



June 25, 2020

Honorable Richard Neal, Chairman
Honorable Kevin Brady, Ranking Member
Ways and Means Committee
United States House of Representatives
Washington, D.C. 20510

Re: Hearing on Examining the COVID-19 Nursing Home Crisis

Dear Chairman Neal and Ranking Member Brady,

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 and Supports Task Force write in response to today's hearing, "Examining the COVID-19 Nursing Home Crisis."

People with disabilities and older adults face a particularly high risk of complications and death if exposed to COVID-19, a risk that has been elevated by the severe outbreaks in institutional and congregate settings across the country. While the media and public have understandably focused on the outbreaks and deaths in nursing homes, people with disabilities and older adults face increased risks in all institutional and congregate settings, which we addressed in an April 21, 2020 [letter](#) regarding the Centers for Medicare and Medicaid Services' (CMS) "New Nursing Homes COVID-19 Transparency Effort" (attached). None of these institutional and congregate settings have been immune to the COVID-19 crisis and conversations around safety must

address all of them, not only nursing homes, if we hope to effectively mitigate the outbreaks these settings face.

Furthermore, given the danger such settings pose to people with disabilities and older adults, conversations around safety must also include strategies to divert unnecessary admissions and to assist people with transitioning back to the community. As we noted in a May 5, 2020 [letter](#) regarding CMS' announced creation of an independent commission to address safety and quality in nursing homes, identifying resources to assist with diversion and transition from institutional settings should be a key part of any strategy to address the impact this crisis is having on such settings (attached). Diverting people from unnecessary admissions into nursing homes and other institutional settings and transitioning people who currently reside in such settings to settings in the community that are smaller and more individualized addresses COVID-19 safety concerns inherent in larger settings. Emphasizing diversion and transition also helps avoid unnecessary institutionalization, vindicating the civil rights of individuals with disabilities to live in community-based settings. We were pleased to see that the [Nursing Home COVID-19 Protection and Prevention Act](#), which was recently introduced in the Senate by Senators Casey and Whitehouse, covers people in a range of institutional settings and includes a focus on transition to the community.

One of the most important ways to prevent unnecessary placement of people with disabilities and older adults in nursing homes and other institutions during the COVID-19 crisis is to increase funding for home and community based services (HCBS). The dedicated funding for HCBS that the House included in the HEROES Act is a crucial component of addressing the crisis in nursing homes. Over 250 disability organizations sent a [letter](#) on June 15 to the Senate urging inclusion of HCBS funding in the final COVID-19 relief package (attached). This funding would help more people with disabilities and older adults receive the services they need in their homes and communities, allowing them to better protect their health during this pandemic.

The dangers posed by institutional and congregate settings did not start with the COVID-19 crisis. Instead, COVID-19 has laid bare the risks inherent in nursing homes and other congregate facilities, where infection control and other safety concerns have always existed. We need to invest in state HCBS systems not only during this acute crisis, but beyond. This is why we also have urged Congress to [permanently reauthorize](#) the Money Follows the Person program (MFP), which provides enhanced funding to states that thus far has helped over 91,000 seniors and people with disabilities who want to move out of institutional care and back to the community make that transition (attached).

We appreciate the opportunity to provide written testimony and thank you for your consideration. If you have any questions, feel free to contact Alison Barkoff (abarkoff@cpr-us.org).

Sincerely,

Long-Term Services and Supports Co-Chairs

Alison Barkoff
Center for Public Representation

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)

Attachments:

April 21, 2020 Letter from CCD LTSS Task Force to CMS re Nursing Home Transparency Initiative

May 5, 2020 Letter from CCD LTSS Task Force to CMS re Nursing Home Initiatives

June 15, 2020 Letter from CCD LTSS Task Force to Senate Leadership re Including HCBS Funding in the Coronavirus Relief Package

December 15, 2019 Letter from CCD LTSS Task Force to Congressional leadership re Permanent Funding of Money Follows the Person



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

April 21, 2020

Honorable Alex Azar
Secretary, U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, DC 20201

Seema Verma
Administrator, Centers for Medicare & Medicaid Services
200 Independence Avenue S.W.
Washington, DC 20201

Robert Redfield, M.D.
Director, Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

By electronic mail

Dear Secretary Azar, Administrator Verma, and Director Redfield,

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 and Supports taskforce write in response to the Administration's "New Nursing Homes COVID-19 Transparency Effort" [announcement](#) earlier this week.

