



National Down Syndrome Congress  
300 Mansell Court, Suite 108  
Roswell, GA 30076

September 25, 2017

United States Senate Committee on Finance  
219 Dirksen Senate Office Building  
Washington, DC 20510-6200  
Senator Orrin Hatch, Chair  
Senator Ron Wyden, Ranking Member

Sent via email to: [GCHcomments@finance.senate.gov](mailto:GCHcomments@finance.senate.gov)

**RE: TESTIMONY IN OPPOSITION TO GRAHAM-CASSIDY BILL (Senate Amendment 586, 115<sup>th</sup> Congress)**

Dear Chairman Hatch, Ranking Member Wyden and Committee Members:

The National Down Syndrome Congress (NDSC) is the country's oldest and largest organization for people with Down syndrome, their families, and the professionals who work with them. NDSC provides support and information about issues related to Down syndrome throughout the lifespan and advocates for people with Down syndrome in matters of public policy. **NDSC strongly opposes the Graham-Cassidy bill based upon the devastating effects it will have on Medicaid and health care for people with Down syndrome.** We urge Congress to work in a bipartisan manner, under the rules of regular order, to improve upon the Affordable Care Act (ACA) and make any necessary changes to the Medicaid system without block grants, cuts or caps.

***Impact on Medicaid Will Devastate the Down Syndrome Community***

Over 10 million people with disabilities, including many people with Down syndrome, rely upon Medicaid for their health care, employment and access to community life. In addition to covering medical care, state Medicaid programs cover a wide-range of services and supports for people with disabilities. The potential loss of these services through funding cuts and restructuring will be devastating to the Down syndrome community.

Under both block grants and per capita cap scenarios in the Graham-Cassidy bill, federal funding will be limited and states will have to make up funding differences to accommodate their populations. A more likely result is that states will make cuts to support services for people with Down syndrome and other disabilities in order to cover the most critical health benefits, since under Medicaid law, home-and community-based services (HCBS) are considered "optional."

Long-term services and supports (LTSS) are services under Medicaid to provide assistance to people with disabilities with the activities of daily living (such as eating, bathing, dressing, preparing meals, housekeeping, preparing medication). They can include home health services, transportation and supported employment services. LTSS can be provided in either institutional settings (which are mandatory services) or home and community-based settings (HCBS) which are provided through HCBS “waivers” (which are optional services).

Because of HCBS waiver services, people with Down syndrome and other disabilities can get the support services that enable them to live and work in their own communities instead of a segregated, institutional setting. The HCBS waiver program has enabled people to live in the same manner and in the same places that non-disabled people live in their community. It has enabled many people with Down syndrome and other disabilities to work in regular jobs.

If Medicaid funding shifts to a block grant/per capita cap model, it is likely that states will cut HCBS waiver programs (optional services) to pay for the shortfall in federal funding. This is likely to result in some people with Down syndrome and other disabilities, particularly those with aging parents, or no family, being institutionalized. This bleak retreat to institutionalization would mean that these individuals would no longer receive the necessary supports to live at home or in the community. The opportunity for those institutionalized to be employed and become tax-paying citizens instead of wards of the state will essentially disappear.

Cuts to Medicaid funding will also negatively impact education for people with Down syndrome. School-based Medicaid programs allow school districts to seek reimbursement for providing Medicaid approved services and equipment to eligible Medicaid-enrolled children. School districts rely upon Medicaid funds to provide services to many students under the Individuals with Disabilities Act (IDEA), such as speech therapy, occupational therapy and physical therapy. Proposed Medicaid cuts or cuts created by shifting to a block grant/per capita cap model will almost certainly result in a reduction of the reimbursement school districts receive for these services, because they would be forced to compete with other providers for more limited funding. Although schools are still required to ensure that students with disabilities have access to necessary supports to ensure a free appropriate public education (FAPE) and early intervention services under IDEA, current underfunding already makes this difficult. The loss of Medicaid reimbursement dollars will make a bad situation even worse. This does not solely affect students who are eligible for Medicaid, because the state or district may have to cut other parts of the education budget to compensate for the reduction in Medicaid funding.

### ***Loss of Affordable, Comprehensive Healthcare is of Grave Concern***

Down syndrome is a common genetic variation that usually causes delay in physical, intellectual and language development. All people with Down syndrome have pre-existing

and co-occurring medical conditions that could threaten their access to affordable health insurance coverage. Thirty to fifty percent of individuals with Down syndrome have heart defects and eight to twelve percent have gastrointestinal tract abnormalities present at birth; most of these defects are now correctable by surgery and other medical interventions. Other medical conditions common in the Down syndrome population include cognitive impairment, leukemia, obstructive sleep apnea, seizure disorders, neurobehavioral problems, pulmonary hypertension, thyroid diseases, celiac disease, Type 1 diabetes, Alzheimer's disease, immune system dysfunction, metabolic dysfunction and mental health disorders. Despite these health conditions, many persons with Down syndrome hold jobs, live independently, and enjoy recreational opportunities. They must have access to high-quality, affordable healthcare in order to reach their full potential and meaningfully participate in their communities.

Although proponents of the Graham-Cassidy bill claim that people with pre-existing conditions would be protected, states will be able to seek a waiver to allow insurers to charge higher prices to customers with pre-existing conditions. Premiums will be prohibitively high, even for people who enrolled in subsidized high-risk pools, and most people with Down syndrome and their families would be priced out of the market.

NDSC is also concerned that "essential health benefits" will be cut or redefined as a result of the Graham-Cassidy bill. Essential Health Benefits (EHBs) are ten types of services that all health insurance plans must provide to comply with the Affordable Care Act: (1) ambulatory patient services; (2) emergency services; (3) hospitalization; (4) maternity and newborn care; (5) mental health and substance use disorder services including behavioral health treatment; (6) prescription drugs; (7) rehabilitative and habilitative services and devices; (8) laboratory services; (9) preventive and wellness services and chronic disease management; and (10) pediatric services, including oral and vision care. The Graham-Cassidy bill would give states the ability to apply to waive the federal definition of "essential health benefits" and/or create their own definitions. To cut costs, states are likely to scale back benefits that are not considered critical to one's health.

Of particular concern for individuals with Down syndrome is the category of rehabilitative and habilitative services. While rehabilitative services help a person recover from an injury or illness, habilitative services are health care services that help a person keep, learn, or improve skills and functioning for daily living. These services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings. Individuals with Down syndrome have cognitive, physical and speech delays and benefit from continual habilitative services, particularly in early childhood. If coverage of these services is not mandated by states or the federal government, insurers are likely to scale back on or drop coverage of these services which provide critical enhancements to the quality of life for people with Down syndrome.

NDSC vehemently believes that the Graham-Cassidy bill and similar proposals will turn back the clock to the years before the Affordable Care Act (ACA) when people with disabilities had very limited options for cost-effective and comprehensive health insurance. It will also permanently restructure the Medicaid system to the detriment of many people

with Down syndrome and other disabilities who rely upon Medicaid for more than just health care, but to be able to access and contribute to their community. On behalf of the approximately 250,000 individuals with Down syndrome in the United States and their families, NDSC strongly urges you to oppose the Graham-Cassidy bill and instead work on bipartisan improvements to the nation's health care system.

Sincerely,

A handwritten signature in black ink that reads "Heather Sachs". The signature is written in a cursive style and is positioned to the right of a small, faint circular stamp.

Heather B. Sachs, J.D.  
Policy and Advocacy Director  
National Down Syndrome Congress  
[www.ndscenter.org](http://www.ndscenter.org)