

The Disability and Aging Collaborative &



January 22, 2025

The Honorable Brett Guthrie
Chairman
Energy & Commerce Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
Energy & Commerce Committee
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Guthrie, Ranking Member Pallone, and Members of the Energy & Commerce Committee:

The undersigned members of the Disability and Aging Collaborative (DAC), the Health and Long-Term Services and Supports Task Forces of the Consortium for Constituents with Disabilities (CCD), and allied organizations write to **urge you to exclude Medicaid cuts, work requirements, or any changes that limit funding or eligibility, from budget reconciliation or other legislation.** People with disabilities, older adults, family caregivers and their children, direct care workers, and other low-income individuals and families depend on Medicaid every day for their health, safety, and independence. Medicaid enables our communities to go to work and to care for their loved ones. It is our communities' lifeline, and we cannot afford for any part of it to be cut.

We are deeply concerned about recent statements from some Congressional leadership supporting proposals that would deeply cut Medicaid funding. Medicaid is already lean and efficient. Funding cuts, caps, or changes that limit eligibility for or make it harder to enroll in or maintain coverage threaten the longstanding Medicaid guarantee for people with disabilities, older adults and their families. Medicaid is critical not only as primary coverage for health care, it is also the primary payer for long-term services and supports (LTSS) that support people with disabilities and older adults. Furthermore, cuts to Medicaid are cuts to Medicare, as Medicaid protects low-income people with Medicare from deep poverty by helping with their out-of-pocket costs and covering benefits that Medicare does not, including dental, vision, hearing and non-emergency medical transportation.

For many people with disabilities and older adults, accessing timely needed care is a life or death matter and Medicaid is the only program that can meet their needs. We strongly oppose Medicaid cuts in any form, whether it is done by imposing work requirements, repealing the eligibility and enrollment rule, imposing spending caps on states, cutting the federal medical assistance

percentage (FMAP), or further limiting the way states fund their share of Medicaid costs. These proposals all lead to the same result: people with disabilities and older adults will lose care and support that keep them healthy and independent.

Cutting Medicaid by Making It Harder to Enroll and Keep Coverage

Work Requirements

Work requirements take away coverage from people who are eligible for Medicaid and have no other insurance options, including people with disabilities, older adults, their caregivers, and direct care workers. Such requirements do not increase employment but instead create costly red tape that puts people with disabilities at particular risk of losing coverage¹ and wastes millions of dollars² that could be used to provide additional Medicaid services or other employment supports such as affordable child care and aging and disability care.

Most working age adults enrolled in Medicaid already work. Many of those not doing paid work are either caregivers or persons with chronic conditions or disabilities (who might either be temporarily unable to work or require supportive services to find and keep a job). Furthermore, Medicaid helps people with disabilities work, by providing them with health care and other important employment supports, such as rehabilitative and habilitative services. People with disabilities, older adults, and their caregivers cannot be effectively “carved out” of work requirements, and will be inevitably harmed. Exemption processes are complicated, expensive, and fundamentally flawed.³ Identifying exactly what qualifies as a disability, ensuring that people know how to request an exemption, and creating an accessible pathway to receive such an exemption has proven both misguided and unworkable.

These overwrought bureaucratic hoops also waste millions that could have gone to cover health care services or dependent care that actually helps people work. Even worse, as Georgia’s experience demonstrates, work requirements add costly bureaucratic burdens for *all* Medicaid enrollees. Not only does this red tape prevent thousands of people with disabilities and caregivers from using Medicaid, it also slows down application processing across the program, as well as enrollment in other key anti-poverty programs, like SNAP, that older adults and people with disabilities rely on.⁴

Ending Policies that Streamline Eligibility and Enrollment

Newly enacted policies are removing bureaucratic hurdles that are costly for states to administer and make it difficult for older adults and people with disabilities who are eligible for Medicaid to

¹David Machledt, NHeLP, “Unfit” to Work? How Medicaid Work Requirements Hurt People with Disabilities (Dec. 2024), <https://healthlaw.org/resource/unfit-to-work-how-medicaid-work-requirements-hurt-people-with-disabilities-2/>.