People with disabilities and older adults are, and will be, particularly at risk for COVID-19, facing a high risk of complications and death if exposed to the virus. While the [media](#) and public have understandably focused on the outbreaks and deaths in nursing homes across the country, people with disabilities and older adults face increased risks in all institutional and congregate settings. Like nursing facilities, there have been similar outbreaks and deaths in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs), including in [Illinois](#) (where the outbreak has been so significant that the National Guard has been called in), [Massachusetts](#) (where nearly half of the residents in a state-

operated ICF are infected), [Utah](#), [Texas](#), and [New Jersey](#) just to name a few; Institutions for Mental Disease (IMDs) and other psychiatric and substance use disorder treatment facilities, including in [Washington state](#), [District of Columbia](#), and [New York](#); and in group homes across the country, including across [New York](#), [Maryland](#), and [New Jersey](#).

We strongly support the steps that CMS announced earlier this week to ensure transparency and information about infections and deaths in nursing homes. These critical steps include: (1) requiring nursing homes to inform residents, their families and representatives of cases of COVID-19 in their facilities; (2) requiring nursing homes to report cases of COVID-19 directly to the Centers for Disease Control and Prevention (CDC), as well as to state and local officials; and (3) requiring nursing homes to fully cooperate with CDC surveillance efforts around COVID-19 spread. **We implore CMS to extend these same requirements to all institutional settings -- including ICF-IIDs, IMDs, substance use disorder treatment facilities, and psychiatric residential treatment facilities -- and other Medicaid-funded congregate settings where older adults and people with disabilities live, including group homes and assisted living facilities.** The need for transparency, information and data collection is equally as critical to protecting the safety and welfare of people in these settings as they are for residents of nursing homes.

We appreciate all of the important efforts the Department has taken during the COVID-19 pandemic. We urge you to act quickly to help protect the lives of ALL people with disabilities and older adults residing in congregate facilities, who are at serious risk during this crisis. If you have any questions, feel free to contact Alison Barkoff (abarkoff@cpr-us.org).

Sincerely,

Long-Term Services and Supports Co-Chairs

Alison Barkoff,
Center for Public Representation

Nicole Jorwic
The Arc of the United States

Julia Bascom,
Autistic Self Advocacy Network

Jennifer Lav,
National Health Law Program

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

Cc: Calder Lynch, Deputy Administrator, CMCS

Alissa DeBoy, Director, Disabled & Elderly Health Programs Group (DEHPG)

Melissa Harris, Deputy Director, DEHPG

David Wright, Director, Center for Clinical Standards and Quality, Quality and Safety Oversight Group



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

May 5, 2020

Honorable Alex Azar
Secretary, U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, DC 20201

Seema Verma
Administrator, Centers for Medicare & Medicaid Services
200 Independence Avenue S.W.
Washington, DC 20201

Lance Robertson
Administrator, Administration for Community Living
330 C St. S.W.
Washington, D.C. 20201

By electronic mail

Re: CMS Nursing Home Initiatives

Dear Secretary Azar, Administrator Verma, and Administrator Robertson:

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 and Supports taskforce write in response to the Administration's recent [announcement](#) of the creation of an independent commission to address safety and quality in nursing homes.

