

# The Disability and Aging Collaborative &



September 25, 2025

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 355 organizations who are members of the Disability and Aging Collaborative (DAC), the Health and Long Term Services and Supports Taskforces of the Consortium for Constituents with Disabilities (CCD), and allied organizations write to urge the swift passage of the Protecting Healthcare and Lowering Costs Act of 2025 to repeal all of the health care provisions in H.R. 1 and make permanent the enhanced Advanced Premium Tax Credits for purchasing marketplace health insurance plans and similar legislation to repeal the harmful cuts to Medicaid included in H.R.1.

The Disability and Aging Collaborative is a coalition of approximately 60 national organizations that work together to advance long-term services and supports policy at the federal level. Formed in 2009, DAC was one of the first coordinated efforts to bring together disability, labor, and aging organizations. The Consortium for Constituents with Disabilities is the largest coalition of national organizations working together to advocate 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, free from discrimination. DAC and CCD have a longstanding history of supporting people with disabilities and aging adults who need care, along with the family caregivers and care workers who provide that care.

The undersigned organizations urge you to pass the Protecting Healthcare and Lowering Costs Act of 2025 (S. 2556/H.R.4849) or similar legislation to repeal the harmful cuts to Medicaid in H.R. 1 to protect the health care of millions of Americans, restore Medicaid, Medicare, and Affordable Care Act (ACA) funding and programs, and protect millions of low and middle income Americans by making the enhanced premium tax credits permanent. [H.R.1 will take health coverage away from at least 10 million people](#), and millions of older adults and people with disabilities will be terminated from Medicaid, including people dually enrolled in Medicare. If Congress allows the Advanced Premium Tax Credits to expire, the number of people who will become [uninsured rises to 14 million](#). Already, [hospitals](#) and [clinics](#) are closing, at least 3 states have announced reduced Medicaid provider rates ([Idaho](#), [Colorado](#), and [North Carolina](#)), and [insurance companies are requesting skyrocketing premium increases](#). H.R.1 will do irreparable harm to millions of people with disabilities and older adults, and we urge Congress to act to prevent these harms.

**H.R. 1 guts home and community-based services (HCBS), ripping critical care away from people with disabilities and older adults who want to remain in their own homes and communities.**

By restricting states' ability to increase and direct provider and insurer taxes and state-directed payments to fund their own Medicaid programs, H.R. 1 will have devastating consequences for the [7.8 million older adults and people with disabilities who rely on Medicaid for home and community-based services \(HCBS\)](#). Neither Medicare nor private insurance meaningfully covers long-term care, leaving people with disabilities, older adults, and family caregivers with only two options when care needs arise – enrolling in Medicaid or [paying tens or hundreds of thousands of dollars out of pocket](#). Medicaid pays for [70% of all HCBS](#), including paying the wages of direct care workers and paying for some family caregiver supports that are desperately needed.

When Medicaid funding is reduced, states must continue to offer mandatory services, [such as nursing facility care](#), forcing states to cut optional services like HCBS. The vast [majority of optional Medicaid spending \(86%\) is spent on services that support people with disabilities and older adults](#). More than [half of all optional Medicaid spending is spent on HCBS](#). [Every single state cuts funding for HCBS during budget shortfalls](#) by reducing the number of people with disabilities and older adults who receive services, reducing per-participant spending on HCBS waivers, or both. 24 states cut the number of people who received services or reduced per-participant spending by at least 20% for one or more HCBS waivers. Decreasing the number of participants and per-participant spending results in fewer hours of care for people who need care most, service reductions, and even more people on waiting lists for HCBS.

The long-term care system is already in crisis, with significant workforce shortages due to low wages and limited benefits, a rapidly aging population, and [more than 710,000 people with disabilities and older adults](#) on waiting lists for Medicaid HCBS, [often waiting years for care](#). Direct care workers are among the most underpaid workers in the US, [earning just \\$25,000 annually](#), and [49% rely on public assistance](#) to make ends meet, including Medicaid. More than

[40% of adults in the US, 105 million people, are family caregivers](#). The cuts to HCBS that H.R. 1 imposes will mean direct care workers getting paid less and leaving for different jobs, family caregivers leaving the workforce and experiencing significant financial strain to provide care, and people with disabilities and older adults ending up in costly institutional settings or going without care entirely.

