

May 24, 2021

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

The Honorable Mitch McConnell
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 Schumer and McConnell and Speaker Pelosi and Leader McCarthy,

As the Biden Administration and Congress turn towards planning for economic recovery from the COVID-19 pandemic, there is not a system whose service delivery model and workforce needs more support for a rebound and expansion than Medicaid Home and Community-Based Services (HCBS). As was laid out in the American Jobs Plan a \$400 billion infusion is needed to address the service expansion and to support the workforce that provides these services.

This investment would fortify a workforce that must continue to expand to meet a rapidly increasing level of need, and also address the long-standing inequities the pandemic exposed and exacerbated. The majority of the direct care workforce are women of color. The HCBS workforce includes home care workers, personal care attendants, peer support specialists, independent providers working at the direction of a consumer, and direct support professionals. The HCBS workforce provide vital services yet have been devalued and underpaid for decades.

Not only have wages been inadequate, but the system itself is not serving everyone who needs home and community-based care and support. People with disabilities of all ages have a legal right to receive services and supports in the most integrated setting, regardless of the source of payment for services. Investments need to be made that support this as yet unrealized goal of the Americans with Disabilities Act. However, currently, older adults who want to age in place and people with disabilities who need support to work, live independently, and be part of their communities are left waiting, often placing the responsibility of care and support on unpaid family caregivers. The burdens of this inadequate system fall disproportionately on People of Color with limited income and wealth. The workforce and earnings losses related to unpaid family caregiving are significant and well-documented, and an investment in HCBS services expansion creates another group of people who can rejoin the economy - family caregivers. Without the investment in services family caregivers will have to continue to fill-in the huge gaps in the system. Addressing all these issues will stimulate economic growth and job creation.

In order to address these issues, organizations representing workers, family caregivers, individuals supported by these services, and providers urge that the next package must include dedicated funding for both the expansion of service delivery options, including increased availability of services, AND funding to ensure that direct care jobs are jobs with career paths,

recognition of existing workers tenure and experience, opportunities to organize, and family sustaining wages. Specifically we recommend:

- A dedicated FMAP increase for Medicaid HCBS to build on the one year of funding that was included in the *American Rescue Plan*. That funding, while imperative, was mostly to offset the lack of Congressional investment in this system for the first year of the pandemic. An ongoing stream of additional federal funding that is equitably distributed across the country, is necessary to ensure that states have the fiscal certainty to actually expand access to and eligibility for services to support older adults and people with disabilities, including people currently on waiting lists for these services, and to improve a system that has been overly reliant on large congregate facilities and unpaid family caregivers for far too long and that has left too many individuals at the mercy of the criminal justice system as a result of its failures. Any funding to support services must provide state flexibility, require a focus on equitable distribution of services, and begin to ensure that there is parity across states on what people with disabilities and aging adults can access. Additionally, states should no longer be allowed to withhold HCBS by arguing that it is less “cost-effective” in an individual circumstance than institutional services. Extra effort and attention should be given to assistance for marginalized groups. Communities of color, sovereign nations, and others should be supported in responding to needs they identify.
- That same FMAP increase must be tied to better workforce supports, including funding to increase wages and expand self-directed models of services--including expanding control over services and individual budgets to the consumer--and tied to recruitment and retention. This includes expanding models where both family and chosen family are paid direct care workers. This funding must also support adequate HCBS infrastructure by supporting entities, including consumer-controlled entities and structures with robust consumer, worker, and stakeholder oversight and engagement, to implement the activities listed above and ensure a pathway for workers to organize and form unions or other workforce organizations, while protecting the consumers right to choice and control over health care and HCBS providers. Funding should also promote the concepts of, and services that support, independent living, self-direction and the dignity of risk.
- This funding must include a mechanism to increase Medicaid funding and rates, both to ensure that states cannot cut services at a time when they should be expanding them and to ensure that workers’ wages are increased adequately and are adjusted for inflation and rising wage standards on an ongoing basis. To accomplish this, HHS and DOL should also work together to better classify the HCBS direct care workforce, including when one worker may be providing multiple types of services. CMS can revise regulations to reflect these new categories and DOL can collect data to support necessary changes. Such data is necessary to ensure that the basis for service rates, and in turn wages for workers, are adequate to ensure that older adults and people with disabilities are able to access high quality services through Medicaid, including services funded through MLTSS. These efforts ultimately should result in ensuring the consumer's' rights to hire, train, supervise, schedule, and if necessary replace their workers

- This funding should not result in loss of services for current recipients of Medicaid or non-Medicaid (Private Pay) consumers.