²Andy Miller & Renuka Rayasam, KFF Health News, “Georgia’s Medicaid Work Requirements Costing Taxpayers Millions Despite Low Enrollment” (March 20, 2024), <https://kffhealthnews.org/news/article/georgia-medicaid-work-requirements-experiment-high-cost-low-enrollment/>

³*Id.*; Kali Grant et al., *Unworkable & Unwise: Conditioning Access to Programs that Ensure a Basic Foundation for Families on Work Requirements*, 43 (2019), <https://www.georgetownpoverty.org/wp-content/uploads/2019/02/Unworkable-Unwise-20190201.pdf>.

⁴KFF Health News, Georgia’s Work Requirement Slows Processing of Applications for Medicaid, Food Stamps (Dec. 5, 2024), <https://kffhealthnews.org/news/article/georgia-work-requirement-medicaid-food-stamps/>.

get and keep coverage. For example, repealing the Streamlining Eligibility and Enrollment Rule would allow states to cut people with disabilities and older adults off Medicaid by requiring more frequent eligibility determinations and eliminating protections for continuous coverage. It would also make it harder to access HCBS for people who have to deduct their out-of-pocket expenses to qualify, leading to worse health outcomes and costlier care in the future. Taking away people's health care through red tape is never acceptable and we oppose repeal of the Streamlining rule or any other measures that protect access to Medicaid.

Cutting Medicaid Funding Will Harm People with Disabilities and Older Adults

Per Capita Caps or Block Grants

Limiting federal Medicaid spending through per capita caps or block grants would shift costs to states, creating huge holes in state budgets. This would likely force states to reduce or eliminate coverage and services for people with the highest cost needs: older adults and people with disabilities who need long-term services and supports. Medicaid enrollees who rely on LTSS comprise only 6% of Medicaid enrollees, but use 37% of Medicaid expenditures.⁵ The result would be devastating cuts to the programs low-income older adults and people with disabilities rely on.

- **Cuts to home and community-based services (HCBS).** States are likely to cut HCBS first when facing reduced budgets because Medicaid law does not require most HCBS to be covered. States could eliminate HCBS programs altogether or reduce waiver slots, meaning more people on waitlists for longer periods of time. These cuts put over 7 million people with disabilities and older adults at risk of not getting the support they need to live in the community and will harm their health. Cuts to HCBS also harm families who have to reduce hours or leave their jobs to care for loved ones.
- **Harm to nursing facility residents.** Two-thirds of people living in nursing facilities rely on Medicaid. If federal funding is cut, access to and quality of nursing facility care would be jeopardized. Many older adults with long-term care needs would be left with limited—and, in some cases, no other comparable options—as states will be unable to fill the funding gap and nursing facilities will close.
- **Worsening workforce shortages.** States will also have to cut provider rates to make up for funding losses. This will greatly exacerbate the direct care workforce shortage, making it even harder to access HCBS and putting nursing facility residents at risk of harm from insufficient staffing.
- **Taking away coverage.** States could respond to funding cuts by tightening eligibility criteria and setting enrollment caps on additional programs. These cuts would harm older adults and people with disabilities who rely on Medicaid for their own health and long-term care, as well as their families, friends, and caregivers—both paid and unpaid.

Future Medicaid cuts would be far easier to make, by simply dialing down or freezing federal spending growth rates from year to year, if the federal financing structure is capped.

⁵ Priya Chidambaram and Alice Burns, KFF, *How Many People Use Medicaid Long-Term Services and Supports and How Much Does Medicaid Spend on Those People?* (Aug. 14, 2023), <https://www.kff.org/medicaid/issue-brief/how-many-people-use-medicaid-long-term-services-and-supports-and-how-much-does-medicaid-spend-on-those-people/>.

Cutting the Federal Medical Assistance Percentage (FMAP)

Whether eliminating the enhanced FMAP for Medicaid Expansion or removing the federal minimum match of 50% for all states, the result of cutting the federal government's share of Medicaid costs and shifting the burden to states would be devastating for people with disabilities and older adults. As with caps and block grants, states would have less money in their budgets and be forced to cut HCBS, tighten eligibility, and reduce provider payments. Furthermore, several states would automatically end their Medicaid Expansion⁶, taking away coverage from millions of people with disabilities and chronic conditions, older adults, and paid and unpaid caregivers who do not qualify for other Medicaid categories and have no other source of health insurance.