**Despite claims to the contrary, people with disabilities, older adults, family caregivers, and direct care workers will lose coverage and care because of H.R. 1.**

Cutting [more than \\$1 trillion from Medicaid, Medicare, and the ACA](#) will inevitably mean that people with disabilities, older adults, family caregivers, and care workers will have coverage and care taken away. While Medicaid covers the needs of many, people with disabilities and older adults make up 1 in 5 Medicaid enrollees but [more than half of Medicaid spending](#). This law stalls efforts to help older adults and people with disabilities who are eligible for Medicaid enroll in and keep their coverage. As a result, H.R. 1 rips Medicaid away from millions of older adults and people with disabilities enrolled in Medicare, making Medicare unaffordable, increasing out-of-pocket costs and preventing access to HCBS, transportation to doctor's appointments, as well as dental, vision, and hearing services that Medicare does not provide.

Additionally, people with disabilities, older adults between 50 and 65, family caregivers, and direct care workers will get caught up and lose coverage when more than a quarter of expansion enrollees<sup>1</sup> become uninsured because of the work requirements in H.R. 1. [Many people with disabilities qualify for Medicaid through expansion](#) because the traditional disability pathway is strict, narrow, and excludes many people with disabilities. While exemptions are written into H.R. 1 for people with disabilities, the exemptions are ill-defined, and states will struggle to automatically or easily identify all of these populations. Processes to prove disability or serious or complex medical disorders are often inaccessible. For new Medicaid expansion applicants, H.R. 1 requires applicants to prove upfront that they are working or should be exempt, leaving people with disabilities in a catch-22 where they must see a medical professional to prove disability, but cannot afford to visit a provider without health insurance.

The work requirements provisions will also [disproportionately punish direct care workers](#). For family caregivers, there is no database or way for states to automatically identify family caregivers. When caregivers can't access health care, the people with disabilities and older adults they care for are also harmed. Even for those fully exempt, like people over age 65 and people with disabilities enrolled through non-expansion pathways, work requirements significantly burden the Medicaid system. The number of Medicaid applicants waiting more than a month and a half for their applications to be processed [nearly tripled](#) in the first year of Georgia's Pathways to Coverage.

---

<sup>1</sup> The nonpartisan Congressional Budget Office [estimates](#) at least 5.3 million people will become uninsured because of the work requirements provisions (section. 71119 of H.R. 1). As of Dec. 2024, [20.1 million people are enrolled in Medicaid expansion](#). At least 25% of current expansion enrollees can be expected to lose coverage because the work requirement provisions only apply to Medicaid expansion or the expansion-like waivers in Georgia and Wisconsin.

H.R. 1 terminates Medicare, Medicaid, and premium tax credit eligibility for certain immigrants who are lawfully present. Most of the people who will have their Medicare coverage taken away are older adults who have lived and worked in the U.S. for decades, paying Medicare taxes. Many of them are women of color who have worked as direct care workers for U.S. Citizens.

Even for people who are not enrolled in Medicaid, H.R. 1 will cause irreparable harm. When one of the [330 at-risk hospitals close](#) because of Medicaid cuts, it is not only Medicaid enrollees who lose access to critical care, but the entire community. By significantly increasing the deficit, H.R. 1 triggers Medicare sequestration, imposing [\\$536 billion in Medicare cuts over the next 9 years](#). If Congress does not act and pass the Protecting Healthcare and Lowering Costs Act of 2025 or another extension of the expiring Advanced Premium Tax Credits, premiums will increase significantly for more than 20 million people with low or middle incomes and 4.2 million additional people will become uninsured, further pushing people into medical debt, increasing uncompensated care, and putting additional strain on the entire healthcare system. These massive cuts and harms cannot stand, and Congress must act.