Allies for Independence
 American Association of People with Disabilities
 The Arc of the United States
 Autistic Self Advocacy Network (ASAN)
 Bazelon Center for Mental Health Law
 Be A Hero
 Caring Across Generations
 Justice in Aging
 Little Lobbyists
 National ADAPT
 National Council on Aging
 National Council on Independent Living (NCIL)
 National Domestic Workers Alliance (NDWA)
 National Health Law Program (NHeLP)
 Service Employees International Union (SEIU)

And:

AAA Ombudsman
 Access to Independence (Madison, WI)
 Accessible Resources for Independence
 Acumen Fiscal Agent, LLC
 ADAPT Capital Region (NY)
 ADAPT Montana
 ADAPT of Texas
 Adult Family Home Council of Washington State
 Age Wave
 AL-South Central AI Development Commission
 Alabama Caregivers for Compromise
 Albatross Training Solutions
 ALCA
 Alliance for Leadership and Education
 Altarum
 Alzheimer's Association and Alzheimer's Impact Movement
 American Association of Service Coordinators
 American Association on Intellectual and Developmental Disabilities
 American Council of the Blind
 American Dance Therapy Association
 American Physical Therapy Association
 American Society on Aging
 American Therapeutic Recreation Association
 Applied Self-Direction
 Association for Gerontology and Human Development in Historical Black Colleges and Universities (HBCUs)
 Association of California Caregiver Resource Centers

Association of People Supporting Employment First (APSE)
Association of University Centers on Disabilities (AUCD)
ATTIC, Inc.
Autism Society of America
Autistic Women & Nonbinary Network — AWN
B&F Home Care Services, Inc
Blue Ridge Independent Living Center
Brain Injury Association of America
CA Brain Injury Association
CA IHSS Consumer Alliance
California Advocates for Nursing Home Reform
California Association for Adult Day Services
California Association of Public Authorities for IHSS (CAPA)
California Collaborative for Long Term Services and Supports (CCLTSS)
California Council of the Blind
California Department of Aging CBAS Branch
California Foundation for Independent Living Centers
California Pan-Ethnic Health Network
CareWorks of Lane County, Eugene, Oregon
Caring Strategies
Catalyst Miami
Center for Advocacy for the Rights and Interests of the Elderly (CARIE)
Center for Elder Law & Justice
Center for Health Law and Policy Innovation
Center for Independence
Center for Independent Living for Western Wisconsin, Inc.
Center for Medicare Advocacy
Center for People With Disabilities
Center for Popular Democracy
Chicagoland Leadership Council
Choice in Aging
Christopher & Dana Reeve Foundation
Citizen Action of Wisconsin
Closing the Women's Wealth Gap
Coalition on Human Needs
CommunicationFIRST
Community Catalyst
Community Life Foundation
Compassionate Care ALS Inc.
Congregation of Our Lady of Charity of the Good Shepherd, US Provinces
Connecticut Association of Adult Day Centers
Consumer Directed Personal Assistance Assoc. of NYS
Council of State Administrators of Vocational Rehabilitation
County of San Diego Aging and Independence Services

CSAVR
Culture Change Network of Georgia
Cure SMA
Delaware Long-Term Care Ombudsman Program
Democratic Disability Caucus of Florida
Disabilities Resource Center of Siouland
Disability Action Center - Northwest
disAbility Law Center of Virginia
Disability Policy Consortium
Disability Rights California
Disability Rights Education and Defense Fund (DREDF)
Disability Rights Florida
Disability Rights Iowa
Disability Rights New Jersey
Disability Rights North Carolina
Disabled In Action of Pennsylvania
Diverse Elders Coalition
Easterseals
Edgartown Council on Aging
Elder & Health Law Clinic, McGeorge School of Law
Elder Justice Committee Rochester, NY
Elder Options, Inc.
ElderTree Care Management Services
Emanuel Enterprises, LLC
empower: abilities
Endeppence Center, INC
Epilepsy Foundation
Fairhill Partners
Families USA
Family Bridges, Inc.
Family Care Council Florida
Family Caregiver Alliance
Family Forward Oregon
Family Values At Work
Family Voices
Family Voices Indiana
Finger Lakes Independence Center
First Focus Campaign for Children
Florida Health Justice Project
Florida Policy Institute
Futures Without Violence
Gateways Community Services
Georgia ADAPT
Georgia Council of the Blind

