Understanding Medicaid Changes and the Impact on Individuals with Down Syndrome

Background

Medicaid is a government program that provides free or low-cost health insurance to eligible individuals. Medicaid plays an important role in the lives of many individuals with Down syndrome by providing access to healthcare and support services.

In fact, according to a 2023 report from Boston University, Medicaid is the primary insurance for the majority of individuals with Down syndrome. Medicaid is also the largest payer of Home and Community-Based Services (HCBS), which help individuals with Down syndrome and other disabilities live independently in their homes and communities.

A new law passed by Congress and signed by the President, the *One Big Beautiful Bill Act,* includes major changes to Medicaid and may affect individuals with Down syndrome and caregivers. While the law does not directly cut medical coverage for individuals with disabilities, the impacts on state budgets could affect availability of HCBS.

New requirements also must be implemented carefully and correctly to ensure continued access to services and to avoid disruptions in care. NDSS is closely monitoring the changes and working to ensure our community stays informed, supported, and protected.

For more information, please contact our policy team at policy@ndss.org.

Understanding Medicaid Changes and the Impact on Individuals with Down Syndrome

Limits on State-Directed Payments and Provider Taxes

Sec 71115 and Sec 71116

States have long used healthcare-related taxes—referred to as "provider taxes"—to help finance their share of Medicaid costs. Provider taxes are a major source of state funding for Medicaid, and also a common funding mechanism for state-directed payments (SDPs). Some states use SDPs to increase payment rates to certain providers and expand access to services such as HCBS. The law prohibits new or increased provider taxes and SDPs for all states, and phases in reductions of current provider taxes for states that expanded Medicaid under the Affordable Care Act ("expansion states").

IMPACT: New limits will make it harder for states to finance their Medicaid programs. Historically, when state Medicaid budgets are tight, HCBS are among the first services to be cut or scaled back, even though they are essential for individuals with Down syndrome and others with intellectual and developmental disabilities. These limits could lead to reduced access to care, longer waitlists for services, and fewer options for community living.

TIMELINE: Limits on new provider taxes and SDPs take effect immediately. The phase-down of current provider taxes for expansion states will begin October 1, 2027.

NDSS is continuing to advocate for a rollback of the provider tax limits. NDSS will also support advocacy at the state level to protect funding for HCBS and other key services.

For more information, please contact our policy team at policy@ndss.org.

Understanding Medicaid Changes and the Impact on Individuals with Down Syndrome

Medicaid Work Requirements

Sec 71119

The law establishes new rules that would require certain Medicaid recipients to work, volunteer, or participate in an educational program for at least 20 hours per week to maintain coverage.

IMPACT: While the law does include an exemption for individuals with disabilities and their caregivers, new processes for identifying and verifying exemptions may be difficult for states to implement and for beneficiaries to navigate, resulting in eligible individuals potentially losing coverage due to system errors or complex reporting requirements.

TIMELINE: States are directed to implement the new work requirements by January 1, 2027.

NDSS is developing informational resources to help individuals and families understand and navigate the new requirements. NDSS will also monitor state implementation of work requirements and exemption processes to protect coverage for individuals with Down syndrome.

For more information, please contact our policy team at policy@ndss.org.

Understanding Medicaid Changes and the Impact on Individuals with Down Syndrome

Retroactive Coverage Reduction

Sec 71112

Currently, states are required to provide retroactive Medicaid coverage for expenses incurred up to 90 days prior to an eligible individual's application for coverage. The law would limit the retroactive coverage "lookback" period to 30 days for beneficiaries who are eligible under Medicaid expansion, and 60 days for beneficiaries in the traditional Medicaid population, which includes individuals with Down syndrome in most cases.

IMPACT: Individuals with Down syndrome often encounter unexpected or sudden health needs, especially at birth. The application process for Medicaid can be lengthy and challenging, and a reduced period of retroactive coverage may result in individuals and families incurring significant out-of-pocket medical expenses.

TIMELINE: The new policy takes effect on January 1, 2027.

NDSS is committed to advocating for policies across the country that ensure families receive the most accurate and up-to-date information available about Down syndrome when receiving a prenatal or postnatal diagnosis, including information on Medicaid enrollment.

For more information, please contact our policy team at policy@ndss.org.