



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

May 21, 2020

Sen. Susan Collins, Chairwoman
Sen. Bob Casey, Ranking Member
United States Senate Special Committee on Aging
G31 Dirksen Senate Office Building
Washington, D.C. 20510

Re: Hearing on Caring for Seniors Amid the COVID-19 Crisis

Dear Chairwoman Collins and Ranking Member Casey,

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, "Caring for Seniors Amid the COVID-19 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 diversion and transition strategies. 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 individuals with disabilities to live in community-based settings. We were pleased to see that the [Nursing Home COVID-19 Protection and Prevention Act](#) introduced 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), as we addressed in a [letter](#) from April 13, 2020 supporting the Coronavirus Relief for Seniors and People with Disabilities Act (HR 6305/S. 3544) (attached). The grants proposed in that bill, or the dedicated increased funding included in the HEROES Act that just passed in the House, 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 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

April 13, 2020 Letter from CCD LTSS Task Force to Congressional 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
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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
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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



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

April 13, 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 undersigned co-chairs of the CCD Long-term Services and Supports taskforce write in response to the growing outbreak of COVID-19 across the United States, and the growing need for home and community-based services (HCBS) of people with disabilities in the face of the pandemic. The first three legislative packages all but ignored the critical need for HCBS and the dire need for funds to stabilize the system through this crisis and support the workforce that provides these essential services.

People with disabilities are, and will be, particularly at risk as COVID-19 continues to spread across the country, facing high risk of complications and death if exposed to the outbreak and needing to isolate themselves for protection. We urge Congress to focus on people with disabilities and their needs in the fourth COVID-19 bill. Specifically, as the fourth piece of legislation moves forward, we urge Congress to ensure that emergency HCBS grant funding is included in the next COVID-19 legislative package.

Meaningful investments in HCBS are one of the most important steps Congress can take to safeguard the disability community. The fourth package must fund HCBS grants, such as the ones found in the [Corona Virus Relief for Seniors and People with Disabilities](#) (HR 6305, S. 3544) to provide additional funds to strapped state HCBS systems and to support the Direct Support Professional (DSP) and Home Health Workforce. Without additional resources, aging adults and people with disabilities will be forced out of their homes and communities and into congregate settings, at grave risk to their health--as

demonstrated by severe and persistent outbreaks in nursing facilities, institutions and other settings that are proving a danger to the health of people with disabilities.

Additionally, Direct Support Professionals (DSPs), personal care attendants, and other direct care workers, whether paid for through Medicaid, the VA or other federal programs, or through private payment arrangements, should be designated essential personnel in order to ensure access to PPE. DSPs and other direct care workers are not currently included in the definitions of Essential Workers who are prioritized for access to personal protective equipment (PPE). DSPs are on the frontlines of the COVID-19 response, assisting people with underlying conditions and disabilities with tasks such as toileting, eating, and bathing. Often these services cannot be provided from 6 feet away and require close personal contact. We are already seeing tragic cases of people with disabilities dying after being infected by their DSPs. The work DSPs do is essential, and they must have access to the tools they need to do their job safely.

We were glad to see that the important work of direct support professionals, personal care attendants and home health aides was included in the “Heroes Fund” proposal. We support the concept of paying essential employees additional wages directly for the work that they are doing during the pandemic. We also are glad to see that there are components to assist with recruitment to this and other vital workforces. Direct care workers are a core part of the infrastructure of our nation’s HCBS system, but there are many other components in jeopardy without immediate funding. This fund would be a valuable supplement to the critical and urgently needed HCBS grants, which will provide crucial resources to stabilize the critical community services provider network, support providers of HCBS services to transform service delivery to reach seniors and people with disabilities who are isolated due to the response to COVID-19, move individuals from HCBS waitlists as needed to address emergencies when other support networks fail, and continue to assure the health and welfare of the people they serve during the extraordinary disruption caused by the pandemic. The broader HCBS grants would also allow states the flexibility to pay for additional training for DSPs, purchase PPE, and pay more overtime wages.

We know that we must act now to prevent much of the worst impact of this outbreak. We urge Congress to act quickly, incorporate these urgent disability community priorities in the 4th COVID-19 legislative package, and promptly pass this crucial legislation. If you have any questions, feel free to contact Nicole Jorwic: jorwic@thearc.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

Nicole Jorwic
The Arc of the United States

Jen Lav,
National Health Law Program

Sarah Meek
American Network Community Options
and Resources (ANCOR)

The Disability and Aging Collaborative &



**CONSORTIUM FOR CITIZENS
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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