

The Disability and Aging Collaborative &



April 14, 2026

The Honorable John Thune
Majority Leader
U.S. Senate
Washington, DC 20515

The Honorable Chuck Schumer
Minority Leader
U.S. Senate
Washington, DC 20515

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, DC 20515

Dear Leader Thune, Minority Leader Schumer, Speaker Johnson, Minority Leader Jeffries, and Members of the United States Senate and House of Representatives,

The undersigned 359 members of the Disability and Aging Collaborative (DAC), the Health and Long Term Services and Supports (LTSS) Taskforces of the Consortium for Constituents with Disabilities (CCD), and allied organizations urge you to exclude any funding cuts or harmful changes to Medicaid from any budget reconciliation or other legislation. Medicaid is our communities' lifeline, and that lifeline just suffered the largest cut in funding since its inception. We cannot afford any further cuts, and we urge Congress to prioritize reinvesting in Medicaid.

People with disabilities, older adults, family caregivers, direct care workers, people with chronic health conditions, and other low-income individuals and families depend on Medicaid every day for their health, safety, and independence. Now our communities and your constituents' lives are at risk as the [\\$900+ billion in cuts to Medicaid from H.R. 1](#) are coming to fruition. [Hospitals](#) are laying off workers and shuttering units, [providers](#) are closing, and [at least 9 states are considering significant cuts](#) to their home and community-based services (HCBS) programs to try to balance their budgets.

These actions by states to cut HCBS and other Medicaid services that older adults and people with disabilities need are devastating but not surprising. As we warned for months prior to the passage of H.R. 1, [states respond to cuts in federal funding by cutting HCBS](#) and other services that federal law does not require them to cover. Even before H.R. 1 passed, nearly [a third of state](#)

[Medicaid programs reported](#) they are taking actions to decrease funding for HCBS due to shrinking budgets. Any additional cuts, caps, or changes to Medicaid that limit eligibility will push the system past the brink, [further imperiling entire HCBS programs and access to health care in every state](#). Moreover, the HCBS system has never been adequately funded to meet the growing need, as there are over [600,000 people on Medicaid waiting lists for HCBS](#). Paying out of pocket is nearly impossible, [costing annually between \\$68,000 to \\$288,000](#). The bottom line is that anytime Medicaid funding is cut or costs are shifted to states—[people with disabilities and older adults are harmed](#).

We are deeply concerned by recent statements from some Congress members supporting proposals that would further cut Medicaid funding. Medicaid is already lean, efficient, and under unprecedented strain from the cuts and onerous administrative burdens imposed by H.R. 1.

Today, [8.4 million older adults and people with disabilities](#) rely on Medicaid for essential support with daily activities, enabling older adults to live in the homes they worked their entire lives for, adults with disabilities to be in their communities instead of nursing facilities, and children with disabilities to grow up at home with their parents and loved ones instead of in pediatric nursing institutions.

HCBS enrollment and spending have been increasing across the country as a direct result of a rapidly growing aging population and decades of work by families, people with disabilities, and older adults who want to live, work, and age with dignity in their own homes and communities. Simply put, [more people are enrolled in Medicaid HCBS](#) and fewer people are relying on institutional care, which is [significantly more expensive for individuals and the state](#). This is a [success story, not a cause for concern— the result of decades of bipartisan federal and state efforts to rebalance funding from institutional care to HCBS](#). Any additional reductions to Medicaid would undermine the decades of bipartisan policies that have led to this success.

Direct care workers and family caregivers are indispensable to ensuring a functioning Medicaid HCBS system. Already, the total direct care workforce [falls far short of the almost 9 million jobs](#) that will need to be filled to meet the needs of people with disabilities and older adults who need care [as the population ages](#) and [people with disabilities live longer](#). The lack of adequate and robust investment in the direct care workforce leaves [massive barriers](#) to community living and aging in place for people with disabilities and older adults. Family caregivers are [often the only option to fill the gap](#), taking on caregiving responsibilities at the expense of employment outside the home. Family caregivers for older adults and people with disabilities who are being paid through Medicaid are doing real, essential labor that otherwise must be provided by professional care workers – an option that is not accessible for many due to long waitlists. In doing this care work, family caregivers help ensure that people with disabilities and older adults who would

otherwise have to go without care or be institutionalized have their needs met. [The minimal compensation family caregivers may receive](#) makes it possible to do this work and provide for their families.

