



The Honorable John Thune
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Charles Schumer
Democratic Leader
United States Senator
Washington, DC 20510

June 4, 2025

Dear Majority Leader Thune and Democratic Leader Schumer:

On behalf of the Down syndrome community we represent, we are writing to express our concerns regarding provisions in the recently passed House Reconciliation Bill that will have unintended negative consequences for people with Down syndrome and those who care for them. While we agree that the Medicaid system must become more efficient and sustainable, we are concerned that the proposals in this bill could disproportionately harm people with Down syndrome, their families, and the caregivers who support them by threatening their health, independence, and well-being.

For more details and evidence supporting these concerns, please see the attached policy brief drafted by the National Down Syndrome Congress, *Medicaid at Risk: What the Reconciliation Bill Means for People with Down Syndrome.*

People with Down Syndrome Rely on Medicaid to Live in Their Communities

Medicaid is a lifeline for most adults with Down syndrome. It is not only their primary health insurer, covering essential medical services, but it also funds Home and Community-Based Services (HCBS)—the “waiver” services and supports that allow people with Down syndrome to live, work, and thrive in their communities. These services are already hard to access due to long waitlists and chronic underfunding. Any reduction in Medicaid’s federal funding will hit HCBS programs first—because they are considered “optional” under federal law, unlike institutional care. If federal Medicaid funding drops in any capacity, states are forced to cut back on these community-based supports, increase waitlists, and lower payments to providers who are already struggling to stay afloat. As a result, more people with Down syndrome risk being institutionalized, hospitalized unnecessarily, or left without essential supports.

People with Down Syndrome Will Still Be Hurt by Work Requirements Even with an Intended Exemption

We understand that proposals like Medicaid work requirements (community engagement) rules are intended to promote accountability and encourage employment. However, even with exemptions for individuals with

disabilities, these policies could be difficult for beneficiaries and states to navigate and could result in eligible individuals, including those with Down syndrome, losing coverage due to paperwork errors, bureaucratic delays, or lack of documentation.

These rules have repeatedly shown to fail in achieving their intended goal of boosting employment. Instead, they create administrative barriers that strip coverage from eligible individuals, particularly those with disabilities. We know from the Arkansas and Georgia experiments that work requirements led to massive coverage losses, longer delays in Medicaid processing, and higher program costs, all with no increase in employment. Not only will these losses impact people with Down syndrome; they will also impact their informal and paid caregivers.

While the bill includes exemptions for people with disabilities, the process of proving one's eligibility for those exemptions is complex, error-prone, and time-consuming. People with Down syndrome may be wrongly disenrolled due to paperwork errors, missed deadlines, or online systems they cannot access. Others—especially those who have not yet been formally deemed “disabled” by Social Security—will fall through the cracks. These consequences are not hypothetical. We've already seen them play out in states that tried to implement similar policies.

Other Harmful Provisions: Provider Taxes and Retroactive Coverage Cuts

The bill's provisions, including restrictions on provider taxes, threaten states' ability to fund Medicaid and may force cuts to essential services like HCBS. Reducing retroactive coverage from 90 to 30 days is especially harmful for newborns with Down syndrome, whose families often face urgent medical needs before learning about available benefits. This shortened window could lead to medical debt, delayed care, and added hardship during a critical time for families who have babies with Down syndrome.

Medicaid Reform Must Protect, Not Harm, People with Down Syndrome and Other Disabilities

We support efforts to improve the Medicaid program. We know it can and should work better for everyone. Imposing work requirements and restricting state flexibility will not solve Medicaid's challenges but will make it harder for people with disabilities to access the varied services that allow them to live in their communities.

We urge the Senate to reject these harmful provisions and to ensure that any Medicaid reform effort remains focused on the needs of those individuals the program was designed to protect. The Down syndrome community stands ready to work with Congress to ensure that any policy changes to Medicaid protect the well-being of people with Down syndrome and other disabilities

Sincerely,

National Down Syndrome Organizations (in alphabetical order)

American Academy of Developmental Medicine and Dentistry

Amy Van Bergen Consulting

Black Down Syndrome Association

Down Syndrome Medical Interest Group-USA

Everything But Typical
GiGi's Playhouse Down Syndrome Achievement Centers
Global Down Syndrome Foundation
LuMind IDSC Down Syndrome Foundation
National Association for Down Syndrome
National Down Syndrome Congress
National Down Syndrome Society
National Task Group on Intellectual Disabilities and Dementia Practices

