NATIONAL
DOWN SYNDROME
CONGRESS

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

NATIONAL DOWN SYNDROME CONGRESS

# Medicaid at Risk: What the Reconciliation Bill Means for People with Down Syndrome

By: Heather Sachs, NDSC Policy & Advocacy Co-Director

The National Down Syndrome Congress (NDSC) is extremely concerned that the budget reconciliation bill ("Reconciliation Bill") recently passed by the U.S. House of Representatives[1] will have unintended negative consequences for people with Down syndrome and their family caregivers, as well as the direct support professionals (DSPs) who provide vital services for people with Down syndrome to live, work, and thrive in the community.

Medicaid is a vital lifeline and serves as the primary health insurance for most adults with Down syndrome.[2] It provides coverage for essential medical services like doctors' visits, hospital stays, and prescriptions. Additionally, it provides funding to schools for many of the services that students with disabilities receive such as speech and occupational therapy, behavioral supports, and more.[3] A combination of state and federal dollars fund Home and Community-Based Services (HCBS) Medicaid waivers for people with Down syndrome and other disabilities. These waivers provide services like job coaching, personal care supports, assistive technology, home health care, and more so that people with Down syndrome can live, work, and thrive in their communities.

NDSC fully recognizes that the current Medicaid system needs to be improved to work better for all stakeholders, including people with Down syndrome and their families. However, the methods included in the Reconciliation Bill will only serve to add more bureaucratic red tape and further destabilize the Medicaid system. Regardless of any good intentions to protect people with Down syndrome from potential harm, the fact is that people with Down syndrome will be hurt in many ways by this legislative proposal.

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[1] https://rules.house.gov/sites/evo-subsites/rules.house.gov/files/documents/rcp_119-3_final.pdf

[2] https://pmc.ncbi.nlm.nih.gov/articles/PMC10422190/

[3] https://www.ed.gov/sites/ed/files/about/offices/list/osers/docs/medicaid-funding-for-school-based-services-03-08-2024.pdf

## MEDICAID HOME AND COMMUNITY-BASED (HCBS) WAIVER SERVICES

The Reconciliation Bill contains many different vehicles to cut the federal share of Medicaid funding.[4] Regardless of which method(s) are adopted, people with Down syndrome and other disabilities will be at risk of losing home and community-based services (HCBS) if there are *any* cuts or changes in the federal share of funding to Medicaid.

Medicaid is so much more than health care. Medicaid Home and Community-Based Services (HCBS) (also known as Medicaid "waiver services" or "1915(c) Waivers") provide people with Down syndrome access to a wide range of non-medical services and supports that help them live in their communities rather than institutions.[5] These waivers enable states to provide these services in the beneficiary's own home or community, rather than in a facility, which would be more costly.[6] While these HCBS waivers vary by state and waiver program, examples include case management (coordination and support for accessing services), homemaker and home health aide (assistance with personal care, household tasks, and daily activities), personal care (assistance with activities of daily living such as bathing, dressing, and toileting), adult day health services (supervision and activities in a day center setting), respite care (short term care for people with disabilities, giving their caregivers a break), transportation (assistance with getting to and from appointments and other activities), and job supports (training, coaching, job development).

Unfortunately, states are not required to implement these HCBS waivers for our most vulnerable citizens and have broad leeway on what services to offer and who gets them. Many people with Down syndrome wait for HCBS waiver services for years, sometimes decades.[7] Because the default Medicaid service for people with disabilities is expensive institutionalized care, HCBS waivers actually waive that institutional requirement so that people can receive services in their communities. Therefore, these waivers are "optional benefits" under the Medicaid statute [8] and thus are at the mercy of state budgets. That means that states can have waiting lists for people who are eligible or cut benefits in ways that they cannot for "mandatory benefits" like institutional services.

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[4] https://rules.house.gov/sites/evo-subsites/rules.house.gov/files/documents/rcp_119-3_final.pdf

[5] https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c

[6] https://www.healthaffairs.org/content/forefront/medicaid-home-and-community-based-services-and-supports-can-chart-pathways-independence

[7] https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/

[8] https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits

## States Will Cut "Optional" HCBS Waiver Services When Federal Medicaid Funding is Reduced

When the federal government reduces its share of Medicaid funding, states are forced to either cut services—like reducing service hours, limiting eligibility, or lowering provider payments—or take money from other essential programs.[9] Because states must continue providing federally mandated services, they often reduce optional services when budgets are tight.[10] Most optional Medicaid spending (86%) goes toward services for people with disabilities and older adults,[11] especially Home and Community-Based Services (HCBS), which make up over half of all optional Medicaid spending by states.[12]

