

August 17, 2021

The Honorable Chuck Schumer
Majority Leader
United States Senate
Washington, D.C.
20510

The Honorable Mitch McConnell
Minority Leader
United States Senate
Washington, D.C.
20510

The Honorable Nancy Pelosi
Speaker
United States House of Representatives
Washington, D.C.
20515

The Honorable Kevin McCarthy
Minority Leader
United States House of Representatives
Washington, D.C.
20515

An Open Letter on Behalf of the Disability and Aging Communities

Dear Congressional Leaders:

We write this letter to you on behalf of the millions of people with disabilities, seniors, and their family caregivers served by our organizations – as well as on behalf of the thousands of direct service professionals we employ to deliver care and support to them.

Our ask is clear, and urgent:

***Fully fund home and community-based services (HCBS)
at the proposed \$400 billion level.***

Anything less would be devastating and would exacerbate the challenges of an already burdened system to address the growing demand for these services, let alone the uncharted impact of a global pandemic.

Too many people's lives are at stake. Too many people continue to go without the critical services and supports they need, deserve, and have every right to access. Home and community-based services are absolutely essential to our country's infrastructure, now more than ever.

Some 30 years later, the proposed \$400 billion for HCBS would finally begin to fulfill the right to needed services so that people with disabilities and the aging can live at home – rights provided under the Americans with Disabilities Act of 1990 and the Olmstead Decision of 1999. Plus, 76% of Americans recently polled voiced support for this funding to improve care for people with disabilities and the elderly.

Consider the lives impacted through Home and Community-Based Services, pre-COVID-19:

- **Roughly 850,000 people with disabilities are currently on waiting lists for HCBS, meaning people go without having their basic daily needs met (bathing, making meals, movement, transportation and other essential activities so many of us take for granted).**
- **Direct support professionals are in crisis, as they face dramatically increasing demand for their HCBS services, yet receive inadequate pay, benefits or professional development. There are simply too few direct support professionals to deliver this care, and not nearly enough resources available to cover the demand.**
- **Without this funding, states are facing increasing pressure to reduce access to these services, even while demand grows exponentially due to the pandemic.**

As the substance of the reconciliation bill is being considered, the debate among lawmakers continues about how much funding should be available for home and community-based services (HCBS).

Let us be clear: [there should be no debate.](#)

The \$400 billion in funding represents the solid building blocks needed for a better future. Without this critical funding support, we are set back further than where we started, and with too few tools to “build back better.”

Thank you for your consideration of this request.

- * ACCSES
- * Allies for Independence
- * American Association of People with Disabilities (AAPD)
- * American Network of Community Options and Resources (ANCOR)
- * The Arc of the United States
- * Augie’s Quest to Cure ALS
- * Autism Society of America
- * Association of University Centers on Disabilities (AUCD)
- * Autistic Self Advocacy Network (ASAN)
- * Barth Syndrome Foundation
- * Center for Autism and Related Disorders

- * Collaboration to Promote Self-Determination (CPSD)
- * Council of State Administrators of Vocational Rehabilitation (CSAVR)
- * Cure SMA
- * Davis Phinney Foundation
- * Easterseals
- * Epilepsy Foundation
- * Genetic Alliance
- * Health Hats
- * Heart Valve Voice US
- * Hypertrophic Cardiomyopathy Association
- * InnovAge
- * International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
- * Lutheran Services in America
- * LeadingAge
- * M-CM Network
- * Mito Action
- * MLD Foundation
- * National Alliance on Mental Illness (NAMI)
- * National Association of Area Agencies on Aging (n4a)
- * National Center for Learning Disabilities (NCLD)
- * National Association of Councils on Developmental Disabilities (NACDD)
- * National Disability Rights Network (NDRN)
- * National Down Syndrome Congress (NDSC)
- * National PACE Association
- * National Respite Coalition
- * NEXT for AUTISM
- * Organic Acidemia Association
- * Partnership for Medicaid Home- Based Care
- * Powerful Patient
- * PXE International
- * Rare New England

- * Spina Bifida Association
- * Texas Rare Alliance
- * TSC Alliance
- * United Cerebral Palsy (UCP)
- * United Spinal Association