The Disability and Aging Collaborative &

CONSORTIUM FOR CITIZENS WITH DISABILITIES

December 7, 2020

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

The Honorable Charles Schumer
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 McConnell and Schumer 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 members of CCD and/or the DAC write with extreme urgency as you consider COVID relief, about the overlooked needs of people with disabilities and aging adults.

We are writing to strongly urge you to include the COVID HCBS Relief Act of 2020 (S. 4947 H.R. 8871) in whatever package ultimately becomes law. This incredibly important piece of legislation was introduced by Senator Casey late last week, 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 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 since the beginning of the pandemic, 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. We have sent several letters from national and state organizations highlighting the urgent needs of the disability community and service systems, and specifically highlighting the need for dedicated funding for HCBS.

Whatever package comes together in December to support the needs of the country in the face of the pandemic, this dedicated HCBS funding MUST be included--lives hang in the balance. This funding is crucial as State HCBS programs must continue to provide these life-sustaining daily in-home services even as they face staff shortages due to sickness, self-isolation, childcare needs, low wages, and the fact that HCBS service workers have struggled to get protective equipment even in the face of higher infection risk. These services are critical to keeping people with disabilities and older adults out of nursing homes and other institutions, where COVID-19 infections and deaths are significantly more likely.

As states face budget crises, they are responding by making cuts to Medicaid, particularly for optional services like HCBS. Simultaneously, with a growing number of uninsured in the country, State Medicaid agencies expect, as happens in countercyclical downturns, an increase in enrollment. That is why, during a pandemic, dedicated funding is necessary to maintain the stability of the program. Without a dedicated funding stream like that offered by the targeted FMAP enhancement included in section 30103 of the HEROES Act, states may not be able to sustain 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.

Several other programs are also set to expire in December that support access to HCBS and limit the risk of unnecessary institutionalization, including the Money Follows the Person (MFP) program and HCBS Spousal Impoverishment Protections. Over the past several years there have been SEVEN short term reauthorizations of MFP. This has led to a destabilization of a program that saved money, and has helped over 105,000 individuals with disabilities and aging adults move out of institutions, nursing homes and other congregate settings to the community. Several states have already stopped transitions under MFP or even dropped out of the program entirely while awaiting the assurance of long-term funding, including NINE states that closed their programs during the pandemic due to lack of funding despite rampant COVID-19 infections and deaths in institutional settings.

The MFP program provides enhanced funding to states to help transition individuals who want to move out of institutional care and back to the community. The enhanced funding states receive assists with the costs of transitioning people back to the community, including identifying and coordinating affordable and accessible housing and providing additional services and supports to make successful transitions. MFP has consistently led to positive outcomes for people with disabilities and older adults and shown cost-savings to states since it was passed

with strong bi-partisan support in 2005. The Centers for Medicare & Medicaid Services (CMS) found an average cost savings of $22,080 in the first year per older adult participant, $21,396 for people with physical disabilities, and $48,156 for people with intellectual disabilities.[1]

The MFP program works, and without it, people with disabilities and older adults would be stuck in institutions and other segregated settings. "The most recent empirical analyses suggest that after five years of operating an MFP demonstration, approximately 25 percent of older adult MFP participants and 50 percent of MFP participants with intellectual disabilities in 17 grantee states would not have transitioned if MFP had not been implemented."[2] We need a permanent reauthorization so that states know the funding is sustainable. And with more than 40% of COVID19 infections to date being in institutions, the MFP program is more critical now than ever.

The program is not compulsory and has not led to anyone who did not choose to participate in the program being forced to move. The program is optional for states and for individuals. The program has been fully evaluated and the data supports positive outcomes for individuals and on state budgets.

Additionally, Medicaid's "spousal impoverishment protections" make it possible for an individual who needs a nursing home level of care to qualify for Medicaid while allowing their spouse to retain a modest amount of income and resources. Since 1988, federal Medicaid law has required states to apply these protections to spouses of individuals receiving institutional long term services and supports (LTSS). This has helped ensure that the spouse who is not receiving LTSS can continue to pay for rent, food, and medication while the other spouse receives their needed care in a facility. Congress extended this protection to eligibility for HCBS in all states beginning in 2014, so that married couples have the same financial protections whether care is provided in a facility or in the community.

This common-sense policy ensures that couples can continue to live together in their homes and communities as they age and families can stay together when caring for loved ones with disabilities and conditions such as dementia, multiple sclerosis, or traumatic brain injury. But it is set to expire on December 11th.

We also urge that funding be extended for Medicare outreach and enrollment efforts to low-income beneficiaries, many of whom are dually eligible for Medicaid. These efforts, originally authorized in 2008 and extended 9 times since then, enable Medicare beneficiaries with the least resources to access assistance for prescription drug coverage and other essential Medicare benefits for which they are eligible. Almost 3 million beneficiaries eligible for prescription drug low-income subsidies (LIS/Extra Help) are not enrolled. Previous allocations for low-income outreach and enrollment activities have led to important, proven results,

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[1] https://www.medicaid.gov/sites/default/files/2019-12/mfp-rtc.pdf (Page 11-12)
https://www.medicaid.gov/sites/default/files/2019-12/mfp-rtc.pdf (Page 19)

including increasing the number of low-income Medicare beneficiaries enrolled in the Medicare Savings Programs from 6.4 million in 2008 to 9.2 million as of December 2019.

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 both the targeted enhanced FMAP as well as a permanent reauthorization of the Money Follows the Person and HCBS Spousal Impoverishment program. If you have any questions, feel free to contact Nicole Jorwic (jorwic@thearc.org).

Sincerely,

Alliance for Retired Americans
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Network of Community Options & Resources (ANCOR)
American Occupational 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
Brain Injury Association of America
Caring Across Generations
Center for Public Representation
Christopher & Dana Reeve Foundation
CommunicationFIRST
Community Catalyst
Easterseals
Epilepsy Foundation
Justice in Aging
Lakeshore Foundation
Lutheran Services in America - Disability Network
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 Multiple Sclerosis Society
National PACE Association
National Respite Coalition
Paralyzed Veterans of America
Partnership for Inclusive Disaster Strategies
Special Needs Alliance
TASH
United Spinal Association