

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](mailto:nicole@caringacross.org), and Natalie Kean, [nkean@justiceinaging.org](mailto: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  
USAgging  
Well Spouse Association

### **138 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 Parent 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 APSE  
Wisconsin Board for People with Developmental Disabilities