

February 23, 2021

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives
Washington, D.C. 20515

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

The Honorable Kevin McCarthy
Leader
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Mitch McConnell
Leader
U. S. Senate
Washington, D.C. 20510

Dear Speaker Pelosi and Leaders Schumer, McConnell, and McCarthy:

The undersigned groups write to express our strong support for the provision in the COVID relief reconciliation bill (section 3108) adopted by the House Energy and Commerce Committee that will provide life-sustaining support for people with disabilities, older adults, and individuals, predominantly low-income women of color, who make up part of the direct care workforce. Modeled on the COVID HCBS Relief Act of 2021 (S. 151/H.R. 525), the bill would provide additional funding for Medicaid Home and Community Based Services (HCBS). We urge you to ensure that this language remains in any final COVID relief package.

The dangers of nursing homes, psychiatric hospitals, and other congregate settings have never been clearer. With less than 1% of the country's population, these settings have comprised almost 40% of COVID deaths,¹ and disproportionately impacted nursing homes with high shares of Black or Brown residents.² Even though COVID outbreaks started in congregate settings, spread through congregate settings, and was most deadly in these settings, funding for alternatives to nursing homes and other congregate settings – people's own homes – was difficult to obtain. This is not just a human tragedy – it is a civil rights violation. Under the Supreme Court's 1999 *Olmstead* decision, people who want to live at home, and who could safely live at home with the proper supports, have a right to live in the community, not an institution.³ Yet, in the midst of a pandemic, our funding priorities have thus far not strengthened the ability to stay safely at home, and largely ignored the workforce that is key to preventing people with disabilities and seniors from being forced to stay in institutions. This problem will only get worse as mounting state budget crises make HCBS programs difficult, if not impossible, to

¹ The COVID Tracking Project, "The Long Term Care COVID Tracker," available at <https://covidtracking.com/nursing-homes-long-term-care-facilities> (data current as of February 4, 2021).

² KFF analysis of Shaping Long Term Care in American Project at Brown University funded in part by the National Institute on Aging, CMS COVID-19 Nursing Home Data (as of October 11, 2020), available [here](#)

³ *Olmstead v. L.C.*, 527 U.S. 581 (1999).

maintain without additional federal help. Underinvestment in HCBS will continue to lead to needless infections and avoidable deaths.

Funding for HCBS workers and services is not just good policy and not just key to saving lives, but is also fundamentally a racial and gender justice issue. Direct support professionals, often called home care workers, are disproportionately women, people of color, and immigrants.⁴ Nearly 9 in 10 workers are women, while 62 percent are people of color (compared to 38 percent of the U.S. labor force), and 31 percent are immigrants.⁵

Black and Brown women, many of whom are themselves disabled, who make up the majority of the direct care workforce have been at the front lines of the pandemic for the past year. Home and community-based services must, by definition, be provided in person, with intimate contact between the worker and client. These essential workers have had to balance their own child care and family care obligations to provide critical care that allows many seniors and people with disabilities to live at home instead of being forced into nursing homes and other congregate settings ravaged by COVID-19. They have risked their own health and that of their families to do this indispensable work and safeguard the health and lives of our loved ones and neighbors during the pandemic, often without regular access to personal protective equipment nor an ability to social distance. Inexplicably, this critical yet underpaid workforce has labored in the shadows and has been largely left out of the national conversation about the pandemic's devastating impact.

The current reconciliation bill language provides the tools needed to address these challenges and to stabilize state HCBS programs. It would provide much-needed and targeted funding, via a 7.35% FMAP increase, to maintain HCBS programs as well as to increase home care worker pay, provide benefits such as paid family leave or sick leave, pay for transportation expenses to and from the homes of those being served, purchase personal protective equipment for workers and those they are supporting, and provide hazard pay. Funding can also be used to support family caregivers and pay for recruitment and training of additional workers.

To equitably address the threats posed by the pandemic, Congress must prioritize not only the needs of older adults and people with disabilities but also the needs of critical direct support professionals who work with them. The inclusion of Section 3108 in any final COVID relief package is absolutely necessary and long overdue. We acknowledge and thank the congressional leaders and committee members, in both the House and Senate, who are taking steps to ensure that people with disabilities, older adults, and home care workers are protected.