Support for Medicaid and home and community-based services specifically is extremely high across all political parties. The vast majority of people – including [94 percent of older adults and 90 percent of people with disabilities](#) – want to live and age in their own homes and communities. Medicaid support has only grown as [97% of voters say Medicaid is important in their communities](#), and 90% of voters across political parties, including 88% of Republicans, 90% of Independents, and 93% of Democrats [want to see increased or steady funding for home and community-based services](#).

Access to Medicaid is a matter of life, death, and independence for millions of people with disabilities, older adults, and their families and loved ones. **We strongly urge Congress to reject Medicaid cuts and harmful changes in any form, whether through changing funding structures, further limiting the way states fund their share of Medicaid costs, or freezing or taking away funding for critical services that people with disabilities and older adults rely on.** The result is the same: taking away coverage from people with disabilities, older adults, and others who cannot otherwise afford health care and long-term services and supports. We implore Congress to instead reinvest in Medicaid and to meet the needs of people with disabilities and older adults. For additional information or any questions, please contact Tory Cross at tory@caringacross.org or Natalie Kean at nkean@justiceinaging.org.

Sincerely,

123 National Organizations

Access Ready Inc.

ADA Watch/Coalition for Disability Rights & Justice

Advocates for Trans Equality

AFSCME

AiArthritis

Alliance for Aging Research

Allies for Independence

American Association of People with Disabilities

American Association on Health and Disability

American Civil Liberties Union

American Music Therapy Association

American Network of Community Options and Resources (ANCOR)

American Speech-Language-Hearing Association

American Therapeutic Recreation Association
Angelman Syndrome Foundation
Asthma and Allergy Foundation of America
Autism Society of Northwest Ohio
Autistic People of Color Fund
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Blood Cancer United
Cancer Nation
Caring Across Generations
Center for Law and Social Policy (CLASP)
Center for Medicare Advocacy
Center for Public Representation
Chronic Disease Coalition
Clearinghouse on Women's Issues
Coalition on Human Needs
CommunicationFIRST
Community Catalyst
Community Change Action
Compassion & Choices
Cure SMA
Disability Belongs
Disability Rights Education and Defense Fund (DREDF)
Diverse Elders Coalition (DEC)
Division for Early Childhood of the Council for Exceptional Children (DEC)
Doctors for America
DQIA: Disabled Queers in Action!
Easterseals, Inc.
Epilepsy Foundation of America
EveryLife Foundation for Rare Diseases
Families USA
Family Caregiver Alliance, National Center on Caregiving
Family Values @ Work
Family Voices National
Feminist Majority
Foundation for Angelman Syndrome Therapeutics (FAST)
Gerontological Society of America
Grantmakers In Aging
Grantmakers In Health

Guided Decisions
Hand in Hand: The Domestic Employers Network
Health Care for America Now (HCAN)
HIV Medicine Association
Hypertrophic Cardiomyopathy Association
Justice in Aging
Lakeshore Foundation
Legal Action Center
Little Lobbyists
Little People of America
Maudes's Awards for Innovation in Alzheimer's Care
MEAction
Medicare Rights Center
Mental Health Association for Chinese Communities
MomsRising
Muscular Dystrophy Association
National Academy of Elder Law Attorneys (NAELA)
National ADAPT
National Alliance to End Homelessness
National Association of Councils on Developmental Disabilities
National Association of Social Workers (NASW)
National Association of the Deaf
National Disability Rights Network (NDRN)
National Domestic Workers Alliance
National Down Syndrome Congress
National Health Council
National Health Law Program
National Kidney Foundation
National Low Income Housing Coalition
National Multiple Sclerosis Society
National Organization for Women
National Partnership for Women and Families
National Patient Advocate Foundation
National Respite Coalition
National Women's Law Center Action Fund
NETWORK Lobby for Catholic Social Justice
Network of Jewish Human Service Agencies
NHCOA
Oxfam America
PFLAG National