## Conclusion

H.R. 1 will be catastrophic for millions of people across the U.S., and the effects are already being felt. People with disabilities, older adults, their families, and millions of people across the US are already struggling to make ends meet and struggling to pay tens or hundreds of thousands of dollars for care, and implementing H.R. 1 will only make affording and accessing care even more difficult. **We implore Congress to act now to pass the Protecting Healthcare and Lowering Costs Act of 2025 to repeal the entirety of the health provisions in H.R. 1 or similar legislation to repeal the harmful Medicaid cuts and to permanently extend the enhanced APTCs to mitigate the impending cost crisis.** For additional information or any questions, please feel free to contact Tory Cross at [tory@caringacross.org](mailto:tory@caringacross.org).

Sincerely,

## **355 National, State, & Local Organizations**

#MEAction

9to5 GA

AccessAbility

Access Ready Inc.

Accessible Alabama

ACLU - Nebraska

ACLU of Kentucky

ADAPT National

ADAPT OF TX

Advocates for Compassionate Therapy Now

AFT: Education, Healthcare, Public Services

AGE of Central Texas  
Agency on Aging Area 4  
AgeUp, Inc.  
AiArthritis  
Alameda County Advisory Commission on Aging  
Alliance Colorado  
Aloha Independent Living Hawaii  
American Academy of Nursing  
American Association of People with Disabilities  
American Association of University Women (AAUW)  
American Association on Health and Disability  
American Civil Liberties Union  
American Federation of State, County and Municipal Employees (AFSCME)  
American Friends Service Committee  
American Music Therapy Association  
American Muslim Health Professionals (AMHP)  
American Network of Community Options and Resources (ANCOR)  
American Therapeutic Recreation Association  
Arc of Greater Aiken  
Area 12 Agency on Aging  
Area Agency on Aging of Western Arkansas  
Arizona Center for Law in the Public Interest  
Arizona Statewide Independent Living Council  
Arkansas State Independent Living Council  
Ask Nurses and Doctors  
Association of Assistive Technology Act Programs  
Association of Regional Center Agencies  
Association of University Centers on Disabilities  
Association on Aging in New York  
Autism Alliance of Michigan  
Autism Society of America  
Autism Society of Greater Akron  
Autism Society of Greater New Orleans  
Autism Society of Greater Phoenix  
Autism Society of Greater Wisconsin  
Autism Society of Northern Virginia  
Autism Society of Oregon  
Autistic Self Advocacy Network  
Autistic Women & Nonbinary Network

Basri Law LLC  
Bay Area Center for Independent Living, Inc.  
Black Californians United for Early Care and Education  
California Advocates for Nursing Home Reform  
California Association for Adult Day Services  
California Association of Area Agencies on Aging (C4A)  
California Elder Justice Coalition  
California Foundation for Independent Living Centers  
California Health Advocates  
California Long-Term Care Ombudsman Association (CLTCOA)  
California Work & Family Coalition  
Call For Caring Inc  
CalPACE  
Care 4 the Caregivers  
Care in Action  
Caregiver Action Network  
Caring Across Generations  
Center for Advocacy for the Rights and Interests of Elders (CARIE)  
Center for Caregiver Advancement  
Center for Caregiver Serenity  
Center for Elder Law & Justice  
Center for Health Law and Policy Innovation  
Center for People With Disabilities  
Center for Public Representation  
Central Coast Center for Independent Living (CCCIL)  
CFILC  
Charlottesville NOW (National Organization for Women)  
Child Neurology Foundation  
Choice in Aging  
Chrysalis Inc.  
Clearinghouse on Women's Issues  
Coalition for Hemophilia B  
Coalition of Texans with Disabilities  
Coalition on Human Needs  
Colorado Consumer Health Initiative  
Colorado Cross-Disability Coalition  
CommunicationFIRST  
Community Catalyst  
Community Development Network of Maryland

Community Employment Alliance  
Community Resources for Independent Living  
Community Resources for Justice  
Compass Community Center  
Congregation of Our Lady of Charity of the Good Shepherd, U.S. Provinces  
Connecticut State Independent Living Council  
Courage California  
DAWN Center for Independent Living  
Deaf Equality  
Delaware Statewide Independent Living Council  
Designing Accessible Communities  
Detroit Disability Power  
Developmental Services of Dickson County  
Disability Belongs  
Disability Law Center of Utah  
Disability Network Mid-Michigan  
Disability Resource Center of the New River Valley  
Disability Rights Arizona  
Disability Rights Arkansas  
Disability Rights California  
Disability Rights Education and Defense Fund (DREDF)  
Disability Rights Maine  
Disability Rights Ohio  
Disability Rights Oregon  
District of Columbia Autism Society  
Diverse Elders Coalition  
Doctors for America  
DQIA: Disabled Queers in Action!  
Drive a Senior Northwest  
Economic Opportunity Institute  
Economic Security Project Action  
Eden Area Village  
El Buen Samaritano  
Empower Missouri  
Epilepsy Foundation of CT  
Epilepsy Foundation of Georgia  
Epilepsy Foundation of Northern California  
Epilepsy Foundation of Texas  
Equal Rights Advocates

