



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

July 15, 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 undersigned co-chairs of the CCD Long-Term Services & Supports (LTSS) Taskforce write to share our overwhelming support for the \$400 billion investment included in the Build Back Better Agenda to support access to Medicaid Home and Community-Based Services (HCBS) and support the direct care workforce.

The pandemic has taken a very real toll on people with disabilities and older adults, who were particularly at risk as COVID-19 spread across the country, facing higher 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 life-sustaining, daily, in-home services in the face of frontline staff shortages due to sickness, self-isolation, and childcare needs; lack of protective equipment even in the face of higher infection risk; and a long history of low wages. These staff shortages and programmatic weaknesses threatened, and continue to threaten, the lives of people with disabilities and older adults.

The bold proposals in the Build Back Better Agenda and the 10% FMAP bump for one year that was included in the American Rescue Plan Act are critical steps to strengthen and expand access to Medicaid HCBS, and we are so appreciative of them. At the same time, we must grapple with the harsh reality that one year of funding cannot address the roots of a crisis decades in the making: our system's over-reliance on congregate settings, the chronic underpayment of direct care workers, and the resulting scarcity of home and community-based services desperately needed by people with disabilities and older adults.

This is why the dedicated \$400 billion to support HCBS included in the Build Back Better agenda is so important to the disability and aging communities. This level of investment is essential for building a sustainable home and community-based service infrastructure that can begin to address the magnitude of need in our communities, both increasing access to Medicaid HCBS *and* addressing the direct care workforce--creating more direct care jobs to support people with disabilities and aging adults, and making those jobs better.

To address the long-standing inequities the pandemic exposed and exacerbated, this investment must fortify a workforce that must continue to expand to meet a rapidly increasing level of need. The HCBS workforce provides vital services, and yet these workers--who are primarily women of color--have been devalued and underpaid for decades, leading to severe staff shortages that can result in crucial gaps in service availability, lengthy waiting lists, service line closures, and additional obstacles to achieving a high quality of life for workers and recipients alike.

Due in large part to inadequate resources, the system itself is not serving everyone who needs home and community-based services, even though most people far prefer to remain in their homes as they age, and research has shown that quality of life is significantly improved when individuals are able to live in the community. Further, 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, 31 years after the passage of the Americans with Disabilities Act, 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 against their wishes because they do not have qualified and trained direct care staff to support them in the setting of their choice. These waiting lists leave people with disabilities, aging adults and their families waiting years and even decades for services. The investments in the Build Back Better Agenda are crucial to reach 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 a part of their communities are left waiting, the responsibility

for 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. An investment in HCBS services expansion creates another group of people who can rejoin the economy--family caregivers--and stimulates economic growth and job creation. Without the investment in services outlined in the Build Back Better Agenda, family caregivers will have to continue to fill in the huge gaps in the service system.

There has been some misunderstanding around how an investment in HCBS may impact other settings, including institutional ones. Nothing in the Better Care Better Jobs Act or any of the Biden Administration's proposals would take away any funding any other Medicaid services, including institutional settings. What this investment *would* do is repair and build the missing infrastructure to enable support for the nearly one million people on waiting lists who want HCBS. HCBS has grown exponentially since its inception forty years ago. Unfortunately, the necessary infrastructure investments, including in the workforce, have not kept pace with this rate of growth. For this reason, these investments are not only essential to shore up the existing system but to ensure a solid foundation for growth for the future. The historic lack of investment by state and federal government in HCBS since their creation forty years ago has led to the need for this investment, and righting this wrong would not hinder any other Medicaid-funded service.

We once again thank you for your leadership and urge that you continue to include and prioritize the \$400 billion investment in the infrastructure of Medicaid HCBS, and the workforce that provides them, as you negotiate recovery legislation. We stand ready to assist you in any way we can. If you have any questions, feel free to contact Nicole Jorwic (jorwic@thearc.org)

Sincerely,

Julia Bascom,
Autistic Self Advocacy Network

Dan Berland
National Association of State Directors
of Developmental Disabilities Services

Nicole Jorwic
The Arc of the United States

Jennifer Lav
National Health Law Program

Sarah Meek
American Network of Community Options and Resources (ANCOR)