Georgians for a Healthy Future
Gulf Coast Adapt
H-CAP
Hand in Hand: The Domestic Employers Network
Harbor Supported Living Services
Health Care Voices
Hispanic Federation
Idaho State Independent Living Council
Idaho State Long Term Care Ombudsman program
Illinois Caregivers for Compromise
Independence First
Independence Now
Independent Living Center of the Hudson Valley, Inc.
Independent Living Resources, Inc
Indiana Statewide Independent Living Council
Indivisible Georgia Coalition
Indivisible Northern Nevada
Institute on Aging
Intermountain Fair Housing Council
Iowa Citizens for Community Improvement
Johnston Senior Center
Kansas Advocates for Better Care
Kentucky Voices for Health
LeadingAge California
Legal Aid Society of San Mateo County
Legal Aid Society of the District of Columbia
Life, A Center for Independent Living
Long Term Care Community Coalition
Los Angeles Homeless Services Authority
MANAELA
Maryland Legal Aid
Massachusetts Advocates for Nursing Home Reform
Massachusetts Senior Action Council
MassADAPT
Medicaid Matters New York
Medicare Rights Center
MetroWest Center for Independent Living
Michigan Disability Rights Coalition
Michigan Elder Justice Initiative
Midstate independent Living Choices
MOCEANS Center for Independent Living
Monroe Assoc for ReMARCable Citizens
Montana Independent Living Project
MSSP OF CALIFORNIA

MyCenter for Independent Living (MyCIL)
National Academy of Elder Law Attorneys
National Advocacy Center of the Sisters of the Good Shepherd
National Alliance for Direct Support Professionals, Inc.
National Alliance to End Homelessness
National Asian Pacific Center on Aging (NAPCA)
National Consumer Voice for Quality Long-Term Care
National Consumers League
National Down Syndrome Congress
National Employment Law Project
National Hispanic Council on Aging
National Indian Council on Aging
National Network for Arab American Communities
National Partnership for Women & Families
National Respite Coalition
National Task Group on Intellectual Disabilities and Dementia Practices
National Women's Law Center
New York Association on Independent Living
New York Legal Assistance Group
New York State Association of Resident Service Coordinators
New York State Wide Senior Action Council
NJ NAELA
NNAAC
North Carolina ADULT SERVICES SOCIAL SERVICES
North Carolina AIDS Action Network
North Country Independent Living
Northeast Pennsylvania Center for Ind Living
Northwest Health Law Advocates
Not Dead Yet
Not Dead Yet Montana
Nursing Home Victims Coalition, Inc
NYCD16 Indivisible
Ohio Association of Area Agencies on Aging
Ohio Office of the State Long-Term Care Ombudsman
Oklahoma Policy Institute
Ombudsman Services of San Mateo County, Inc.
Options for Independent Living
Our Lifeline Inc
Our Mother's Voice
Oxnard Family Circle ADHC
Paraquad
Partners in Care Foundation
Partners in Home Care
Pedestrian Safety Action Coalition - Oregon

Pennsylvania Council on Independent Living
Pennsylvania Health Access Network
Personal Attendant Coalition of Texas (PACT)
Pioneer Network
Pittsylvania County Dept. of Social Services
Poway ADHC
Protect Our Care
Public Advocacy for Kids (PAK)
RCA
REGAL HOME CARE, LLC
REV UP Texas
RI Long Term Care Ombudsman
Rural Resources Community Action
SAGE
San Antonio Independent Living Services
SC ADAPT
SEN Law, PLLC
Senior Advocates of the Desert
Senior Citizens' Law Office, Inc.
Senior Network Services
Senior Services Coalition of Alameda County
Shared Support Maryland, Inc.
SHIP Medicare Counseling
Shriver Center on Poverty Law
Solkoff Legal
Southeast Asia Resource Action Center (SEARAC)
Southeast Center for Independent Living
Spina Bifida Association of Northeastern New York
Sundance Home Care
Sunny Cal ADHC
Sunrise Fiduciary
Sustainable Housing for Ageless Generations (SHAG)
TakeAction Minnesota
TARP Inc Center for Independent Living
TASH
Tempus Unlimited, Inc.
Tennessee Disability Coalition
Tennessee Health Care Campaign
Tennessee Justice Center
Thai Health And Information Services
The Arc of Arizona
The Center for Independent Living of North Florida
The Partnership for Inclusive Disaster Strategies
The Statewide Independent Living Council of Illinois

The Viscardi Center
The Will Center
United Disabilities Services Foundation
United States International Council on Disabilities
United Vision for Idaho
Universal Health Care Action Network of Ohio
UsAgainstAlzheimer's
Virginia Association of Area Agencies on Aging (V4A)
Virginia Poverty Law Center
Volunteers of America Northern New England
West Virginians for Affordable Health Care
Western Center on Law and Poverty
WI Coalition of Independent Living Centers, Inc.

Cc: President Biden