We appreciate the Administration's efforts to protect the health and safety of people in nursing homes, where there have been extremely high numbers of outbreaks and deaths of residents. But as we discussed in our [April 21, 2020 letter](#) to you regarding your new "Nursing Homes COVID-19 Transparency Effort," **people with disabilities and older adults face increased risks in all institutional settings, not just nursing homes.** Like nursing facilities, there have been similar outbreaks and deaths in

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs), including in [Illinois](#), [Massachusetts](#), [Utah](#), [Texas](#), and [New Jersey](#) just to name a few. In Illinois, the outbreak is so significant that the National Guard has been called in, and in Massachusetts nearly half the residents (44 individuals) of a state-operated ICF have been infected. Serious outbreaks are also taking place in Institutions for Mental Disease (IMDs) and other psychiatric and substance use disorder treatment facilities, including in [Washington state](#), [District of Columbia](#), and [New York](#).

The lives of people with disabilities in these settings are equally as at risk – and equally as worth protecting – as people in nursing homes. We again implore you to expand any efforts to protect the lives of people in nursing homes from COVID-19 to other Medicaid-funded institutional and congregate settings.

We know that people with disabilities and older adults are at higher risk for infection and death from COVID-19 in institutional settings. As the Administration moves forward with its safety initiatives, we encourage you to include strategies for diverting people from unnecessary admissions and transitioning people from institutions to smaller, more individualized settings in the community. This not only is critical to addressing safety concerns, but also would help vindicate the civil rights of these individuals to receive services in the community instead of in institutional settings under the Americans with Disabilities Act and the Supreme Court's decision in *Olmstead v. L.C.* We encourage CMS to work with states – and for ACL to work with its disability and aging networks – to identify resources available to assist with diversion and transition activities.

We appreciate all of the important efforts the Department has taken during the COVID-19 pandemic. We urge you to act quickly to help protect the lives of ALL people with disabilities and older adults residing in institutions, who are at serious risk during this crisis. If you are willing, we would be interested in meeting with you to discuss these strategies further. Please contact Alison Barkoff (abarkoff@cpr-us.org) to schedule a meeting.

Sincerely,

Long-Term Services and Supports Co-Chairs

Alison Barkoff,
Center for Public Representation

Nicole Jorwic
The Arc of the United States

Julia Bascom,
Autistic Self Advocacy Network

Jennifer Lav,
National Health Law Program

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

Cc: Calder Lynch, Deputy Administrator, CMCS

David Wright, Director, Center for Clinical Standards and Quality, Quality and Safety Oversight Group

Alissa DeBoy, Director, Disabled & Elderly Health Programs Group (DEHPG)

Melissa Harris, Deputy Director, DEHPG

Roger Severino, Director, Office of Civil Rights

The Disability and Aging Collaborative &



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

June 15, 2020

The Honorable Mitch McConnell
Majority Leader
U.S. Senate
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader
U.S. Senate
Washington, DC 20515

The **252** undersigned member organizations of the Consortium for Citizens with Disabilities (CCD), Disability and Aging Collaborative (DAC), and other state and national organizations write to urge you to include the vital needs of people with disabilities and aging adults in the next COVID-19 relief package.

While the COVID-19 legislative packages passed by Congress thus far were expansive, they all but ignored the critical needs of the disability and aging communities. Thankfully, the HEROES Act that passed the House on May 15, 2020 did include several provisions imperative to the lives of people with disabilities and aging adults. These provisions must remain in the bill that ultimately passes the Senate.

In particular, the dedicated funding for Medicaid Home and Community-based (HCBS) services is of utmost importance for the disability and aging communities. Those funds are necessary to support the workforce that provides critical services to people with disabilities and aging adults, the service providers that employ that workforce, and the people who rely on those services to live safely in their homes and communities. The home and community-based service system, already overburdened before the pandemic, does not have the resources it needs to safely support people with disabilities and aging adults through this crisis. Without additional resources, aging adults and people with disabilities will be forced to leave their homes and communities and move into congregate settings, a failure to safeguard their civil rights and a grave risk to their health--as demonstrated by severe and persistent outbreaks in nursing facilities, institutions and other congregate settings.

