

The Disability and Aging Collaborative &



March 9, 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

RE: The critical role and efficiency of Home and Community-Based Services (HCBS) in the lives of people with disabilities and older adults.

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

The undersigned 153 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 oppose actions by the current Administration that would restrict crucial Medicaid home and community-based services (HCBS) and harm people with disabilities and older adults.

CCD is the largest coalition of national organizations advocating for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. DAC is a coalition of national and state organizations that work together to advance long-term services and supports policy at the federal level. DAC and CCD have a longstanding history of advocating for people with disabilities and aging adults to access needed care in their communities, and supporting the family caregivers and care workers who provide that care.

The undersigned organizations write to express deep concern about the Centers for Medicare & Medicaid Services' (CMS) continued attacks on HCBS and drastic responses to concerns about fraud. We strongly disagree with CMS' implication that increased spending on HCBS, including

mental health services, and other integral services for people with disabilities and the increased number of direct care workers alone are indicative of issues with program integrity. The Administration is taking misguided and sweeping actions that put the health, well-being, and independence of people with disabilities and older adults at risk.

People with disabilities and older adults rely on Medicaid HCBS every day, when personal care aides and direct support professionals help a person with a disability find employment and get ready for work or ensure they are able to eat, transport brings a grandmother with Alzheimer's to an adult day center to socialize and combat loneliness, and paid family caregivers fill the gaps in the direct care labor market. More than [1 in 4 people in the U.S. have disabilities](#), and across the country, more than [one in five adults receive ongoing support](#) with these and other everyday functional needs, like bathing, dressing, and taking medications.

Increased overall spending in HCBS reflects the [increase in the number of Medicaid HCBS enrollees](#) and is the result of 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 alongside federal and state efforts to rebalance funding to HCBS from institutional facility care. [Rebalancing](#) by utilizing Medicaid funding to keep people with disabilities and older adults in their communities instead of expensive institutions both serves more people and [can save considerable money](#).

Family caregivers and direct care workers for older adults and people with disabilities being paid through Medicaid are providing life-saving, essential care that will be compromised by these actions. The increase in direct care workers and in support for family caregivers also reflects the needs of [a rapidly aging population](#) and [already underpaid workforce](#). Employment projections from the Bureau of Labor Statistics demonstrate [the demand for direct care workers will continue to grow](#). Today's [workforce growth already has not kept pace with the demand for services](#). Family caregivers' work fills critical gaps in the labor market and looks different from the typical caregiving family members tend to do for each other, and instead can involve fully bathing and grooming a grown adult, transferring someone from a bed to a wheelchair, and even skilled medical care like changing tracheotomies and monitoring ventilators.

The people with disabilities and older adults who rely on Medicaid are harmed, not protected, when the funding for their services is frozen. During debates over Medicaid spending during 2025, we heard repeatedly that Members of Congress promise to protect Medicaid for people with disabilities and older adults. Freezing hundreds of millions of dollars that pay for Medicaid HCBS does not protect people with disabilities and older adults.

More funding, not less, is needed for care. There are real crises facing the aging and disability care system. The [US population is older today than it has ever been](#), and [people turning 65 have a nearly 70 percent chance of needing long-term care](#). There is a drastic shortage of direct care workers [across every state](#). Care is not affordable – [paying out of pocket for care costs tens or hundreds of thousands of dollars each year](#). Family caregivers are being pulled to their breaking points. Several states, including [Idaho](#), [Colorado](#), [Utah](#), [Missouri](#), and [Washington](#) are proposing eliminating or reducing funding for some or all HCBS following the drastic Medicaid cuts from H.R.1. Measures such as targeted audits, data-driven oversight, and strengthened safeguards that would actually address fraud are being discounted and dismantled.

Access to Medicaid HCBS is a matter of life, death, and independence for millions of Americans with disabilities, older adults, and their families and loved ones. **We strongly oppose the overly broad actions CMS is taking to freeze funding for Medicaid HCBS services in Minnesota and the threats to freeze funding for services across the country.** The result is the same: taking away critical services from people with disabilities and older adults who have nowhere else to turn. If you have any questions, contact Tory Cross, (tory@caringacross.org) and Natalie Kean (nkean@justiceinaging.org).