⁴ Some HCBS services are also provided by residential care aides, who provide care in group homes, assisted living facilities, and other community settings. Residential care aides have similar demographics to those described here for home care workers.

⁵ PHI, *Direct Care Workers in the United States: Key Facts*, September 28, 2020, at 6-7 (available at <https://phinational.org/wp-content/uploads/2020/09/Direct-Care-Workers-in-the-United-States-2020-PHI.pdf>).

Thank you for your consideration and your efforts. Please don't hesitate to contact Nicole Jorwic (jorwic@thearc.org), Vania Leveille (vleveille@aclu.org), or Maria Town (mtown@aapd.com) if you have any questions or need more information.

Sincerely,

#UpgradeMedicaid - Iowa
501(c) Services
A Better Balance
Ability360, Inc.
ACCESS (Arab Community Center for Economic and Social Services)
Access Alaska, Inc.
Access Concepts & Training Inc.
Accessible Resources for Independence Incorporated
ADAPT Montana
ADAPT National
ADAPT of Texas
Aging Life Care Association
AIDS Foundation Chicago
AIDS Law Project of Pennsylvania
Alabama Disabilities Advocacy Program
Alliance for Aging Research
Althea Gibson CTA
Alzheimer's Association
Alzheimer's Impact Movement
American Association of People with Disabilities
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Behcet's Disease Association (ABDA)
American Civil Liberties Union
American Congress of Rehabilitative Medicine
American Council of the Blind
American Geriatrics Society
American Music Therapy Association
American Network of Community Options & Resources (ANCOR)
American Physical Therapy Association
American Therapeutic Recreation Association
Association for Individual Development (AID)
Association of People Supporting Employment First (APSE)
Association of University Centers on Disabilities (AUCD)
Audacity Group Social Enterprise
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Autoinflammatory Alliance
Bazelon Center for Mental Health Law

Be A Hero
Black AIDS Institute
Boston Center for Independent Living
Brain Injury Association of America
Brain Injury Association of Georgia
Brain Injury Association of Kansas and Greater Kansas City
Brain Injury Association of New York State
Brazoria County Center for Independent Living
Bridge the Gap - SYNGAP Education and Research Foundation
Bronx Independent Living Services
CancerCare
Caregiver Action Network
Catskill Center for Independence
Center for Autism and Related Disorders
Center for Disability Rights
Center for Eldercare Improvement, Altarum
Center for Independence
Center for Independent Living of Central PA
Center for Law and Social Policy (CLASP)
Center for LGBTQ Economic Advancement & Research
Center for Living and Working INC
Center for Public Representation
CenterLink: The Community of LGBT Centers
Christopher & Dana Reeve Foundation
Civil Rights Education and Enforcement Center
Coalition of Labor Union Women
CommunicationFIRST
Community Access Services
Community Legal Services of Philadelphia
Consumer Directed Personal Assistance Association of NYS
Costello Syndrome Family Network
Council of State Administrators of Vocational Rehabilitation
Creative Employment Opportunities
Cure SMA
Democratic Disability Caucus of Florida
Disabilities Resource Center of Siouxland
Disability Action Center - Northwest
Disability Action for America
Disability Allied Law Students Association, NYU Law
Disability Empowerment Center
disAbility Law Center of Virginia
Disability Law Colorado
Disability Policy Consortium
Disability Resource Center
Disability Rights Advocates
Disability Rights California

Disability Rights Center – NH
Disability Rights Center of Kansas
Disability Rights Education and Defense Fund (DREDF)
Disability Rights Florida
Disability Rights Iowa
Disability Rights Maine
Disability Rights Michigan
Disability Rights Nebraska
Disability Rights North Carolina
Disability Rights Ohio
Disability Rights South Carolina
Disability Rights Tennessee
Down Syndrome Alliance of the Midlands
DQIA DISABLED queers in action
DS ACT
Easterseals
Epilepsy Foundation
Epilepsy Foundation Central & South Texas
Epilepsy Foundation of Colorado
Epilepsy Foundation of Michigan
Epilepsy Foundation Texas
Equal Rights Advocates
Feminist Majority Foundation
Florida ADAPT
Florida Association of Centers for Independent Living
Fort Bend Center for Independent Living
Genetic Alliance
Georgia ADAPT
Girls for Gender Equity
Global Liver Institute
Granite State Independent Living
Greater Good Business, Inc.; Partnering With Purpose, LLC
Hannah’s Hope Fund
Hepatitis C Mentor and Support Group-HCMSG
Hispanic Federation
Honest Doula
Hospice Council of West Virginia
Houston Center for Independent Living
Hydrocephalus Association
ICAN, International Cancer Advocacy Network
Idaho Association of Community Providers
Idaho SILC
IMAGE Center of Maryland
In Our Own Voice: National Black Women’s Reproductive Justice Agenda
Independent Living Inc.
Indiana Statewide Independent Living Council (INSILC)