Equality California  
Every Texan  
Families USA  
Family Caregiver Center of New Mexico  
Family to Family Network  
Family Values @ Work  
Family Voices NJ  
Fayette Fair Share PAC WV  
Feminist Majority  
FIRSTwnc  
Florida Alliance for Retired Americans  
Florida Voices for Health  
FLYY  
Gem State Developmental Center  
Generations United  
Georgia ADAPT  
Georgia Values Action  
Gerontological Society of America  
GO2 for Lung Cancer  
Goddard Riverside  
Good Work Austin  
Grantmakers in Aging  
Gulf Coast ADAPT  
Hand in Hand: The Domestic Employers Network  
HASL Center for Independent Living  
Health Alliance for Austin Musicians  
Health Care for All - Washington  
Heathcare is a Human Right WA  
Homeless Action Center  
HOPE North Carolina  
Huntington's Disease Society of America  
ICMRS-Inter-County Medical Reimbursement Specialists  
Idaho Families of Adults with DisAbilities, Inc.  
Illinois Accountability Initiative  
Illinois Network of Centers for Independent Living  
Illinois Valley Center for Independent Living  
Illinois-Iowa Center for Independent Living  
Independent Living Resource Center SF  
Indivisible Fairfield County



Indivisible Marin  
Indivisible Upper Cape  
Inspire Positivity Inc  
Institute for Policy Studies' Poverty Project  
Inter Agency Council of Developmental Disabilities Agencies, Inc.  
International Registry of Rehab Technology Suppliers  
Islamic Civic Engagement Project  
J Badger Consulting Inc  
Just Solutions  
Justice in Aging  
Kaleidoscope, Inc.  
Kentucky Protection and Advocacy  
Kids Above All  
Laguna Adult Day Health Center  
Lakeshore Foundation  
Lane Independent Living Alliance (LILA)  
Latino Texas Policy Center  
LEAC  
LeadingAge California  
League of United Latin American Citizens (LULAC)  
Legal Assistance for Seniors  
Linking Employment, Abilities & Potential  
Little Lobbyists  
LiveOn NY  
Living Independence Network Corporation  
Long Island Center for Independent Living, Inc. (LICIL)  
Louisiana Democratic Party Disability Caucus  
Louisiana Statewide Independent Living Council  
Marin Center for Independent Living  
Maryland Citizens' Health Initiative  
Maryland Inclusive Housing  
Maryland Statewide Independent Living Council  
Max Higbee Center  
Medicaid Matters New York  
Medicare Rights Center  
Melwood, Inc.  
Mental Health Research  
Mephibosheth LLC  
Michigan Alliance for Special Education

Michigan Developmental Disabilities Institute  
Michigan Statewide Independent Living Council  
Mid South Liver Alliance  
Mixed Greens Savannah  
MO Statewide Independent Living Council  
MomsRising  
Muscular Dystrophy Association  
NAMI Northwoods  
National Adult Day Services Association (NADSA)  
National Advocacy Center of the Sisters of the Good Shepherd  
National Alliance for Direct Support Professionals, Inc.  
National Alliance on Mental Illness  
National Alliance to End Homelessness  
National Association of Councils on Developmental Disabilities  
National Association of Pediatric Nurse Practitioners  
National Association of Social Workers (NASW)  
National Association of Statewide Independent Living Councils - NASILC  
National Center for Pediatric Palliative Care Homes  
National Coalition for the Homeless  
National Consumer Voice for Quality Long-Term Care  
National Council of Jewish Women  
National Council on Independent Living  
National Disability Institute  
National Disability Rights Network (NDRN)  
National Domestic Workers Alliance  
National Down Syndrome Congress  
National Health Law Program  
National Hispanic Medical Association (NHMA)  
National Low Income Housing Coalition  
National Mental Health Consumers' Self-Help Clearinghouse  
National Partnership for Women & Families  
National Respite Coalition  
National Women's Law Center  
Nebraska Association of Service Providers  
NETWORK Lobby for Catholic Social Justice  
Network of Jewish Human Service Agencies  
New Disabled South  
New Jersey Citizen Action  
New Mexico Center on Law and Poverty

