

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,<sup>1</sup> and disproportionately impacted nursing homes with high shares of Black or Brown residents.<sup>2</sup> 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.<sup>3</sup> 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

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<sup>1</sup> 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).

<sup>2</sup> 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](#)

<sup>3</sup> *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.<sup>4</sup> 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.<sup>5</sup>

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.

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<sup>4</sup> 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.

<sup>5</sup> 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](mailto:jorwic@thearc.org)), Vania Leveille ([vleveille@aclu.org](mailto:vleveille@aclu.org)), or Maria Town ([mtown@aapd.com](mailto: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