We were pleased to see that the HEROES Act included a broad FMAP increase for Medicaid. Millions of people with disabilities, aging adults and their families rely on the Medicaid system

to support them in their homes and communities and for their other healthcare needs. When faced with budget crises and other stressors, states have often responded by cutting Medicaid benefits, eligibility or payments to providers. During a pandemic it is imperative that funding flows to states to support the stability of the Medicaid program. We urge you to support a broad FMAP increase and urge you to maintain the strong maintenance of effort (MOE) protections that were included in the Families First Act. Any weakening of the MOE would put Medicaid coverage, eligibility and services at risk.

The broad FMAP enhancement, while important, is not targeted to vitally important HCBS programs, which every state relies on to keep people out of, or enable them to transition from, institutions. Because HCBS are optional Medicaid services, they are some of the most at risk for cuts in budget crises, placing people with disabilities and older adults at serious risk of unnecessary institutionalization. The funding dedicated to HCBS is necessary to keep people with disabilities and aging adults safely in their homes and communities. Therefore, we again urge that the package ultimately passed in the Senate MUST INCLUDE the targeted 10 percent FMAP increase for HCBS included in the House package in addition to a broader FMAP increase for all Medicaid services.

We must act now to prevent much of the worst impact of this outbreak, and we are grateful for the prompt action so far taken. We urge the Senate to address the serious, destabilizing deficits facing our Nation's only publicly funded long-term care system by including both the broad enhanced FMAP and the targeted enhanced FMAP for HCBS in its coronavirus response package. For additional information or questions, feel free to contact CCD LTSS and DAC co-chair Nicole Jorwic: jorwic@thearc.org.

Sincerely,

Agencies on Aging of CT
Aging Life Care Association
Aging Services Consultant
Alabama Conference of Executives of The Arc
Alabama Lifespan Respite
Alzheimer's Association
Alzheimer's Impact Movement
Altarum, Program to Improve Eldercare
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Civil Liberties Union
American Dance Therapy Association
American Geriatrics Society
American Kidney Fund
American Network of Community Options & Resources (ANCOR)
American Physical Therapy Association
American Therapeutic Recreation Association

Area Agencies on Aging Association of Michigan
Arizona ADAPT
Arizona Association of Area Agencies on Aging
Association of People Supporting Employment First (APSE)
Association of Programs for Rural Independent Living
Association of University Centers on Disabilities (AUCD)
Autism Family Services of New Jersey
Autism Society Greater Baton Rouge, Inc.
Autism Society Greater Harrisburg Area
Autism Society Greater Philadelphia
Autism Society Louisiana
Autism Society of America
Autism Society of Baltimore-Chesapeake
Autism Society of Boulder County
Autism Society of Greater Akron
Autism Society of Greater New Orleans
Autism Society of Greater Wisconsin
Autism Society of Iowa
Autism Society of Maine
Autism Society of Minnesota
Autism Society of North Louisiana
Autism Society of Northern Virginia
Autism Society of Oregon
Autism Society of South Central Wisconsin
Autism Society Of Southeastern Wisconsin
Autism Society of Texas
Autism Society of the Greater Capital Region
Autism Society River Cities
Autism Society Southwest New Jersey Affiliate 532
Autism Society Ventura County
Autistic Self Advocacy Network (ASAN)
BIAA-KY
Brain Injury Association of America
Brain Injury Association of Delaware
Brain Injury Association of Kansas and Greater Kansas City
Brain Injury Association of Michigan
Brain Injury Association of New York State
Brain Injury Association of Rhode Island
Brain Injury Association-KY Chapter
Brainwave Neurorehab, PLLC
California Down Syndrome Advocacy Coalition
Caregivers of New Jersey
Caring Across Generations
Center for Health Law and Policy Innovation
Center for Public Representation
Central MN Council on Aging
Channel Islands Social Services
Chesapeake Down Syndrome Parent Group

