

The Disability and Aging Collaborative &



March 16, 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 169 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,

National Organizations

Access Ready Inc.

ADAPT National

AFSCME

AFT: Education, Healthcare, Public Services

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

Autism Society of America

Autistic People of Color Fund

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Brain Injury Association of America

Care in Action

Caring Across Generations

Center for Public Representation
Clinician Task Force
Coalition on Human Needs
Community Catalyst
Disability Belongs
Disability Rights Education and Defense Fund (DREDF)
Diverse Elders Coalition (DEC)
Easterseals, Inc.
Epilepsy Foundation of America
Falling Forward Foundation
Family Values @ Work
Family Voices National
Gerontological Society of America
Hand in Hand: The Domestic Employers Network
International Association for Indigenous Aging
Justice in Aging
Kaiser Permanente
Lakeshore Foundation
Little Lobbyists
MEAction
Medicare Rights Center
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

NHCOA
Our Mother's Voice
Paralyzed Veterans of America
PHI
Protect Our Care
Public Advocacy for Kids (PAK)
Rogan's List
SAGE
Samaritas
Service Employees International Union
TDIforAccess
TechTonic Justice
The Arc of the United States
Transitions Clinic Network
Triage Cancer
Union for Reform Judaism
Unitarian Universalists for Social Justice
United States International Council on Disabilities
Village to Village Network
Voices of Health Care Action
Well Spouse Association
World Institute on Disability
Youth Law Center

State and Local Organizations

Alabama

New Disabled South
North Alabama Area Labor Council, AFL-CIO

Arizona

The Arc of Arizona
William E. Morris Institute for Justice

Arkansas

Arkansas Advocates for Children and Families
New Disabled South

California

Access Central Coast
All Things Disability Equity
California Long-Term Care Ombudsman Association (CLTCOA)

California PACE Association
Disability Rights California
Disability Services and Legal Center (DSLCL)
FREED Center for Independent Living
InSpirit
LeadingAge California
Long Beach Alliance for Clean Energy
Marin Center for Independent Living
PathPoint
The Arc of California

Colorado

ADVOCACYDENVER
Association for Community Living in Boulder & Broomfield Counties
Colorado Consumer Health Initiative
Colorado Cross Disability Coalition
Disability Law Colorado
Integrated Life Choices
Mental Health Colorado
Rocky Mountain Multiple Sclerosis Center
The Arc Arapahoe, Douglas & Elbert Counties
The Arc of Aurora
The Arc of Colorado
The Arc of Southwest CO

Florida

New Disabled South

Georgia

Inspire Positivity Inc
New Disabled South

Idaho

Gem State Developmental Center
Idaho Families of Adults with Disabilities

Illinois

CJE SeniorLife
The Arc of Illinois

Indiana

The Arc of Indiana

Kentucky

Kentucky Voices for Health

New Disabled South

Louisiana

New Disabled South

Maine

Maine Council on Aging

Maryland

Public Justice Center

Massachusetts

The Arc of Massachusetts

Michigan

Detroit Disability Power

Disability Network Mid-Michigan

Michigan Elder Justice Initiative

Michigan League for Public Policy

The Arc Michigan

Mississippi

New Disabled South

Missouri

Community Health Commission of Missouri

KC Rehab Doctors LLC

Montana

ADAPT Montana

Nebraska

Disability Rights Nebraska

South Central Nebraska Area Agency on Aging

Nevada

Bridge To Possibilities

New Hampshire

Disability Rights Center - NH

New Jersey

Disability Rights New Jersey

Family Voices NJ

SPAN Parent Advocacy Network

New York

Center for Elder Law & Justice

Cerebral Palsy Associations of NYS

Medicaid Matters New York

New York Legal Assistance Group (NYLAG)

Person Centered Care Services

The Arc New York

North Carolina

ANCHORNC

Disability Rights North Carolina

New Disabled South

Ohio

The Arc of Ohio

Oklahoma

New Disabled South

Oklahoma Policy Institute

The Arc of Oklahoma

Oregon

Access Care Anywhere

Pennsylvania

Community Legal Services of Philadelphia

Pennsylvania Health Law Project

South Carolina

New Disabled South

South Carolina Appleseed Legal Justice Center

The Arc of South Carolina

Tennessee

Tennessee Justice Center, Inc.
New Disabled South

Texas

Coalition of Texans with Disabilities
Disability Rights Texas
New Disabled South

Utah

Disability Law Center of Utah

Virginia

Blue Ridge Independent Living Center
Legal Aid Justice Center
New Disabled South
Virginia Poverty Law Center

Washington

Kokua
Puget Sound Assisted Living
The Arc of Washington State
Total Living Concept
Vibrant Health Homecare
Village Community Services

West Virginia

New Disabled South

Wisconsin

Center for Caregiver Serenity
Disability Rights Wisconsin