North Carolina Council of Churches  
North Dakota Protection & Advocacy Project  
Northwest Health Law Advocates  
Open Doors for the Developmentally Challenged, Inc.  
Opulent Mobility  
Oregon Statewide Independent Living Council  
Our Home, ICC  
Our Mother's Voice  
Parent Network of WNY  
Parent/Professional Advocacy League, Inc.  
Parents Reaching Out  
PathPoint  
Pennsylvania Health Law Project  
People Power United  
People's Action Institute  
Person Centered Care Services  
Personal Assistance Services Council  
Personal Attendant Coalition of TX  
PHI  
Placer Independent Resource Services  
Placer Independent Resource Services  
Progressive Democrats of America  
Progressive Democrats of America WV Chapter  
Protect Our Care  
Public Advocacy for Kids ( PAK)  
Public Justice Center  
Pushing Limits Radio  
Reach for Resources  
Reframe Health and Justice  
Resource Center for Disability Solutions  
Resource Center for Independent Living  
REV UP Texas  
RISE Child Development Center, Inc.  
Rural Advocates for Independent Living, Inc.  
San Francisco Senior and Disability Action  
Self-Advocates of Michigan  
Senior Services Coalition of Alameda County  
Service Center for Independent Life  
Service Employees International Union

Serving at-risk families everywhere, Inc.  
Show and Tell  
Silver State Equality  
SIMS Foundation  
SIX Action  
SKIL Resource Center  
Sourcewise  
Southeast Michigan Senior Regional Collaborative  
Southern Tier Independence Center  
Spa Area Independent Living Services  
SPAN Parent Advocacy Network  
Special Education Advocacy Services of Luzerne, LLC  
SPOKES Unlimited  
Statewide Independent Living Council of Tennessee - SILCTN  
Supporting Autism and Families Everywhere, Inc  
Supporting Illinois Brothers and Sisters  
TDIforAccess  
Tennessee Caregiver Coalition  
Tennessee Health Care Campaign  
Tennessee Justice Center  
Texas Health Action  
Texas Impact  
Texas Parent to Parent  
The Advocacy Institute  
The AIDS Institute  
The Alaska Christian Conference  
The Arc Fond du Lac, Inc.  
The Arc New York  
The Arc of Arizona  
The Arc of Aurora  
The Arc of Bay County  
The Arc of California  
The Arc of Illinois  
The Arc of Macomb County, Inc.  
The Arc of New Jersey  
The Arc of South Carolina  
The Arc of the United States  
The Arc of Whatcom County  
The Arc Prince George's County

The Arc Tennessee  
The Arc Wisconsin  
The Carefullist  
The Freedom Center  
The Independence Center  
The Kelsey  
The Mediation Offices of Eric A. Deutsch  
The Pride Center at Equality Park  
The Self-Direction Center  
The Statewide Independent Living Council of Illinois  
Timber River Connections  
UDW/AFSCME Local 3930  
Union for Reform Judaism  
Unitarian Universalist Justice Ministry of North Carolina  
University District Food Bank  
Village to Village Network  
Virginia Board for People with Disabilities  
Voices of Health Care Action  
VOR - A Voice Of Reason  
Well Spouse Association  
West Pinellas National Organization for Women  
West Virginians for Affordable Health Care  
Western Reserve Independent Living Center  
Will County NOW  
Will-Grundy CIL dba Disability Resource Center  
William E. Morris Institute for Justice  
Wilson Clinical Services, PLLC.  
Wisconsin Alliance for Excellent Schools  
Wisconsin Family Ties, Inc.  
Wise  
Wyoming SILC  
Young Invincibles