PHI
Poder Latinx
Professional Beauty Association
Protect Our Care
Public Advocacy for Kids (PAK)
Rogan's List
Rolling Start, Inc.
RRF Foundation for Aging
SAGE
San Diego Seniors Community Foundation
Say it with Symbols LLC
Second Wind Dreams, Inc.
Service Employees International Union
TASH
The Arc of the United States
The Cancer Network
The Holistic Healing Source
The National MLTSS Health Plan Association
The People's Response Network
Treyeo, LLC
Triage Cancer
Union for Reform Judaism
United Spinal Association
United States International Council on Disabilities
Unrig Our Economy
USAging
Village to Village Network
VisionServe Alliance
Voices of Health Care Action
Well Spouse Association

236 State and Local Organizations

Abortion Forward
Access Care Anywhere
ACCESS REPRODUCTIVE JUSTICE
AHRC Nassau
AHRC New York City
AIDS Foundation Chicago
Allies for Children
Alternatives for the Older Adult, Inc.

Alzheimer's Los Angeles
Arc Middlesex County
Arc of Indiana
ArcMorris, Morris County Chapter NJ., Inc
Ashby Village
Autism Society Tidewater
Autism Society Berks County
Autism Society Central Ohio
Autism Society District of Columbia
Autism Society Greater Harrisburg Area
Autism Society Greater Hudson Region
Autism Society Greater Philadelphia
Autism Society Inland Empire
Autism Society Lehigh Valley
Autism Society Northeastern PA
Autism Society Northern Virginia
Autism Society Northwestern Pennsylvania
Autism Society of America Greater Baton Rouge Chapter
Autism Society of America Nassau Suffolk
Autism Society of Florida, Inc.
Autism Society of Greater Detroit
Autism Society of Greater New Orleans
Autism Society Of Greater Phoenix
Autism Society of Idaho
Autism Society of Indiana
Autism Society of Iowa
Autism Society of Maryland
Autism Society of Massachusetts
Autism Society of North Carolina
Autism Society of Ohio
Autism Society of Oregon
Autism Society of Southern Arizona
Autism Society of Southern Illinois
Autism Society of Texas
Autism Society of the Bluegrass
Autism Society of Tidewater Virginia
Autism Society of Washington
Autism Society Orange County
Autism Society San Diego
Autism Society Ventura County

Autism Society Western New York
Autism Society- Louisiana State Chapter, Inc.
Autism Society-Greater Baton Rouge, Inc.
Bet Tzedek Legal Services
Boomers Collaborative Foundation
Brio Living Services
Bronx Developmental Center
Bronx Developmental Disabilities Council, Inc.
Brooklyn Center for Independence of the Disabled
Brooklyn Org
California Advocates for Nursing Home Reform
California Alliance for Retired Americans
California Association for Adult Day Services
California Association of Area Agencies on Aging
California Commission on Aging
California Domestic Workers Coalition
California Elder Justice Coalition
California Foundation For Independent Living Centers
California Health Advocates
California In-Home Supportive Services Consumer Alliance (CICA)
California Long-Term Care Ombudsman Association (CLTCOA)
Californians for Disability Rights Inc.
CalPACE
Center for Elder Law & Justice
Cerebral Palsy Associations of New York State
Charles River Center
Choice in Aging
City of Akron Commission on Aging
Colorado Consumer Health Initiative
Community Legal Services in East Palo Alto
Daybreak Independent Services Inc
Detroit Disability Power
Disability Law Center
Disability Law Center of Utah
Disability Rights Arizona
Disability Rights California
Disability Rights Florida
Disability Rights Idaho
Disability Rights Iowa
Disability Rights Nebraska

