

May 18, 2022

The Honorable Chuck Schumer
Majority Leader
U.S. Senate

The Honorable Mitch McConnell
Minority Leader
U.S. Senate

Dear Leader Schumer and Leader McConnell,

The undersigned advocacy organizations representing millions of seniors, people with disabilities, family caregivers, direct care workers, and allies write to express our strong and unified support for including a robust investment in Medicaid Home and Community-Based Services (HCBS) in the next legislative package.

We are grateful for the American Rescue Plan Act funding that has allowed states to provide hazard pay to the direct care workforce and maintain access to vital HCBS that have enabled people with disabilities and older adults to remain living safely in their own homes during the pandemic. However, those rescue funds are temporary and have stopped accruing. Without a large permanent investment in HCBS, the direct care workforce crisis will worsen and HCBS access will decrease. Timely investment is needed to provide greater sustainability for states, individuals who rely on HCBS, their family caregivers, and the paid workforce providing these critical services.

As you know, the House of Representatives passed a \$150 billion investment in HCBS last year and we call upon the Senate to do the same as soon as possible. This investment is essential for building a sustainable HCBS infrastructure that can begin to address the magnitude of need in our communities. This investment will both increase access to Medicaid HCBS and create more high-quality direct care jobs to support the people who do this work as well as people with disabilities of all ages and their families. **HCBS are also more cost effective for states and the federal government than institutional care, making this investment an all-around win for individuals, families, workers, and state and federal governments.**

When older adults who want to age in place and people with disabilities who need support to work, live independently, and be a part of their communities are left waiting, the responsibility for care and support often falls on unpaid family caregivers, who also need financial assistance. [Over 90% of people with disabilities and aging adults living in the community receive unpaid support.](#) The workforce and earnings losses related to unpaid family caregiving are significant and well-documented. The costs of this inadequate system fall disproportionately on people of color with limited income and wealth. For example, family caregivers spend on average 26% of their annual income on caregiving expenses, but the [share of income African American/Black and Hispanic/Latino family caregivers report spending is 34% and 47%](#), respectively.

To address the long-standing inequities the pandemic exposed and exacerbated, this investment is critical to fortify a workforce that must expand to meet a rapidly increasing level of need. The HCBS workforce provides vital services, and yet these workers—who are primarily

women of color—have been devalued and underpaid for decades, leading to severe staff shortages that result in crucial gaps in service availability, lengthy waiting lists, service line closures, and additional obstacles to achieving a high quality of life for workers and recipients alike.

This investment is also necessary to help people who are in nursing facilities and other institutions return to the community. Many people are in institutions who do not need to be because persistent underfunding and bias have created an inadequate HCBS infrastructure to meet the demand. The HCBS legislation passed by the House would directly address this issue by making the widely successful Money Follows the Person program permanent. It would also help married individuals who rely on Medicaid to remain living at home with their spouse by permanently extending the federal spousal impoverishment protections to HCBS.

Investing in home-based care has strong bipartisan support. An [April 2022 survey](#) of over 1200 likely voters shows that affordable long-term care for seniors and people with disabilities is the most popular provision in the investment package with support from 87% of all respondents and 85% of Republicans. A survey last year of 1,400 voters age 50 and older found that 87% supported increasing resources for in-home care, including 82% of Republicans, and another survey of 800 people age 18 and older found that 89% of Americans support an increased public investment in affordable home care services.

We thank you for your leadership and urge that you continue to include and prioritize the large investment in Medicaid HCBS, and the workforce that provides them, as you negotiate the next legislative package. To that end, the undersigned advocacy organizations, representing millions of constituents across the country, stand ready to work with you to ensure these HCBS investments become law. If you have any questions feel free to contact Nicole Jorwic, nicole@caringacross.org, and Natalie Kean, nkean@justiceinaging.org.

Sincerely,

69 National Organizations

AARP

ACA Consumer Advocacy

Aging Life Care Association®

Alliance for Retired Americans

The American Association of People with Disabilities (AAPD)

American Association of Service Coordinators

American Association on Health and Disability

American Civil Liberties Union

American Geriatrics Society

American Network of Community Options and Resources (ANCOR)

Applied Self-Direction

The Arc of the United States

Association of Maternal & Child Health Programs

Association of University Centers on Disabilities

Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Be a Hero
Caregiver Action Network
Caring Across Generations
Center for Medicare Advocacy
Coalition on Human Needs
CommunicationFIRST
Community Catalyst
Corporation for Supportive Housing (CSH)
Disability Rights Education and Defense Fund (DREDF)
Easterseals
Epilepsy Foundation
Families USA
Health Care Voices
The Jewish Federations of North America
Justice in Aging
Lakeshore Foundation
The Leadership Conference on Civil and Human Rights
LeadingAge
Medicare Rights Center
MomsRising
National Academy of Elder Law Attorneys (NAELA)
National Adult Day Services Association (NADSA)
National Alliance for Caregiving
National Alliance for Direct Support Professionals, Inc.
National Association for Home Care and Hospice
National Association of ACOs
National Association of Councils on Developmental Disabilities
National Association of Nutrition and Aging Services Programs (NANASP)
National Association of Social Workers (NASW)
National Association of State Directors of Developmental Disabilities Services
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Committee to Preserve Social Security and Medicare
National Consumer Voice for Quality Long-Term Care
National Council on Independent Living
National Disability Rights Network (NDRN)
National Domestic Workers Alliance
National Employment Law Project
National Health Law Program
National PACE Association
National Respite Coalition