Restricting How States Fund Their Share of Medicaid Costs

States use a variety of revenues to maximize their ability to meet the Medicaid needs of their state. Every state uses provider and insurer taxes -- they are and have been integral to Medicaid funding for decades. Further restricting allowable provider taxes or other revenue sources would create huge budget deficits for states. As with any Medicaid funding cut, the only way states can respond is by taking away coverage and services. HCBS and other services that people with disabilities and older adults rely on will be the first on the chopping block.

Conclusion

Access to Medicaid is a matter of life, death, and independence for millions of Americans with disabilities, older adults, and their families and friends. **We strongly oppose per capita caps, block grants, work requirements, restrictions on eligibility, barriers to enrollment and any other cuts or harmful changes to the Medicaid program.** 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 will oppose cuts in every form because they will all harm people with disabilities and older adults. If you have any questions, contact Nicole Jorwic, nicole@caringacross.org; Natalie Kean, nkean@justiceinaging.org; Jennifer Lav, lav@healthlaw.org; and Elise Aguilar, eaguilar@ancor.org.

Sincerely,

107 National Organizations:

ACA Consumer Advocacy

Access Ready Inc.

ACLU

ADA Watch/Coalition for Disability Rights & Justice (CDRJ)

ADAPT National

AFT: Education, Healthcare, Public Services

Allies for Independence

American Association of People with Disabilities

American Association on Health and Disability

⁶Adam Searing, Georgetown CCF, *Federal Funding Cuts to Medicaid May Trigger Automatic Loss of Health Coverage for Millions of Residents of Certain States* (Nov. 27, 2024). <https://ccf.georgetown.edu/2024/11/27/federal-funding-cuts-to-medicare-may-trigger-automatic-loss-of-health-coverage-for-millions-of-residents-of-certain-states/#71ded725-43af-4bad-9cc0-f88522f80725>

American Federation of State, County and Municipal Employees (AFSCME)
American Foundation for the Blind
American Geriatrics Society
American Music Therapy Association
American Network of Community Options and Resources
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Amputee Coalition
Asian & Pacific Islander American Health Forum
Assistive Technology Law Center
Association of University Centers on Disabilities
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Care in Action
Caring Across Generations
Center for Health Law and Policy Innovation
Center for Law and Social Policy (CLASP)
Center for Medicare Advocacy
Center for Public Representation
Christopher & Dana Reeve Foundation
Coalition on Human Needs
CommunicationFIRST
Community Catalyst
Community Change Action
CSH
Disability Belongs
Disability Rights Education and Defense Fund (DREDF)
Diverse Elders Coalition
Doctors for America
DQIA Disabled Queers In Action
Epilepsy Foundation of America
Families USA
Family Caregiver Alliance, National Center on Caregiving
Family Values @ Work
Family Values@Work Action
Gerontological Society of America
GO2 for Lung Cancer
Hand in Hand: The Domestic Employers Network
Health Care for America Now (HCAN)
Huntington's Disease Society of America
IEC (Institute for Exceptional Care)
Justice in Aging

Lakeshore Foundation
LeadingAge
League of United Latin American Citizens
Legal Action Center
Little Lobbyists
Lutheran Services in America
MEAction
Meals on Wheels America
Medicare Rights Center
MomsRising
Muscular Dystrophy Association
NASTAD
National Advocacy Center of the Sisters of the Good Shepherd
National Alliance for Caregiving
National Association of Councils on Developmental Disabilities
National Association of Nutrition and Aging Services Programs (NANASP)
National Association of Social Workers (NASW)
National Association of State Long-Term Care Ombudsman Programs
National Center for Disability, Equity, and Intersectionality
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Consumer Voice for Quality Long-Term Care
National Council of Jewish Women
National Council on Aging
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 Partnership for Women & Families
National Resource Center on Domestic Violence
National Women's Law Center
NETWORK Lobby for Catholic Social Justice
Network of Occupational Therapy Practitioners with Disabilities and Supporters (NOTPD)
OT Leaders and Legacies Society
PHI
Service Employees International Union
Southeast Asia Resource Action Center (SEARAC)
Supermajority
The Arc of the United States
The Kelsey
Touch the Future Inc
Tourette Association of America
Triage Cancer