Historically, in response to a reduction in Medicaid funding from the federal government, every state and DC has cut spending to one or more HCBS programs.[13] Service reductions and the reduced number of people enrolled greatly increased the waiting lists for the HCBS programs.[14] In anticipation of federal cuts, states are already considering what to do with their optional services. For example, Idaho passed legislation in March 2025 that requires their Department of Health and Welfare to "take any action necessary to offset the increase in state funding, including but not limited to reductions in provider payment rates or elimination of optional benefits."[15] Any elimination or even slight decrease in optional benefits will harm people with Down syndrome and other disabilities.

## Decreased Access to HCBS Will Result in Decline in Health and Well-Being and Increased Institutionalization for People with Disabilities

Medicaid is the only source of support for many older adults and people with disabilities who need services to live safely at home and in their communities. Without access to key benefits like Home and Community-Based Services (HCBS), these individuals are more likely to be placed in expensive institutional care, face avoidable hospital stays, and see their overall health decline.[16]

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[9] https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/

[10] .https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/

[11] https://www.kff.org/medicaid/issue-brief/how-is-the-affordable-care-act-leading-to-changes-in-medicaid-long-term-services-and-supports-ltss/

[12] https://crsreports.congress.gov/product/pdf/R/R43847

[13] https://www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled

[14] https://www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled

[15] https://legislature.idaho.gov/wp-content/uploads/sessioninfo/2025/legislation/H0345.pdf

[16] https://www.macpac.gov/wp-content/uploads/2023/06/Chapter-4-Access-to-Home-and-Community-Based-Services.pdf

Proposals to cut Medicaid funding or change eligibility rules would seriously harm this population, as they all shift costs to states—either by directly reducing federal contributions or by adding new administrative burdens.[17] In response, states would likely cut benefits, reduce enrollment, lower provider payments, or do all three. HCBS and other optional services that people with disabilities and older adults depend on to live independently would be especially vulnerable.[18]

## WORK REQUIREMENTS (COMMUNITY ENGAGEMENT REQUIREMENTS)

Section 44141 of the Reconciliation Bill[19] would require states to establish Medicaid "community engagement requirements for certain individuals" beginning December 31, 2026 or earlier at the option of the state. Community engagement activities include at least 80 hours/month of work and other educational or work-related activities. Noncompliance results in disenrollment, termination, or lock out of beneficiaries from marketplace coverage premium tax credits. Mandatory exceptions include those under 19, pregnant, aged and disabled, or those formerly incarcerated.

Although this provision may not be intended to hurt people with Down syndrome, it will surely have unintended negative consequences for people with Down syndrome, their direct care workers, and their unpaid family caregivers.

### Work Requirements Do Not Increase Employment but Do Increase Administrative Burdens and Lead to Massive Loss of Coverage

There are a myriad of studies and resources showing that work requirements do not actually increase employment but rather just serve as a vehicle to remove people from the Medicaid program and increase administrative burdens for enrollees and the state itself. [20]Most people who receive Medicaid are already working.[21] Evidence from state-level experiments with Medicaid work requirements in Arkansas and Georgia has been conclusive: they do not increase employment but rather increase bureaucratic red tape leading to longer wait times for things like eligibility determinations and claims

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[17] https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/

[18] https://www.kff.org/medicaid/issue-brief/how-is-the-affordable-care-act-leading-to-changes-in-medicaid-long-term-services-and-supports-ltss/

[19] https://rules.house.gov/sites/evo-subsites/rules.house.gov/files/documents/rcp_119-3_final.pdf

[20] https://healthlaw.org/wp-content/uploads/2024/09/013-PMF-Low-Wage-Workers.pdf

[21] https://www.kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work-an-update/

processing,[22] significantly increase administrative and program costs for states,[23] and result in massive loss of coverage. [24] All of these factors negatively impact the systems that serve people with Down syndrome.

Adding work requirements to Medicaid increases administrative burdens on states, slowing down application processing for everyone—including those seeking Medicaid and other services like the Supplemental Nutrition Assistance Program (SNAP). In Georgia, after the launch of Pathways to Coverage, the percentage of Medicaid applicants who waited more than 45 days nearly tripled.[25] When Arkansas implemented work requirements in 2018, more than 18,000 eligible people lost coverage within seven months. Many had to pay out of pocket for care, and the number of people with serious medical debt doubled—despite no increase in employment.[26] These added administrative hurdles strain state budgets and lead to cuts in optional Medicaid services, such as Home and Community-Based Services (HCBS), which are vital for people with disabilities.[27]

Coverage losses from work requirements also reduce hospital funding—especially in rural areas—putting facilities at risk of closure and making care harder to access for everyone.[28] These impacts are especially harmful to the systems that support people with Down syndrome.