Chicagoland Disabled People of Color Coalition
Children's Aid
Christopher & Dana Reeve Foundation
Chronic Disease Coalition
Coachella Valley Autism Society
Coalition on Human Needs
Colorado Cross-Disability Coalition
CommunicationFIRST
Community Catalyst
Community Options, Inc.
Congress of California Seniors
Cure SMA
DC Special Kids
Democratic Disability Caucus of FLORIDA
Disability Rights Education and Defense Fund (DREDF)
Disability Rights Florida
Disability Voices United
DISABLED QUEERS IN ACTION (NAT)
Down Syndrome Alliance of the Midlands
Down Syndrome Association of Central California
Down Syndrome Association of Connecticut
Down Syndrome Association of Northern Virginia
Down Syndrome Connection of the Bay Area
Down Syndrome Foundation of Florida
Down Syndrome Guild of Greater Kansas City
Down Syndrome Partnership of North Texas
Easterseals
Easterseals Serving Southern Georgia and the Big Bend of Florida
Epilepsy Alliance America
Epilepsy Foundation
Epilepsy Services of New Jersey
Equality North Carolina
Exceptional Family Center
Families USA
Family Caregiver Alliance
Family Caregiver Alliance of Rhode Island
Family Voices
GEORGIA ADAPT
Howard County Autism Society
Human Rights Campaign
Idaho Association of Area Agencies on Aging (IAA)
Indiana Association of Area Agencies on Aging
Kansas ADAPT
Kern Down Syndrome Network
KIIDS (Knowledge & Information about Individuals with Down Syndrome)
Lakeshore Foundation
Lifespan of Greater Rochester
Lifespan Respite WA at PAVE

Little Lobbyists
Lupus and Allied Diseases Association, Inc.
Lutheran Services in America - Disability Network
Maryland Respite Care Coalition
Massachusetts Down Syndrome Congress
MassADAPT
Medicare Rights Center
Mental Health Association in Michigan
Mississippi Family Caregiver Coalition
Missouri Association of Area Agencies on Aging
Montana ADAPT
Montana Lifespan Respite Coalition
NAACP
Nassau Suffolk Chapter of the Autism Society of America
National Academy of Elder Law Attorneys
National ADAPT
National Adult Day Services Association (NADSA)
National Asian Pacific Center on Aging (NAPCA)
National Association of Area Agencies on Aging (n4a)
National Association of Councils on Developmental Disabilities
National Association for Home Care & Hospice
National Association of Nutrition and Aging Services Programs (NANASP)
National Association of RSVP Directors (NARSVPD)
National Association of State Directors of Developmental Disabilities Services (NASDDDS)
National Association of State Head Injury Administrators
National Coalition for the Homeless
National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Health Council
National Health Law Program
National MLTSS Health Plan Association
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Organization on Disability
National Organizations for Rare Disorders
National PACE Association
National Respite Coalition
National Senior Corps Association
NC Association of Area Agencies on Aging
NETWORK Lobby for Catholic Social Justice
Network of Occupational Therapy Practitioners with Disabilities and Supporters (NOTPD)
Nevada Lifespan Repite Care Coalition
New Jersey Lifespan Respite Coalition
New Mexico Caregivers Coalition
North Central PA ADAPT

