national down syndrome society
ndss®

June 23, 2025

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| The Honorable John Thune<br>511 Dirksen Senate Office Building<br>Washington, DC 20510 | The Honorable Charles Schumer<br>322 Hart Senate Office Building<br>Washington, DC 20510 |
| The Honorable Mike Crapo<br>239 Dirksen Senate Office Building<br>Washington, DC 20510 | The Honorable Ron Wyden<br>221 Dirksen Senate Office Building<br>Washington, DC 20510 |

CC: Members of the United States Senate

Dear Majority Leader Thune, Minority Leader Schumer, Chairman Crapo, and Ranking Member Wyden:

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 write today to express our deep concern about several provisions in the Senate Finance Committee's updated budget reconciliation legislation. While we appreciate ongoing bipartisan efforts to strengthen and improve the Medicaid program, the updated Senate bill makes changes that go beyond the already troubling House-passed version, increasing the risk of harm to individuals with Down syndrome and others with disabilities.

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. However, we are concerned about the unintended consequences that could happen as a result of the Senate proposed 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:

### Prohibition on CMS' Medicaid and CHIP Eligibility and Enrollment Rule

> The Senate bill goes further than the House bill by prohibiting, not just delaying, implementation of the Centers for Medicare and Medicaid Services' (CMS) two-part final rule aimed at simplifying Medicaid and CHIP enrollment and renewal processes. This rule was designed to reduce administrative burdens and help eligible individuals maintain coverage. This is especially important for individuals with intellectual and developmental disabilities who may face complex application requirements or intermittent eligibility due to changes in income or support systems.

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

By outright prohibiting these streamlining reforms, the Senate bill risks reversing progress toward more access to care, placing even more families at risk of unnecessary coverage loss.

**Deeper Cuts to Provider Tax Policy**

We remain very concerned that the House bill includes a moratorium on new or increased provider taxes, a move that would restrict states' ability to generate the non-federal share of Medicaid funding and threaten the stability of critical health programs. However, we are even more concerned that the Senate proposal goes further, lowering the provider tax threshold from 6% to 3.5% and capping Medicaid reimbursement rates at Medicare levels. These changes would further constrain states' flexibility and weaken Medicaid's financing foundation. While intended to ensure states contribute their fair share, these changes risk undermining the ability of states to sustain essential services, particularly in home- and community-based care, which is a lifeline for many individuals with disabilities and complex needs.

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 that supports these payments could constrain states' ability to maintain or expand access to critical Medicaid services today, and in the future, as medical cost 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 the decades of progress toward inclusion and independence for individuals with Down syndrome and other disabilities.

**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.

We are also very concerned to see that the Senate proposal eliminates exemptions for parents and caregivers of children over the age of 14. This represents a dangerous shift that fails to reflect the realities of caregiving. Many individuals with Down syndrome require lifelong support and older children often have high care needs that continue well into adolescence and adulthood. For individuals with Down syndrome, who have an over 90% chance of developing Alzheimer's disease, this often means they will require increasing levels of support over their lifetime – support that is most often provided by aging parents and family members.[2] These caregivers frequently remain responsible well into their own retirement years, managing complex medical, behavioral, and daily living needs. Eliminating exemptions for these caregivers ignores this reality and places both individuals with Down syndrome and their families at serious risk of losing essential coverage and stability.

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.[3] 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.[4] The red tape that Medicaid work requirements create slows application processing, creates backlogs, and drains resources that could instead fund direct services, dependent care, or employment supports for people with disabilities. For caregivers already stretched thin by complex medical and educational systems, these requirements would add one more barrier to stability.

### Retroactive Coverage Reduction (90 to 30 Days)

The Senate bill maintains the problematic proposal to reduce Medicaid retroactive eligibility from 90 to 30 days. This threatens newborns with Down syndrome who receive a diagnosis at birth and may face multiple surgeries and hospital stays in their first weeks of life, as well as aging adults newly diagnosed with Alzheimer's disease the leading cause of death for people with Down syndrome.[5]

The application process for Medicaid is often long and difficult. Without the 90-day retroactive window, individuals and families may incur catastrophic medical debt during some of the most vulnerable moments of their lives.

Taken together, these changes reflect a sharp move away from protecting the most vulnerable Medicaid beneficiaries. They threaten not only access to care but also the progress our nation has made in ensuring that individuals with disabilities have the opportunity to live independently and participate fully in their communities.

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

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

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

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

NDSS remains committed to working with Congress to strengthen Medicaid in ways that improve access, quality, and efficiency. We respectfully urge you to reject the harmful provisions in the current Senate proposal and instead work toward bipartisan solutions that preserve Medicaid's foundational role for individuals with disabilities.

Sincerely,

Kandi Pick

Kandi Pickard
President and CEO
National Down Syndrome Society