Sincerely,

150+ National, State, & Local Organizations

Access Care Anywhere
Access Central Coast
Access Ready Inc.
ADAPT Montana
ADAPT National
AFSCME
AFT: Education, Healthcare, Public Services
All Things Disability Equity
American Association of Service Coordinators
American Association on Health and Disability
American Civil Liberties Union
American Friends Service Committee
American Physical Therapy Association
American Speech-Language-Hearing Association
American Spinal Injury Association
ANCHORNC
Arkansas Advocates for Children and Families

Autistic People of Color Fund
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Blue Ridge Independent Living Center
Brain Injury Association of America
Bridge To Possibilities
California Long-Term Care Ombudsman Association (CLTCOA)
California PACE Association
Care in Action
Caring Across Generations
Center for Caregiver Serenity
Center for Elder Law & Justice
Center for Public Representation
Cerebral Palsy Associations of NYS
CJE SeniorLife
Clinician Task Force
Coalition of Texans with Disabilities
Coalition on Human Needs
Colorado Consumer Health Initiative
Colorado Cross Disability Coalition
Community Catalyst
Community Health Commission of Missouri
Detroit Disability Power
Disability Belongs
Disability Law Center of Utah
Disability Law Colorado
Disability Network Mid-Michigan
Disability Rights California
Disability Rights Center - NH
Disability Rights Education and Defense Fund (DREDF)
Disability Rights Nebraska
Disability Rights New Jersey
Disability Rights North Carolina
Disability Rights Texas
Disability Rights Wisconsin

Disability Services and Legal Center (DSLCL)
Diverse Elders Coalition (DEC)
Easterseals, Inc.
Epilepsy Foundation of America
Falling Forward Foundation
Family Values @ Work
Family Voices National
Family Voices NJ
FREED Center for Independent Living
Gem State Developmental Center
Gerontological Society of America
Hand in Hand: The Domestic Employers Network
High Note Consulting, LLC
Idaho Families of Adults with Disabilities
Inspire Positivity Inc
InSpirit
International Association for Indigenous Aging
Justice in Aging
KC Rehab Doctors LLC
Kentucky Voices for Health
Kokua
Lakeshore Foundation
LeadingAge California
Legal Aid Justice Center
Little Lobbyists
Long Beach Alliance for Clean Energy
Marin Center for Independent Living
MEAction
Medicaid Matters New York
Medicare Rights Center
Mental Health Colorado
Michigan Elder Justice Initiative
MomsRising
Muscular Dystrophy Association
National Adult Protective Services Association
National Alliance Caregiving

National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Association of Social Workers (NASW)
National Association of the Deaf
National Consumer Voice for Quality Long-Term Care
National Disability Rights Network (NDRN)
National Domestic Workers Alliance
National Down Syndrome Congress
National Health Law Program
National Low Income Housing Coalition
National Multiple Sclerosis Society
National Partnership for Women & Families
National PLAN Alliance
National Respite Coalition
National Women's Law Center Action Fund
NETWORK Lobby for Catholic Social Justice
New Disabled South
New York Legal Assistance Group (NYLAG)
NHCOA
North Alabama Area Labor Council, AFL-CIO
Oklahoma Policy Institute
Our Mother's Voice
Paralyzed Veterans of America
PathPoint
Pennsylvania Health Law Project
Person Centered Care Services
PHI
Protect Our Care
Public Advocacy for Kids (PAK)
Public Justice Center
Rogan's List
SAGE
Service Employees International Union
South Carolina Appleseed Legal Justice Center
South Central Nebraska Area Agency on Aging
SPAN Parent Advocacy Network

TDIforAccess
TechTonic Justice
Tennessee Justice Center, Inc.
The Arc Michigan
The Arc New York
The Arc of California
The Arc of Illinois
The Arc of Indiana
The Arc of Ohio
The Arc of Oklahoma
The Arc of South Carolina
The Arc of the United States
The Arc of Washington State
Total Living Concept
Transitions Clinic Network
Triage Cancer
Union for Reform Judaism
Unitarian Universalists for Social Justice
United States International Council on Disabilities
Village Community Services
Village to Village Network
Virginia Poverty Law Center
Voices of Health Care Action
Well Spouse Association
William E. Morris Institute for Justice
World Institute on Disability
Youth Law Center