State Down Syndrome Organizations

ALABAMA
Down Syndrome Alabama

ARIZONA
The Arc of Arizona, Inc.
The Arc of Tucson

ARKANSAS
Arkansas Down Syndrome Association
Down Syndrome Advancement Coalition
Down Syndrome Connection NW Arkansas
Gigi's Playhouse Arkansas

CALIFORNIA
California Down Syndrome Advocacy Coalition
Club 21 Learning and Resource Center
Down Syndrome Association of Los Angeles
Down Syndrome Association of San Diego
Down Syndrome Connection of the Bay Area
Down Syndrome Foundation of Orange County
Inland Valley Down Syndrome Association
Kern Down Syndrome Organization

COLORADO
Rocky Mountain Down Syndrome Association

CONNECTICUT
Down Syndrome Association of Connecticut

DELAWARE
321 Foundation
Down Syndrome Association of Delaware

FLORIDA

CCMG

Down Syndrome Association of Central Florida

GEORGIA

Down Syndrome Association of Atlanta

Down Syndrome Association of Greater Columbus

ILLINOIS

Down Syndrome Association of Greater St. Louis

Supporting Illinois Brothers and Sisters

United Parent Support for Down Syndrome

INDIANA

Down Syndrome Association of Northeast Indiana

Down Syndrome Indiana

IOWA

Northwest Iowa Down Syndrome Society

KANSAS

Kansas City Warrior Moms of Down Syndrome

Targeted Case Management of Kansas, LLC

KENTUCKY

Down Syndrome of Louisville

Down Syndrome Association of Central Kentucky

LOUISIANA

Down Syndrome Association of Greater New Orleans

Jefferson Parish Developmental Disabilities Regional Advisory Committee

Louisiana Statewide Independent Living Council

MAINE

Down Syndrome Advocacy Project of Maine

MARYLAND

Down Syndrome Association of Maryland

Down Syndrome Association of Southern Maryland

Down Syndrome Network of Montgomery County

F.R.I.E.N.D.S.

Isaac's aNORable Homes, LLC

Maryland Down Syndrome Advocacy Coalition

Parents of Children with Down Syndrome of Prince George's County

The Luckiest Light Corp.

MASSACHUSETTS

Massachusetts Down Syndrome Congress

MINNESOTA

Down Syndrome Association of Minnesota

MISSISSIPPI

Mississippi Coalition for Citizens with Disabilities

Mississippi Down Syndrome Advocacy Coalition

Pine Belt Down Syndrome Outreach

MISSOURI

Down Syndrome Association of Greater St. Louis

NEBRASKA

Down Syndrome Alliance of the Midlands

NEVADA

Down Syndrome Connections Nevada

Down Syndrome Organization of Southern Nevada

NEW JERSEY

Down Syndrome Association of Southern New Jersey

NEW MEXICO

Rio Grande Down Syndrome Network

NEW YORK

Down Syndrome Advocacy Group

The Down Syndrome Parents Group of Western New York

NORTH CAROLINA

North Carolina Down Syndrome Alliance

NORTH DAKOTA

Designer Genes of North Dakota

OHIO

Developmental Disabilities Practice-Based Research Network

Down Syndrome Association of Greater Cincinnati

Down Syndrome Association of Northeast Ohio

OKLAHOMA

Down Syndrome Association of Tulsa

PENNSYLVANIA

Chester County Down Syndrome Interest Group, Inc.
Down Syndrome Association of Pittsburgh
Pennsylvania Down Syndrome Advocacy Coalition (PDSAC)

RHODE ISLAND

Down Syndrome Society of Rhode Island

SOUTH CAROLINA

Grand Strand Down Syndrome Society

TENNESSEE

Down Syndrome Association of Middle Tennessee

TEXAS

DFW Down Syndrome Families
Down Syndrome Association of Central Texas
Down Syndrome Association of Houston
Down Syndrome Guild of Dallas
My Possibilities
Rio Grande Down Syndrome Association

VIRGINIA

Virginia Down Syndrome Association

WEST VIRGINIA

Down Syndrome Network of West Virginia