national down syndrome society
ndss

May 20, 2025

The Honorable John Thune 511 Dirksen Senate Office Building Washington, DC 20510	The Honorable Charles Schumer 322 Hart Senate Office Building Washington, DC 20510
The Honorable Mike Johnson 521 Cannon House Office Building Washington, DC 20515	The Honorable Hakeem Jeffries 2267 Rayburn House Office Building Washington, DC 20515

CC: Members of the United States House and Senate

Dear Majority Leader Thune, Democratic Leader Schumer, Speaker Johnson, and Democratic Leader Jeffries:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. We are writing today to express concerns about several provisions in the budget reconciliation bill recently passed by the House Energy and Commerce Committee.

For individuals with Down syndrome, a traditional Medicaid beneficiary population, Medicaid is a critical lifeline. Research shows that Medicaid is the primary insurance for the vast majority of individuals with Down syndrome.[1] Even so, many individuals with Down syndrome still struggle to access the basic healthcare and home and community-based services (HCBS) that allow them to live and thrive in their communities. **Medicaid is not and has never been perfect.**

We appreciate the tireless efforts of Members of Congress on both sides of the aisle to make Medicaid more efficient and effective in order to provide the highest quality of care to beneficiaries. That being said, **we are concerned about the unintended consequences that could happen as a result of the recently passed budget reconciliation bill that could pose significant risks to the health, independence, and financial stability of people with disabilities.** We urge you to consider the following areas of concern as the legislative process continues:

State Directed Payments (SDP) Tax Decrease

> While the proposal to change State Directed Payments (SDPs) is framed as a way to ensure states contribute their fair share to Medicaid, it risks destabilizing Medicaid financing and reducing the ability of states to sustain critical health programs, particularly home and community-based services (HCBS).

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

SDPs have become an important tool that states use to draw down federal matching funds to bolster provider payments, especially for Medicaid services that support people with disabilities. Limiting the provider tax which supports these payments could constrain states' ability to maintain or expand access to critical Medicaid services today and in the future as medical costs continue to increase. States facing these shortfalls may be forced to either backfill the loss with their own general revenue or, more likely, scale back services to balance their budgets.

Historically, when Medicaid budgets are tight, HCBS is among the first areas to be cut, even though it is essential for people with Down syndrome and others with intellectual and developmental disabilities. HCBS provides the supports that allow individuals to live in their homes and communities rather than being forced into institutional settings. These services include personal care aides, supported employment, transportation, day programs, and habilitative therapies.

Simply put, limiting the provider tax which finances SDPs could result in less access to care, more time on waitlists, fewer options for community living, and a serious setback to decades of progress toward inclusion and independence for individuals with Down syndrome and other disabilities.

Retroactive Coverage Reduction (90 to 30 Days)

The proposal to reduce Medicaid's retroactive eligibility period from 90 days to just 30 days could disproportionately harm individuals with Down syndrome and their families in several ways. As a traditional Medicaid beneficiary population, many children with Down syndrome are eligible for Medicaid at birth. Down syndrome is a chromosomal abnormality that is often detected and diagnosed prenatally; however, this is not always the case. Many families receive a Down syndrome diagnosis at or shortly following birth after choosing not to undergo prenatal testing or receiving a false negative in the prenatal testing. For these families, the unexpected diagnosis at birth and lack of education or awareness on Medicaid eligibility may cause a delay in applying for Medicaid coverage that they are legally entitled to receive.

The first few months of life for children with Down syndrome often includes many additional and perhaps sudden health challenges. Approximately 50% of babies with Down syndrome are born with a Congenital Heart Defect (CHD) which often requires several invasive and expensive heart surgeries to correct.[2] Without Medicaid, many families would be unable to pay for the costly procedures and the myriad of doctors appointments and medications that accompany them. The first few months of life for any new child and their family can be filled with unexpected and unplanned health needs but this is especially true for individuals with Down syndrome. By limiting these families'

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[2] https://adc.bmj.com/content/97/4/326

ability to obtain retroactive coverage, it places them at risk of incurring catastrophic medical debt during an already overwhelming and vulnerable time.

The same is often true for individuals with Down syndrome as they age because they are at a significantly higher risk for a range of serious health conditions including Alzheimer's disease. Individuals with Down syndrome have an over 90% lifetime risk for developing Alzheimer's disease and it is the leading cause of death for this community.[3] As these individuals age, they often rely on long-term services and supports (LTSS), and Medicaid is the only provider. For those who have not previously been on Medicaid or who have mistakenly unenrolled when they became eligible for Medicare, without the 90-day retroactive coverage, they could face overwhelming out-of-pocket costs when obtaining LTSS for the first time.

The process of applying for Medicaid, particularly for long-term services and supports (LTSS) is complex, lengthy, and difficult to navigate. This is an especially high burden for caregivers who are already managing complex medical needs or other needs. Whether it is supporting families welcoming a newborn with Down syndrome or caregivers assisting aging loved ones, the 90-day safety net helps ensure that unexpected health needs don't force families and beneficiaries to choose between essential care and overwhelming medical debt.

Medicaid Work Requirements

We understand that proposals like Medicaid work requirements 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 alike 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.

Evidence from state-level experiments highlights these concerns. Arkansas' implementation of Medicaid work requirements through a Section 1115 waiver in 2017 led to delays and disruptions in access to care for eligible beneficiaries due to administrative burdens. The work requirements also did not result in increased employment rates statewide.[4] Georgia's recent implementation of work requirements for its Medicaid expansion population has been costly for taxpayers with almost 5 times as much spent on administrative and program costs than on healthcare benefits for enrollees.[5] The red tape that Medicaid work requirements create slows application

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[3] https://pmc.ncbi.nlm.nih.gov/articles/PMC9387748/

[4] https://onlinelibrary.wiley.com/doi/10.1111/1475-6773.14624

[5] https://gbpi.org/georgias-pathways-to-coverage-program-the-first-year-in-review/

processing, creates backlogs, and drains resources that could instead fund direct services, dependent care, or employment supports for people with disabilities.

Once again, we appreciate the efforts made to improve the efficiency and sustainability of the Medicaid program, especially for traditional Medicaid beneficiary populations such as individuals with Down syndrome. We urge Congress to consider these potential outcomes carefully. If enacted, these proposals could have the unintended consequence of limiting access to critical supports and services for hundreds of thousands of individuals with Down syndrome and their families.

NDSS stands ready to work with Congress to ensure that any policy changes to Medicaid protect, rather than jeopardize, the well-being of people with disabilities.

Sincerely,

Kandi Pick

Kandi Pickard
President and CEO
National Down Syndrome Society