North Dakota Protection & Advocacy Project
Northeastern IL AgeGuide
NYS Caregiving and Respite Coalition
Oregon State Council for Retired Citizens
Paralyzed Veterans of America
Paraquad
Partners in Caregiving, LLC
Partnership for Inclusive Disaster Strategies
Personal Attendant Coalition of Texas
Public Advocacy for Kids (PAK)
RetireSafe
Roads to Freedom Center for Independent Living
San Antonio ADAPT
Service Employees International Union (SEIU)
Social Security Works
Sooner SUCCESS
South Carolina ADAPT
South Carolina Association of Area Agencies on Aging
TASH
Tennessee Respite Coalition
Texas ADAPT
The Arc of Anchorage (Alaska state chapter)
The Arc Georgia
The Arc Maryland
The Arc Michigan
The Arc New York
The Arc of Arizona
The Arc of California
The Arc of Central Alabama
The Arc of Colorado
The Arc of Connecticut, Inc.
The Arc of Delaware
The Arc of Greater Pittsburgh/Achieva
The Arc of Harrisonburg and Rockingham County
The Arc of Florida, Inc.
The Arc of Illinois
The Arc of Indiana
The Arc of Iowa
The Arc of Massachusetts
The Arc of Nebraska
The Arc of New Jersey
The Arc of New Mexico
The Arc of North Carolina
The Arc of Ohio
The Arc of Oregon
The Arc of Pennsylvania
The Arc of Rhode Island
The Arc of South Carolina

The Arc of Texas
The Arc of the Mid Ohio Valley
The Arc of Virginia
The Arc of Washington State
The Arc of West Virginia
The Arc Tennessee
The Arc of the United States
The Arc Wisconsin
The Coelho Center for Disability Law, Policy and Innovation
The Family Resource Network
The Gerontological Society of America
The Illinois Respite Coalition
The Kelsey
The Starkloff Disability Institute
TARC
Topeka Independent Living Resource Center
Touch the Future Inc
Union for Reform Judaism
United Seniors of Oregon
United States International Council on Disabilities
United States International Council on Disabilities
Verde Valley Seniors in Action Coalition aka Northern Arizona Seniors in Action Coalition
Virginia Association of Area agencies on Aging
Washington Association of Area Agencies on Aging
Williams Syndrome Association
WomenHeart: The National Coalition for Women with Heart Disease
World institute on Disability

The Disability and Aging Collaborative &



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

December 15, 2019

The Honorable Mitch McConnell
Majority Leader
U.S. Senate
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader
U.S. Senate
Washington, DC 20515

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 undersigned member organizations of the Consortium for Citizens with Disabilities (CCD), Disability and Aging Collaborative (DAC), and other state and national organizations write to urge you to pass the permanent extension of the Money Follows the Person Program (MFP) and Spousal Impoverishment Protections included in the bi-partisan Prescription Drug Pricing Reduction and Health and Human Services Improvement Act. While we have appreciated the short-term extensions passed this Congress, and the 4 ½ year extension that the House passed in June 2019, permanent reauthorization is necessary to ensure that states continue to participate in the MFP program. Several states have already stopped transitions under MFP or even dropped out of the program entirely while awaiting the assurance of long-term funding.

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. The program has helped over 91,000 people with disabilities and older adults transition back to their communities.

MFP has consistently led to positive outcomes for people with disabilities and older adults and shown cost-savings to states since it began 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 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.

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 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 at the end of this year.

On behalf of people with disabilities and older adults, we request that Congress pass the permanent re-authorization of both Money Follows the Person and HCBS Spousal

¹ <https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/mfp-rtc.pdf> (Page 11)

² <https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/mfp-rtc.pdf> (Page 11)

Impoverishment Protections. For additional information or questions, feel free to contact CCD LTSS and DAC co-chair Nicole Jorwic: jorwic@thearc.org.