## People with Down Syndrome and Other Disabilities Cannot be Effectively Excluded from Work Requirements

Although the Reconciliation Bill includes exemptions for people with disabilities, the process for proving exemption is complex and error-prone. People may not know they qualify for an exemption, or miss deadlines, or fail to complete paperwork correctly. The result is that individuals eligible for the exemptions lose coverage simply due to administrative errors or red tape.[29]

Only people who have gone through the formal disability determination process (e.g., Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) are automatically exempt. While people with Down syndrome are typically on Medicaid

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[22] https://www.cbpp.org/research/health/pain-but-no-gain-arkansas-failed-medicaid-work-reporting-requirements-should-not-be

[23] https://gbpi.org/wp-content/uploads/2024/10/PathwaystoCoverage_PolicyBrief_2024103.pdf

[24] https://www.urban.org/urban-wire/what-happened-people-affected-work-requirements-arkansas

[25] https://kffhealthnews.org/news/article/georgia-work-requirement-medicaid-food-stamps/

[26] https://www.urban.org/urban-wire/what-happened-people-affected-work-requirements-arkansas

[27] https://www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled

[28] https://www.commonwealthfund.org/publications/issue-briefs/2019/sep/how-will-medicaid-work-requirements-affect-hospital-finances-update

[29] https://www.kff.org/medicaid/issue-brief/understanding-medicaid-work-requirements-and-exemptions

through this pathway, more than 2/3rds of people with other disabilities enrolled in Medicaid are enrolled through a non-SSI pathway, and many of these individuals are enrolled through the expansion pathway.[30] Moreover, approval for SSI can sometimes take over a year, and people with disabilities like Down syndrome could be missing vital healthcare services while waiting for approval to be deemed disabled by the Social Security Administration.

People with Down syndrome and other disabilities will also be subject to implementation errors and system failures. States that have implemented work requirements (like Arkansas) have seen people lose coverage even when they were eligible due to online-only reporting systems that were difficult or impossible for many to access or use and lack of adequate notice or support.[31]

Even if people with disabilities are officially exempt from Medicaid work requirements, the real-world implementation often leads to coverage loss. These policies can disproportionately harm people with Down syndrome and others with disabilities—especially those who are not on SSI, have fluctuating health, and face administrative or technological barriers.

## Work Requirements Threaten the Stability of the Direct Care Workforce

Direct Support Professionals (DSPs) are direct care workers who play a critical role in supporting people with Down syndrome and other disabilities, enabling them to live independently and participate fully in their communities.[32] DSPs provide supports for various aspects of community living, such as personal care, transportation, job coaching, and medication management. Despite broad advocacy efforts to increase funding for DSPs, fair wages, and recognition of the essential role of DSPs in the Medicaid system, DSPs still earn very low wages and are often subject to unpredictable and unstable scheduling, leading to a very high turnover rate.[33] The shortage in direct care workers is already dire, with 90% of Medicaid waiver service providers reporting a 90% “moderate or severe” staffing shortage in the past year, with 39% saying they needed to discontinue programs or services.[34]

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[30] https://www.kff.org/medicaid/issue-brief/5-key-facts-about-medicaid-coverage-for-people-with-disabilities/

[31] https://www.nejm.org/doi/full/10.1056/NEJMsr1901772

[32] https://www.dol.gov/agencies/odep/program-areas/individuals/DSP

[33] https://nadsp.org/hcbs-what-direct-support-professionals-need-to-know/

[34] https://www.ancor.org/resources/the-state-of-americas-direct-support-workforce-crisis-2024/

Nearly one-quarter of DSPs rely on Medicaid for their own health insurance, and Medicaid is also the largest payer of long-term care services for DSPs.[35] With low wages and limited access to affordable employer-sponsored health insurance, most DSPs already work two or three jobs to make ends meet.[36] DSPs are more prone to workplace injuries and have poorer health outcomes than workers in similar industries.[37] Medicaid work requirements could force some DSPs to work more hours than they are safely able to, leading to burnout and potentially leaving their jobs.[38] Medicaid work requirements could exacerbate the DSP workforce shortage, further reducing much-needed care for people with Down syndrome and other disabilities.[39]