International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
International Pemphigus Pemphigoid Foundation
It's A Juicy Life LLC
JAYDS Home Care LLC
Justice in Aging
Kentucky Protection and Advocacy
Lakeshore Foundation
The Leadership Conference on Civil and Human Rights
Lehigh Valley Center for Independent Living, Inc. (LVCIL)
Life Pieces To Masterpieces, Inc.
Life, A Center for Independent Living
Little Lobbyists
Living Independence Network Corporation
Livpact
Long Island Center for Independent Living, Inc. (LICIL)
Lupus and Allied Diseases Association, Inc.
Mass Families Organizing for Change
MassADAPT
Mental Health America
Mid-Minnesota Legal Aid/Minnesota Disability Law Center
MLD Foundation
MomsRising
Murn and Associates LLC
National Academy of Elder Law Attorneys
National ADAPT
National Alliance for Hispanic Health
National Alliance on Mental Illness
National Asian Pacific Center on Aging
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 Councils on Developmental Disabilities
National Council of Jewish Women
National Association of State Directors of Developmental Disabilities Services
National Association of State Head Injury Administrators
National Center for Law and Economic Justice
National Council on Aging
National Council on Independent Living
National Crittenton
National Disability Rights Network (NDRN)
National Domestic Workers Alliance
National Down Syndrome Congress
National Employment Law Project
National Employment Lawyers Association
National Health Council
National Health Law Program

National Hispanic Council on Aging
National Human Services Assembly
National Human Services Organization
National Indian Council on Aging
National MPS Society
National Multiple Sclerosis Society
National Organization for Women
National Organization on Disability
National Partnership for Women & Families
National Respite Coalition
National Urea Cycle Disorders Foundation
National Women's Law Center
NBIA Disorders Association
NCBWR
ND Protection & Advocacy Project
Nevada Disability Advocacy & Law Center
North Alabama Sickle Cell Foundation, Inc.
PA Families Need Nurses Now
Paralyzed Veterans of America
Paraquad
Phelan-McDermid Syndrome Foundation
Pulmonary Hypertension Association
PXE International
RASopathies Network
RespectAbility
RESULTS
SEIU
SeniorLAW Center
Sickle Cell Anemia Foundation of Oregon, Inc.
Sickle Cell Association of Kentuckiana
SKIL Resource Center
Southeast Alaska Independent Living (SAIL)
Southeast Asia Resource Action Center (SEARAC)
Southern Tier Independence Center
Spina Bifida Association
Sudden Arrhythmia Death Syndromes (SADS) Foundation
Supermajority
Taconic Resources for Independence, Inc.
TASH
The Ability Center
The Advocacy Institute
The Arc of the United States
The Bonnell Foundation: Living with Cystic Fibrosis
The Century Foundation
The Coelho Center for Disability Law, Policy and Innovation
The Dayle McIntosh Center

The Disability Resource Center of the Rappahannock Area, Inc.
The Forum for Youth Investment
The Gerontological Society of America
The Immanuel House
The Partnership for Inclusive Disaster Strategies
The Sickle Cell Disease Association of America, Inc.
The Smart Cookie Collective LLC
The Well Project
TIME'S UP Now
Union for Reform Judaism
United Cerebral Palsy
United Spinal Association
United State of Women (USOW)
University of Pittsburgh
US International Council on Disabilities
VHL Alliance
Vision for Equality
Voices for Progress
Walden University
Washington ADAPT
West Virginia Statewide Independent Living Council
West Virginians for Affordable Health Care
Whistleblowers of America
Winning Strategies
Women's Law Project
Wounded Warrior Project