UnidosUS
Union for Reform Judaism
United Spinal Association
Upturn
USAgging
VOR - A Voice Of Reason
Well Spouse Association
Wilson Clinical Services, PLLC.
World Institute on Disability
Young Center for Immigrant Children's Rights

230+ State and Local Organizations:

Alabama

Alabama Disability Advocacy Program (ADAP)

Arizona

Ability360
Arizona Developmental Disabilities Planning Council
Care 4 the Caregivers
Disability Rights Arizona
Raising Special Kids
The Arc of Arizona
The Arc of Tempe
The Opportunity Tree
William E. Morris Institute for Justice

Arkansas

Spa Area Independent Living Services

California

AJL Community Health
Alzheimer's Los Angeles
Archstone Foundation
California Advocates for Nursing Home Reform
California Alliance for Retired Americans
California Association for Adult Day Services
California Coverage & Health Initiatives
California Elder Justice Coalition
California Foundation for Independent Living Centers
California Health Advocates
California Long-Term Care Ombudsman Association (CLTCOA)
California PACE Association
Center For Independence of Individuals with Disabilities
Choice in Aging
Courage California
CRLA Foundation
Disability Rights California

East Bay Sanctuary Covenant
Equality California
Family Caregiver Alliance, National Center on Caregiving
Family Voices of California
FREED Center for Independent Living
Gray Panthers of San Francisco
Helping Hands ADP
Indivisible Marin
LeadingAge California
Legal Assistance for Seniors
Marin Center for Independent Living
Meals on Wheels California
Northeast Valley Health Corporation
Placer Independent Resource Services
San Diegans for Healthcare Coverage
Senior and Disability Action
Senior Coastsiders
Sonrisas Dental Health
Stanford Settlement, Inc.
Support for Families of Children with Disabilities
The Children's Partnership
The Public Interest Law Project
UDW/AFSCME Local 3930
We Are Not Invisible
Western Center on Law and Poverty

Colorado

Center for People with Disabilities
Colorado Center on Law and Policy
Colorado Consumer Health Initiative
Colorado Developmental Disabilities Council
El Grupo Vida, Inc.
Family Voices Colorado
PEAK Parent Center
Show and Tell
The Independence Center

Connecticut

Disability Rights Connecticut
PATH CT

District of Columbia

Bread for the City

Delaware

LeadingAge New Jersey & Delaware

Florida

Florida Health Justice Project

Georgia

9to5 GA

Georgia ADAPT

Georgia Values Action

Indivisible Georgia Coalition

Inspire Positivity Inc

New Georgia Project Action Fund

Walton Options for Independent Living

Idaho

Disability Rights Idaho

Idaho Anti-trafficking Coalition

Idaho Council on Developmental Disabilities

Idaho State Independent Living Council

Illinois

Access Living

Disability Resource Center

EHDQC-J Michael Fitzgerald LP Apartments

Going Home Coalition - The Arc of Illinois

Great Lakes ADA Center

Health Justice Project

Illinois Council on Developmental Disabilities

IMPACT CIL

Legal Council for Health Justice

The Arc of Illinois

The Statewide Independent Living Council of Illinois

Trellus

Indiana

Center for At Risk Elders

Future Choices Inc

Great Lakes ADA Center

Iowa

Disability Rights Iowa

Iowa Developmental Disabilities Council

Kansas

Families Together Inc./Family to Family Health Information Center

Keys for Networking

SKIL

Kentucky

Kentucky Equal Justice Center

Kentucky Protection and Advocacy

Louisiana

Bayou Land Families Helping Families
Families Helping Families of Acadiana

Maine

Disability Rights Maine
Maine Council on Aging
Maine Developmental Disabilities Council
Maine Equal Justice
Maine Parent Federation

Maryland

Accessible Resources for Independence, Inc.
Maryland Developmental Disabilities Council
Public Justice Center
The Arc Maryland
The Freedom Center
The Parents' Place of MD
Voices of Hope - Maryland

Massachusetts

Boston Center for Independent Living
Community Servings
Disability Law Center (MA)
Disability Policy Consortium
Federation for Children with Special Needs
Health Care For All (HCFA)
Health Law Advocates
Independence Associates
Massachusetts Law Reform Institute
MassADAPT
MetroWest Center for Independent Living

Michigan

Center for Civil Justice
Detroit Disability Power
Disability Rights Michigan
Great Lakes ADA Center
Michigan Developmental Disabilities Institute
Michigan United
The Arc Grosse Pointe Harper Woods
The Arc Michigan
The Arc of Macomb County, Inc.