**Work Requirements Will Harm Family Caregivers**

There are more than 53 million Americans providing ongoing, complex care for friends or family members with disabilities or health care needs, often referred to as "informal caregivers" or "family caregivers."[40] While this role is most commonly filled by parents (especially mothers), approximately 15% of all informal caregivers are not related to the person for whom they are providing unpaid care.[41]

Medicaid plays a central role in supporting family caregivers by offering essential training and support services, expanding access to respite care, and providing direct payments in certain cases.[42] A study on caregiving and the workforce showed that approximately two in 10 employed caregivers had to stop working and four in 10 had to reduce their working hours to provide care.[43] Due to the financial challenges of being a caregiver and the shortage of DSPs, a handful of states have provided the opportunity for unpaid family

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[35] https://www.phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Public+Assistance

[36] https://www.aaidd.org/news-policy/policy/position-statements/direct-support-professionals-(dsp)-workforce#:~:text=Wages%20paid%20to%20direct%20support,Wages%20need%20to%20be%20increased.

[37] https://www.phinational.org/medicaid-work-requirements-will-harm-direct-care-workers/

[38] https://www.phinational.org/medicaid-work-requirements-will-harm-direct-care-workers/#:~:text=Medicaid%20work%20requirements%20could%20exacerbate,care%20workers'%20health%20insurance%20away.

[39] https://www.phinational.org/medicaid-work-requirements-will-harm-direct-care-workers/#:~:text=Medicaid%20work%20requirements%20could%20exacerbate,care%20workers'%20health%20insurance%20away.

[40] https://acl.gov/sites/default/files/2024ProgressReport_StrategyToSupportCaregivers.pdf#:~:text=Each%20year%2C%20at%20least%2053%20million%20people1,people%20with%20lifelong%20complex%20medical%20conditions%20.&text=Family%20caregivers%20most%20often%20provide%20support%20to,in%20nursing%20homes%20and%20other%20institutions%20.

[41] https://www.caregiver.org/resource/caregiver-statistics-demographics/

[42] https://www.advancingstates.org/sites/default/files/NAC_Policy-Brief-Medicaid_022425.pdf

[43] https://rosalynncarter.org/wp-content/uploads/2021/09/210140-RCI-National-Surveys-Executive-Summary-Update-9.22.21.pdf

caregivers to be paid under Medicaid self-directed waiver rules.[44] However, the amount of money paid to caregivers under these opportunities is significantly less than they would earn in equivalent roles in the private sector.[45]

This central role and need to provide more support to family caregivers was recognized in the National Strategy to Support Family Caregivers, created pursuant to the RAISE Family Caregiver Act, legislation signed into law by President Donald Trump.[46] Many of these supports for family caregivers (such as respite care) are part of state HCBS waiver systems and thus will be in jeopardy when states are forced to decrease funding for HCBS waivers due to Medicaid cuts at the federal level.[47]

Many caregivers are themselves on Medicaid. Due to loss of income and opportunities, family caregivers tend to have lower incomes than non-caregiving families, and they are more likely to experience food insecurity and receive public assistance.[48] Rural caregivers face additional financial challenges due to limited access to resources and services.[49]

NDSC has heard countless stories of family members being forced to change careers, reduce work hours, or leave the workforce entirely to provide care for their loved ones with Down syndrome. Informal caregiving for a person with Down syndrome is a team effort, with parents, siblings, grandparents, and family friends often pitching-in. If work requirements are applied to informal caregivers who receive Medicaid, they may become unavailable to support their family members who use HCBS. This could jeopardize the quality of care they deliver or eliminate their ability to provide care altogether, potentially leading to higher costs as states may need to replace unpaid care with expensive paid services or costly institutional care.[50]

## The Caregiver Exemption under the Reconciliation Bill Needs to Be Clarified

The Reconciliation Bill provides an exception for work requirements for a "specified excluded individual who is the parent, guardian, or caretaker relative of a disabled individual or a dependent child." (Section 44141 (a) (xx) (9) (A) (ii) (III)). However, this definition does not specify whether it would apply to more than one caretaker from the

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[44] https://www.ncsl.org/health/caring-for-the-caregivers-state-strategies-to-support-an-unpaid-workforce?

