



Protecting and Strengthening Medicaid

Legislative Request

Please stand with the disability community to protect Medicaid and oppose cuts or harmful changes to the program.

Down Syndrome and Medicaid

Medicaid is a critical lifeline to the vast majority of individuals with Down syndrome and their families. According to a 2023 report from Boston University, Medicaid is the primary insurance for the majority of individuals with Down syndrome and the only insurance for a substantive portion of the population who are low-income or dependents of aging parents.¹ Medicaid is also the largest federal payer of long-term services and supports (LTSS), which is necessary for millions of children and adults with disabilities.² LTSS provides assistance with essential tasks, such as feeding, dressing, bathing, and walking. It can also include activities like managing finances, shopping, meal preparation, and housecleaning. Additionally, because Medicaid is the only provider of Home and Community-Based Services (HCBS) currently in the United States, tens of thousands of individuals with Down syndrome rely on Medicaid to receive the vital services HCBS provides such as personal care, therapy, job coaching, and assistive technology to support independent living.³

Impacts of Cuts

Loss of Coverage and Care Leading to Poor Health Outcomes

Medicaid covers 2.3 million children with disabilities and over 13 million adults with disabilities.⁴ Cuts to the program could leave countless Americans with disabilities without the healthcare they need to survive.

Increased Financial Burden on States, Families, and Individuals

Cuts to federal support for Medicaid would force states, families, and individuals with disabilities to carry this burden, which would further entrench them in poverty and increase their overall need for more government support.

1 <https://pmc.ncbi.nlm.nih.gov/articles/PMC10422190/#H1-5-AOI230052>

2 <https://www.kff.org/medicaid/issue-brief/how-many-people-use-medicaid-long-term-services-and-supports-and-how-much-does-medicaid-spend-on-those-people/>

3 <https://www.manatt.com/insights/newsletters/health-highlights/medicaid-s-role-in-empowering-people-with-intellect>

4 <https://www.kff.org/medicaid/issue-brief/5-key-facts-about-medicaid-coverage-for-people-with-disabilities/>

Threat to Independence and Disincentive to Work

Medicaid cuts could create a “benefits cliff,” where workers lose coverage as their income increases, discouraging career growth and full-time employment due to the loss of essential health care.

Greater Burden on Family Caregivers

Many families already struggle to provide the care and support their loved ones with disabilities need. Cutting the critical supports and services provided by Medicaid would only make this situation worse.

Impact of Work Requirements

Medicaid work requirements are policies that require certain Medicaid recipients to work, volunteer, or participate in job training for a minimum number of hours per week to maintain their health coverage. Exemptions and carve-outs for individuals with disabilities are often included in Medicaid work requirement proposals. However, these exemptions are not adequate enough to ensure that qualified individuals with disabilities maintain access to coverage.

Increased Bureaucracy and Administrative Red Tape

Exemptions require extensive paperwork and documentation which only create an additional administrative burden for governmental agencies and hurdles for disabled beneficiaries to comply with. Additionally, vague standards, such as “unfit to work,” and narrow criteria, such as only exempting those who receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), create confusion and increased bureaucracy.

Hinder Employment Opportunities for Individuals with Disabilities

Exemptions force individuals with disabilities to obtain a label as “unfit to work,” which reinforces negative stereotypes and further perpetuates barriers to employment for individuals with disabilities. Disabled individuals who choose to not seek the exemption risk losing Medicaid coverage if they cannot consistently meet and report the required hours.

Summary

Medicaid is a critical lifeline that supports the health and well-being of millions of Americans with Down syndrome and other disabilities. Medicaid also supports individuals with disabilities in their ability to contribute to their communities and gain increased independence meaningfully. Medicaid cannot and should not be weakened, diminished, or restricted for eligible beneficiaries with disabilities.

For more information, please contact Anna Fedewa, National Down Syndrome Society Senior Manager of Government Relations, at afedewa@ndss.org