National Women's Law Center
Network of Jewish Human Service Agencies
Not Dead Yet
Our Mother's Voice
PHI
RESULTS
SEIU
Shriver Center on Poverty Law
TASH
United Spinal Association
USAging
Well Spouse Association

137 State & Local Organizations

A-Team Delaware
AAA4
Advisory Council, Napa/Solano Area Agency on Aging
Agape' Energy Solutions
Aging and Disability Professionals Association of Wisconsin
Alliance for Leadership and Education
AltaMed Health Services
Alzheimer's Orange County
American Association of Caregiving Youth
Aptiv, Inc.
Benton Franklin Patent Coalition
California Advocates for Nursing Home Reform
California Disability Services Association
Center For Accessible Living Murray
Center for Advocacy for the Rights and Interests of Elders (CARIE)
Center for Disabilities Studies, University of Delaware
Center for Elder Law & Justice
Center for Independence of the Disabled, NY
Chinese-American Planning Council (CPC)
CICA CA IHSS Consumer Alliance
Coalition for Compassionate Care of California
Communities Actively Living Independent & Free
Community Alliance
Council on Aging Southern California
Curtis Care Management, LLC
Democratic Disability Caucus of Florida
Detroit Disability Power
Disability Network Southwest Michigan
Disability Policy Consortium
Disability Rights Florida

Disability Rights New York
Easterseals, Illinois
ElderNet of Lower Merion and Narberth
Fairhill Partners
Family Based Services Association of NJ
Family Caregiver Alliance/National Center on Caregiving
Family Partners of Morris and Sussex Counties
Family Voices NJ
Family Voices of California
Federation for Children with Special Needs.
Florida Health Justice Project
Florida Voices for Health
Geriatric Care Management and Dementia Consulting
Grant, Adams & Lincoln Parent Coalition
Greater WI Agency on Aging Resources, Inc.
Grotta Fund
Hawaii Families As Allies
Haywood County Health and Human Services
Home Care Association of Florida
Hudson Valley Elder Care
Idaho Caregiver Alliance
Independent Living Center of the Hudson Valley
Indiana Disability Rights
JEVS Human Services
Jewish Family & Career Services
Jewish Family Service of Greater Dallas
Jewish Family Service of Greater New Orleans
Johnston Senior Center
JVS SoCal
JVS+Kadima
Kansas Lifespan Respite Coalition
Keeping It REAL Caregiving
LeadingAge California
Long Term Care Ombudsman, Georgia
Maine Parent Federation
Maryland CPUSA
Massachusetts Advocates for Nursing Home Reform
Maximizing Independent Living Choices
Mental Health Project, Urban Justice Center
Michigan Developmental Disabilities Institute
Michigan Disability Rights Coalition
Michigan Elder Justice Initiative
Michigan Family Voices
Mississippi Department of Human Services/Division of Aging and Adult Services

Montgomery County Commission on Aging
National Council on Aging
New Jersey Parents Caucus
New Jersey Psychiatric Rehabilitation Association
New Mexico Caregivers Coalition
New York Legal Assistance Group (NYLAG)
Northwest Health Law Advocates
Olmstead Coalition
Parent to Parent of NYS
People First Wisconsin
Personal Assistance Services Council
Placer Independent Resource Services
PROVAIL
Ranni Law Firm
Region IV Area Agency on Aging
Respite Care Association of Wisconsin (RCAW)
Rural Advocates For Independent Living, Inc.
Salem CLC
Service Opportunities By and For Disabled Adults (SODA)Adults
SidebySide
SPAN Parent Advocacy Network
Survival Coalition of Wisconsin Disability Organizations
Team Gleason Foundation
Tennessee Association of Adult Day Services
Tennessee Justice Center
The Arc Michigan
The Arc New York
The Arc of Allegan County
The Arc of Calhoun County
The Arc of Central Alabama
The Arc of Colorado
The Arc of Connecticut, Inc.
The Arc of Cowlitz County
The Arc of Florida, Inc.
The Arc of Grays Harbor
The Arc of Illinois
The Arc of King County
The Arc of Massachusetts
The Arc of New Mexico
The Arc of NJ
The Arc of Northwest Wayne County
The Arc of Oakland County
The Arc of Ohio
The Arc of Snohomish County

The Arc of South Carolina
The Arc of Spokane
The Arc of Texas
The Arc of the Mid Ohio Valley
The Arc of Tri Cities
The Arc of Washington State
The Arc of West Virginia
The Arc of Whatcom County
The Arc Western Wayne County
The Arc/Newaygo County
The Parents' Place of MD
U.S. Against Alzheimer's
United Way of Greater Los Angeles
Vermont Family Network
Vermont Long-Term Care Ombudsman Project
VIC Valley InterCommunity Council
WESLEY LIVING WOODLAND HOMES
Wisconsin Aging Advocacy Network
Wisconsin Board for People with Developmental Disabilities