[45] ttps://www.researchgate.net/publication/292401277_UnPaid_Labor_Medicaid_Home_and_Community_Based_Services_Waivers_That_Pay_Family_as_Personal_Care_Providers

[46] https://trumpwhitehouse.archives.gov/briefings-statements/president-donald-j-trump-signs-h-r-3759-law/

[47] https://www.advancingstates.org/sites/default/files/NAC_Policy-Brief-Medicaid_022425.pdf

[48] https://www.caregiveraction.org/caregiver-statistics/

[49] https://pmc.ncbi.nlm.nih.gov/articles/PMC11593738/

[50] https://www.advancingstates.org/sites/default/files/NAC_Policy-Brief-Medicaid_022425.pdf

same family circle. Furthermore, it does not extend this exemption to informal caregivers who are not related to the individual for whom they provide care.

***While NDSC opposes the inclusion of any work requirements in the Reconciliation Bill, if they are included, then we suggest clarifying that the family caregiver exemption may be extended to more than one member of the same family and also to non-related informal caregivers for disabled or elderly individuals.***

## PROVIDER TAXES

The Reconciliation Bill Section 44132 would prevent states or units of local government from increasing provider taxes after the date of enactment, meaning that states cannot impose any new taxes on health care providers going forward (or else risk reduced federal reimbursement for Medicaid services). While current provider taxes would remain in place, this provision hamstrings states' ability to raise new revenues to respond to state needs.

On average, provider taxes account for about 17% of the state share of Medicaid funding.[51] All states except Alaska use at least one provider tax to help cover their Medicaid costs.[52] These taxes give states flexibility to fund their programs based on their unique budget needs, within federal guidelines.

If federal policy limits provider taxes, states would lose a key funding source. To make up the difference, they would either have to shift funds from other areas or cut optional Medicaid services—like Home and Community-Based Services (HCBS)—that many older adults and people with disabilities rely on[53].

***While NDSC opposes the inclusion of this provision in the Reconciliation Bill, if it is included, then we suggest establishing a ceiling on the amount of provider taxes for federal-state cost-sharing calculations but allowing states to raise provider taxes above that ceiling to provide additional sources of revenue.***

## RETROACTIVE COVERAGE REDUCTION

Section 44122 of the Reconciliation Act would modify retroactive coverage under the Medicaid Children's Health Insurance Program (CHIP) programs by reducing it from 90 days

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[51] https://ccf.georgetown.edu/2025/02/04/medicaid-provider-taxes-a-critical-source-of-medicaid-funding-for-states/

[52] https://www.macpac.gov/publication/macstats-medicaid-and-chip-data-book/

[53] https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/

to only one month prior to enrollment. Retroactive coverage provides a critical safeguard for new enrollees as it allows them to receive reimbursement for past medical expenses incurred up to 90 days prior to their official Medicaid enrollment date. This reduction is particularly harmful for people experiencing new life events like pregnancy or childbirth, and particularly harmful to families receiving a Down syndrome diagnosis.

Down syndrome is the most common genetic condition, affecting 1 out of 640 live births, with approximately 5700 babies with Down syndrome born each year in the United States.[54] It can be diagnosed prenatally or postnatally, and is often accompanied by co-existing conditions such as congenital heart defects, gastrointestinal issues, thyroid problems, hearing and vision loss, and more.[55] Regardless of when they received the Down syndrome diagnosis, families of babies with Down syndrome often report feeling overwhelmed by their new journey.[56]

The first few months of life for a baby with Down syndrome are often filled with countless doctors' appointments, medical testing and, in many cases, major surgeries. These cause medical bills to quickly accumulate. During this time, many families are just trying to grapple with their new baby's health needs and will certainly need more than 30 days to understand and apply for Medicaid, assuming they even know about their baby's eligibility. In fact, many families who have babies with Down syndrome report not being provided with information about government benefits such as Medicaid until weeks or months after birth.[57]

***NDSC opposes this proposed new 30-day retroactive coverage rule. However, if the rule is to be implemented, then we suggest retaining the current 90-day retroactive coverage rule for certain categories of Medicaid eligibility such as disability.***

NDSC recognizes that the intent of the Reconciliation Bill is to improve the efficiency and sustainability of the Medicaid program but is highly concerned that the proposals outlined above could have unintended consequences for people with Down syndrome, their families, and the informal and professional caregivers who support them. Please contact Heather Sachs, Co-Director of Policy and Advocacy, for further questions or information, at heather@ndsccenter.org.

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[54] https://www.cdc.gov/birth-defects/living-with-down-syndrome/index.html
[55] https://www.nichd.nih.gov/health/topics/down/conditioninfo
[56] https://pmc.ncbi.nlm.nih.gov/articles/PMC7814853
[57] https://pubmed.ncbi.nlm.nih.gov/38619097/