Disability Rights New Jersey
Disability Rights North Carolina
Disability Rights Pennsylvania
Disability Rights South Carolina
Disability Rights Vermont
DMV Disability & Senior Community Group
Employment Resources Inc
Family Voices Colorado
Florida Health Justice Project
Florida Policy Institute
Gem State Developmental Center
Georgia ADAPT NDN
Golden Connection Senior Services
Graceland Center for Purposeful Aging
Hawaii Family Caregiver Coalition
Health & Medicine Policy Research Group
HICAP of San Mateo County
Homeless Action Center
Hospital to Home Alliance of Ventura County
ICMRS
Incompass Human Services
Indiana Association of Area Agencies on Aging
Indivisible Westside Los Angeles
InSpirit
Inter Agency Council of Developmental Disabilities Agencies, Inc.
J Badger Consulting Inc
LeadingAge California
LeadingAge Pacific West
Legal Aid Society of San Mateo County
LIANDD
Liberty Resources, Inc.
Life Works - The Arc of Cowlitz County
Little Lobbyists Pennsylvania
LiveOn NY
Marin Center for Independent Living
Maryland Citizens' Health Initiative
Mental Health Partnerships
Metta Fund
Midsouth Aging Consultant
MidState Arc, Inc.

Mississippi Coalition for Citizens with Disabilities
Mississippi Down Syndrome Advocacy Coalition
Missouri Association of Area Agencies on Aging
Mothers War on Violence
MUSIC MEMORY LANE INC
New Disabled South
New York Alliance for Developmental Disabilities
North Dakota Protection & Advocacy Project
Northwest Health Law Advocates (NoHLA)
Ohio Association of Area Agencies on Aging
Older Women Embracing Life (OWEL)
On Lok
PA Association of Area Agencies on Aging
PathPoint
Person Centered Care Services, Inc
Personal Assistance Services Council
Placer Independent Resource Services
Public Health Solutions
Refugee Women's Network
Resources for Independence Central Valley
Rocky Mountain Multiple Sclerosis Center
Sacramento County, California
SACRI (Senior Agenda Coalition of RI)
San Diegans for Healthcare Coverage
San Francisco IHSS Public Authority
San Francisco Senior and Disability Action
SCIboston
SDSU Center for Excellence in Aging & Longevity
Senior Centers, Inc.
SeniorLAW Center
Service Employees International Union Local 105
Services for the Developmentally Challenged
Serving At Risk Families Everywhere, Inc.
Serving Seniors
Sound Generations
South Asian Network
South Carolina Appleseed Legal Justice Center
South Carolina Human Services Providers Association
St. Louis Arc
Store to Door

Texas Ramp Project
The Arc - Jefferson, Clear Creek & Gilpin Counties
The Arc Arenac Area
The Arc Baton Rouge
The Arc Davidson County & Greater Nashville
The Arc for the River Valley Fort Smith Arkansas
The Arc Maryland
The Arc Michigan
The Arc Middlesex County
The Arc Montgomery County
The Arc NCR
The Arc New York
The Arc Noble County Foundations
The Arc of Amador and Calaveras
The Arc of Anchorage
The Arc of Aurora
The Arc of Butler County
The Arc of California
The Arc of East Central Iowa
The Arc of Essex County
The Arc of Grays Harbor
The Arc of Greater Williamsburg
The Arc of Harris County-Houston
The Arc of Haywood County
The Arc of Hunterdon County
The Arc of Illinois
The Arc of King County
The Arc of LaGrange County
The Arc of Laramie County
The Arc of Lehigh & Northampton Counties
The Arc of Litchfield County, Inc.
The Arc of Loudoun
The Arc of Macomb County, Inc.
The Arc of Middlesex
The Arc of New Jersey
The Arc of North Carolina
The Arc of North Central Virginia
The Arc of Ohio
The Arc of Pennsylvania
The Arc of Placer County

The Arc of Racine County
The Arc of Snohomish County
The Arc of South Carolina
The Arc of Southside
The Arc of Southwest Colorado
The Arc of Spokane
The Arc of Texas
The Arc of The Glades, Inc
The Arc of the Piedmont
The Arc of Tri-Cities
The Arc of Virginia
The Arc of Washington State
The Arc of Whatcom County
The Arc Pikes Peak Region
The Arc Upper Valley
The Autism Society of Boulder County
The Autism Society of Greater Detroit
The Autism Society of Wisconsin
The California LGBTQ Health and Human Services Network
The Listen Center
Trilogy
UDW/ AFSCME Local 3930
Union Community Health Center
VersAbility Resources
WA Association of Area Agencies on Aging (W4A)
Washtenaw Health Project
Wisconsin Family & Caregiver Support Alliance (WFACSA)
York County Community Foundation