Minnesota

Children's Minnesota
Governor's Council on Developmental Disabilities
Great Lakes ADA Center
Lifeworks Services, Inc.

North Star Policy Consulting
Reach for Resources
Upstream Arts, Inc.

Mississippi

Mississippi Center for Justice

Missouri

Empower Missouri
Heartland Independent Living Center
Independent Living Center of Southeast Missouri
Independent Living Resource Center (ILRC)
Missouri Developmental Disabilities Council
NorthEast Independent Living Services
On My Own, Inc.
Paraquad
Rural Advocates for Independent Living, Inc.
Southwest Center for Independent Living dba empower: abilities

Montana

ADAPT Montana

Nebraska

Ollie Webb Center, Inc.

Nevada

Silver State Equality

New Hampshire

NH Legal Assistance

New Jersey

Association for Special Children and Families
Disability Rights New Jersey
Family Voices NJ
LeadingAge New Jersey & Delaware
New Jersey Council on Developmental Disabilities
SPAN Parent Advocacy Network
The Arc of New Jersey

New Mexico

Centro Savila
New Mexico Center on Law and Poverty
Parents Reaching Out

New York

Center for Elder Law & Justice
Coalition for Asian American Children and Families
Families On The Move of NYC, Inc.
Independent Living Center of the Hudson Valley, Inc.
New York Legal Assistance Group (NYLAG)
The Mediation Offices of Eric A. Deutsch

North Carolina

Charlotte Center for Legal Advocacy
Disability Rights North Carolina
NC Statewide Independent Living Council
North Carolina Justice Center
Pisgah Legal Services

North Dakota

North Dakota DD Council
North Dakota Protection & Advocacy Project

Ohio

Great Lakes ADA Center
Linking Employment, Abilities & Potential (LEAP)
Mid Ohio Board for an Independent Living Environment
Ohio Olmstead Task Force
Ohio Statewide Independent Living Council
The Ability Center of Greater Toledo

Oregon

FACT Oregon
Unite Oregon

Pennsylvania

Center for Advocacy for the Rights and Interests of Elders (CARIE)
Community Legal Services of Philadelphia
Disability Pride Pennsylvania
Disability Rights Pennsylvania
Parent Education and Advocacy Leadership (PEAL) Center
Pennsylvania Health Law Project
Transitional Paths to Independent Living
Voices for Independence

Rhode Island

Protect Our Healthcare Coalition RI
RIPIN

South Carolina

Able South Carolina, Inc.
Brain Injury Association of South Carolina
Disability Rights South Carolina
Family Connection of South Carolina
NAACP South Carolina State Conference of Branches
NAMI South Carolina
South Carolina Appleseed Legal Justice Center
South Carolinians for Alternatives to the Death Penalty (SCADP)
Walton Options for Independent Living

South Dakota

Disability Rights South Dakota
South Dakota Council on Developmental Disabilities

Tennessee

Disability Rights Tennessee
Family Voices of Tennessee
Tennessee Disability Coalition
Tennessee Justice Center

Texas

ADAPT of Texas
Coalition of Texans with Disabilities
Disability Rights Texas
Every Body Texas
Every Texan
Latino Texas Policy Center
Personal Attendant Coalition of Texas
REV UP Texas
Texans Care for Children
Texas Parent to Parent
Woori Juntos

Utah

Disability Law Center of Utah
Utah Developmental Disabilities Council
Utah Statewide Independent Living Council

Vermont

Vermont Center for Independent Living

Virginia

Legal Aid Justice Center
Virginia Board for People with Disabilities

Washington

Center For Independence
PAVE

West Virginia

West Virginia Citizen Action Group
West Virginia Developmental Disabilities Council
WV FREE (WV Focus: Reproductive Education and Equity)

Wisconsin

Access to Independence
Disability Rights Wisconsin
Employment Resources Inc
Great Lakes ADA Center
People First Wisconsin
Wisconsin Board for People with Developmental Disabilities