American Association on Health and Disability
American Network of Community Options and Resources
Association of University Centers on Disabilities
Autism Society of America
Caring Across Generations
Community Catalyst
Disability Policy Consortium
Disability Rights Education and Defense Fund (DREDF)
Epilepsy Foundation
Hand in Hand: The Domestic Employers Network
Justice in Aging
Lakeshore Foundation
LeadingAge
National Academy of Elder Law Attorneys
National ADAPT
National Association for Home Care & Hospice
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Consumer Voice for Quality Long-Term Care
National Domestic Workers Alliance (NDWA)
National Health Law Program
National PACE Association
Personal Attendant Coalition of Texas (PACT)
Service Employees International Union
The Arc of the United States
Well Spouse Association

Cc: Shalanda D. Young, Director, Office of Management and Budget
White House Domestic Policy Council Staff