Sincerely,

Access Living

Aging Life Care Association

American Association on Health and Disability

American Association on Intellectual and Developmental Disabilities

American Civil Liberties Union

American Network of Community Options and Resources (ANCOR)

American Therapeutic Recreation Association

APSE

Association of University Centers on Disabilities (AUCD)

The Arc of the United States

The Arc of Colorado

The Arc of Delaware

The Arc of Indiana

The Arc of Kentucky

The Arc of Massachusetts

The Arc of Minnesota

The Arc of New Jersey

The Arc of New Mexico

The Arc of North Dakota

The Arc of Oregon

The Arc of South Carolina

The Arc of Tennessee

The Arc of West Virginia

Autism Society of America

Autistic Self Advocacy Network

Arkansas Long-Term Care Ombudsman Program

Association of Programs for Rural Independent Living

Autism Speaks

Bay Path Elder Services

Bet Tzedek Legal Services

Buffalo Trace Long Term Care Ombudsman Program

California Advocates for Nursing Home Reform

California Association of Public Authorities for IHSS

California Down Syndrome Advocacy Coalition (CDAC)

California Foundation for Independent Living Centers

Caring Across Generations

Center for Elder Law and Justice

Center for Public Representation

Choice in Aging

Christopher & Dana Reeve Foundation

Coalition of Disability Health Equity

Colorado Cross-Disability Coalition

Community Catalyst

Community Residential Services Association

Delta Center for Independent Living

Disability Law Center

Disability Law Center of Alaska

Disability Law Center of Virginia

Disability Law Colorado

Disability Rights Education and Defense Fund

Disability Rights Arkansas

Disability Rights California

Disability Rights Florida

Disability Rights Iowa

Disability Rights Center-New Hampshire

Disability Rights New Jersey

Disability Rights New York

Disability Rights North Carolina

Disability Rights Ohio

Disability Rights South Dakota

Disability Tennessee

Disability Rights Texas

Disability Rights Vermont

Disability Rights Washington

Disability Rights West Virginia

Down Syndrome Alliance of the Midlands

Down Syndrome Association of Delaware

Down Syndrome Indiana, Inc.

Easter Seals

Epilepsy Foundation

Family Voices

Hawaii Disability Rights Center

Healthcare Rights Coalition

Independence Inc.

Independent Connection Inc.

Indiana Disability Rights

Individual Family Social Work Counseling

Iowa Developmental Disabilities Council

Lakeshore Foundation

Long Term Care Community Coalition

The Jewish Federations of North America

Justice in Aging

Lutheran Services in America-Disability Network

Life Path Inc.

Maine Long-Term Care Ombudsman Program

Meals on Wheels of America

Medicare Rights Center

Michigan Protection & Advocacy Service, Inc. (MPAS)

Missouri Hospice and Palliative Care Association

National Academy of Elder Law Attorneys

National Alliance for Caregiving

National Association for Home Care and Hospice

National Association of Area Agencies on Aging (n4a)

National Association of Councils on Developmental Disabilities

National Association of State Directors of Developmental Disabilities Services

National Association of State Head Injury Administrators

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Council on Aging

National Council on Independent Living

National ADAPT

ADAPT Montana

ADAPT of Texas

National Association of Social Workers (NASW)

National Consumer Voice for Quality Long-Term Care

National Disability Rights Network

National Down Syndrome Congress

National Health Law Program

Nevada Disability Advocacy & Law Center

National Respite Coalition

Nursing Home Victims Coalition Inc.

Oklahoma Disability Law Center, Inc.

Office of the State Long-Term Care Ombudsman

Ohio Region 5 Long-Term Care Ombudsman Program

On Lok PACE

Our Mother's Voice

Paralyzed Veterans of America

Partners in Care Foundation

Personal Assistance Services Council

Personal Attendant Coalition of Texas

The Program to Improve Eldercare, Altarum

Protection and Advocacy Project North Dakota

Protection and Advocacy for People with Disabilities South Carolina

Service Employees International Union (SEIU)

Starkloff Disability Institute

SKIL Resource Center

SourceAmerica

TASH

Three Rivers Inc.

Topeka Independent Living Resource Center

United Spinal Association

United Spinal Association, Iowa Chapter

United Spinal Association, Louisiana Chapter

United Spinal Association, New Mexico Chapter

United Spinal, Oregon Spinal Cord Injury Connection

United Spinal, South Carolina Spinal Cord Association