

# The Disability and Aging Collaborative &



February 2, 2021

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

The Honorable Mitch McConnell  
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 with extreme urgency as you consider COVID relief legislation to share our profound concern regarding the continued omission of the needs of people with disabilities and aging adults in prior passed packages.

We strongly urge you to include the COVID HCBS Relief Act of 2021 (S. 151, H.R. 525) in whatever package ultimately becomes law, in addition to continued support for Medicaid and continuation of the PHE. This incredibly important piece of legislation was introduced by Senator Casey on January 28, 2021 and was introduced in the House under the same name by Representative Dingell. This funding is desperately needed since NONE of the legislation that Congress has ultimately passed has included any dedicated funding for the Home and

Community-Based Services (HCBS) upon which people with disabilities and older adults rely to stay safe in their own homes and communities.

As we have written several times in the past year, people with disabilities and older adults are 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 struggle 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. As states face budget crises, they are responding by making cuts to Medicaid, particularly for waiver services like HCBS. Simultaneously, with a growing number of uninsured in the country, State Medicaid agencies are experiencing increases in enrollment. These lifesaving services are at particular risk because under the Federal Medicaid law, they are considered optional, and so when cuts to state budgets come due to the stress and strain from the pandemic, they come first to HCBS.

Without a dedicated funding stream like that offered by the targeted FMAP enhancement included in The COVID HCBS Relief Act, states may not be able to sustain the vital HCBS that people with disabilities and aging adults rely on to stay safely in their homes and communities and lower the risks of infection that are inherent in institutions. We have sent several letters from national and state organizations highlighting the urgent needs of the disability community and service systems, and specifically stressing the need for dedicated funding for HCBS, as state and local funding and provider relief funds have not trickled down to meet the needs of this service system.

Absent enhanced HCBS funds, people with disabilities and older adults are forced to rely on dangerous 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. **Whatever package comes together to support the needs of the country in the face of the pandemic, dedicated HCBS funding MUST be included.** Lives hang in the balance.

We urge lawmakers and leadership to continue their efforts to incorporate the above priorities as you negotiate any COVID-19 relief, as well as the funding packages. Congress must act to address the serious, destabilizing deficits facing our nation's only publicly funded long term care system by including the targeted enhanced FMAP included in The COVID HCBS Relief Act. If you have any questions, feel free to contact Nicole Jorwic ([jorwic@thearc.org](mailto:jorwic@thearc.org)).

Sincerely,

Alliance for Retired Americans  
American Association on Health and Disability  
American Association on Intellectual and Developmental Disabilities  
American Civil Liberties Union (ACLU)

American Network of Community Options & Resources (ANCOR)  
American Occupational Therapy Association  
American Physical therapy Association  
American Therapeutic Recreation Association  
The Arc of the United States  
Association of People Supporting Employment First (APSE)  
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  
Caring Across Generations  
Center for Public Representation  
Christopher & Dana Reeve Foundation  
CommunicationFIRST  
Community Catalyst  
CureSMA  
Disability Rights Education and Defense Fund (DREDF)  
Easterseals  
Epilepsy Foundation  
Justice in Aging  
Lakeshore Foundation  
LeadingAge  
Lutheran Services in America - Disability Network  
Meals on Wheels America  
Medicare Rights Center  
National Academy of Elder Law Attorneys  
National ADAPT  
National Association of Councils on Developmental Disabilities  
National Association for Home Care and Hospice  
National Association of Area Agencies on Aging (n4a)  
National Association of State Head Injury Administrators  
National Consumer Voice for Quality Long-Term Care  
National Committee to Preserve Social Security  
National Council on Aging  
National Council on Independent Living (NCIL)  
National Disability Rights Network (NDRN)  
National Down Syndrome Congress  
National Health Law Program (NHeLP)  
National Multiple Sclerosis Society  
National Organization on Disability  
National PACE Association  
National Respite Coalition  
National Senior Corps Association

Network of Jewish Human Services Organization  
Paralyzed Veterans of America  
Partnership for Inclusive Disaster Strategies  
Special Needs Alliance  
TASH  
Well Spouse Association  
United Spinal Association  
World Institute on Disability