

The Disability and Aging Collaborative &



May 27, 2021

The Honorable Chuck Schumer
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader
U.S. Senate
Washington, DC 20510

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
Washington, DC 20515

Dear Leaders Schumer and McConnell and Speaker Pelosi and Leader McCarthy,

The Consortium for Citizens with Disabilities (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. 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 CCD and DAC members write to share our priorities for Congress as you put together legislation, specifically around the \$400 billion included in President Biden's American Jobs Plan to support Medicaid Home and Community-Based Services (HCBS).

The pandemic has taken a very real toll on people with disabilities and older adults who were particularly at risk as COVID-19 spreads across the country, facing high risk of complications and death if exposed to the virus and needing to isolate to protect themselves. State HCBS programs struggled to continue to provide these life-sustaining, daily, in-home services in the

face of staff shortages due to sickness, self-isolation, and childcare needs; low wages; and lack of protective equipment even in the face of higher infection risk. At the same time, State Medicaid agencies are experiencing increases in enrollment, potentially causing pressure on state budgets. If states must reduce their Medicaid spending due to the stress and strain of the pandemic, these lifesaving HCBS services are at particular risk. This is because under the Federal Medicaid law, HCBS are considered optional, and thus are targets for reduction if states are looking for services to cut. This is why the disability and aging communities have advocated for dedicated funding.

We once again express our thanks for the 10% FMAP bump for one year that was included in the American Rescue Plan Act to strengthen and expand access to Medicaid HCBS. This funding was desperately needed to keep more people with disabilities and older adults from unnecessarily entering large congregate settings, such as nursing facilities and other institutions, where COVID-19 infections and deaths are significantly more likely and which are frequently the center of COVID-19 outbreaks, making them much more dangerous. However, it is only one year of funding and cannot address the roots of a crisis decades in the making: our system's over-reliance on congregate settings, underpayment of direct care workers, and the overall scarcity of home and community-based services desperately needed by people with disabilities and older adults. Without longer-term Federal support to address these structural issues, the next pandemic will be no different.

This is why the dedicated \$400 billion to support HCBS included in the American Jobs Plan is so important for long-term change in the nation's long-term services and supports system. The only specific policy proposal that was included in the AJP was permanent reauthorization of both the Money Follows the Person program, something DAC and CCD have long been advocating for and which will need only a fraction of the total funding. Beyond that, the proposal generally spells out that the \$400 billion should be spent over eight years in order to increase BOTH access to Medicaid HCBS and address the direct care workforce--creating more direct care jobs to support people with disabilities and aging adults, and making those jobs better.

This investment would fortify a workforce that must continue to expand to meet a rapidly increasing level of need, and also address the long-standing inequities the pandemic exposed and exacerbated. The majority of the direct care workforce are women of color. The HCBS workforce represents a broad array of home care workers, personal care attendants, peer support specialists, independent providers working at the direction of a consumer, and direct support professionals. The HCBS workforce provides vital services yet have been devalued and underpaid for decades.

Not only have wages been inadequate, but the system itself is not serving everyone who needs home and community-based services. People with disabilities of all ages have a legal right to

receive services and supports in the most integrated setting, regardless of the source of payment for services. Yet, over 800,000 people with disabilities are currently on waiting lists for the Medicaid-funded services needed to make that possible, and many more are entering institutions because they do not have the resources to bridge the gaps. These waiting lists leave people with disabilities, aging adults and their families waiting years and even decades for services. Investments must be made to support this as yet unrealized goal of the Americans with Disabilities Act.

When older adults who want to age in place and people with disabilities who need support to work, live independently, and be part of their communities are left waiting, the responsibility of care and support often falls on unpaid family caregivers. The costs of this inadequate system fall disproportionately on people of color with limited income and wealth. The workforce and earnings losses related to unpaid family caregiving are significant and well-documented. But an investment in HCBS services expansion creates another group of people who can rejoin the economy - family caregivers. Without the investment in services, family caregivers will have to continue to fill in the huge gaps in the service system. Addressing all these issues will stimulate economic growth and job creation.

In order to address these issues, the undersigned members of CCD and DAC recommend:

- A dedicated FMAP increase for Medicaid HCBS to build on the one year of funding that was included in the American Rescue Plan. An ongoing stream of additional federal funding 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.
- Any funding to support services must require a focus on equitable distribution of services, and begin to ensure that there is parity across states on what people with disabilities and aging adults can access. Extra effort and attention should be given to assistance for marginalized groups. Communities of color, sovereign nations, and others should be supported in responding to needs they identify.
- That same FMAP increase must be tied to better workforce supports, including initiatives to increase wages, recruitment, and retention. This funding must also support adequate HCBS infrastructure, including funding for states to build the service infrastructure and direct care workforce and pay a family-sustaining wage to those who provide direct care to support all individuals who need HCBS.
- The increase should also be tied to expanding self-directed models of services, including expanding consumer control over services and budgets, and supporting models where both family and other support network individuals can be paid direct care workers. Funding should promote the concepts of, and services that support, independent living,

self-direction and the dignity of risk, meaning allowing HCBS beneficiaries to make their own choices, and not be protected from asserting their will..

- 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.
- Legislation should also include outcome and quality measures and allow for data collection. Such data is necessary to ensure that the basis for service rates, and in turn wages for workers, are adequate to ensure that older adults and people with disabilities are able to access high quality services through Medicaid.
- These efforts ultimately should result in ensuring the consumers' rights to hire, train, supervise, schedule, and if necessary replace their workers
- This funding should not result in loss of services for current recipients of Medicaid or non-Medicaid (Private Pay) consumers.

We urge lawmakers and leadership, as you turn to recovery, infrastructure and other priorities to include the \$400 billion investment in the infrastructure of Medicaid HCBS, and the workforce that provides them. Congress must act to address the serious, destabilizing deficits facing our nation's only publicly funded long term care system by including this funding. If you have any questions, feel free to contact Nicole Jorwic (jorwic@thearc.org).

Sincerely,

AARP

Allies for Independence

American Association on Health and Disability

American Association on Intellectual and Developmental Disabilities (AAIDD)

American Network of Community Options & Resources (ANCOR)

American Physical Therapy Association

American Therapeutic Recreation Association

The Arc of the United States

Association of Assistive Technology Act Program

Association of University Centers on Disabilities (AUCD)

Autism Society of America

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

Brain Injury Association of America

The Center for Eldercare Improvement, Altarum

CommunicationFIRST

Disability Rights Education and Defense Fund (DREDF)

Easterseals

Epilepsy Foundation

Justice in Aging
Lakeshore Foundation
Lutheran Services in America
National Association for Home Care & Hospice
National Association of Area Agencies on Aging
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Down Syndrome Congress
National Health Law Program
National Multiple Sclerosis Society
RespectAbility
The Viscardi Center
World Institute on Disability