

# 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](mailto:tory@caringacross.org) or Natalie Kean at [nkean@justiceinaging.org](mailto: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