



House Passage of the American Health Care Act (AHCA)

May 5, 2017

The National Down Syndrome Society continues to have a number of serious concerns with legislation (H.R. 1628) approved by the House of Representatives on May 4 to repeal and begin replacing the Affordable Care Act (ACA). As the legislation advances to the next stage in the process, we urge the House leadership to work with their counterparts in the Senate to make changes to those provisions that are detrimental to individuals with Down syndrome and their families.

Examples of provisions of H.R. 1628 that are of serious concern include:

- Caps on Medicaid Payments to the States – Medicaid is a program that reaches far beyond the scope of healthcare and encourages people with Down syndrome to live and work in their communities, develop assets that reduce dependence on public benefits, and avoid costly and segregated nursing homes or institutions. Enactment of a per capita Medicaid spending cap threatens to halt the progress that has been made nationally in promoting home and community-based services, improving the coordination of care and services resulting from medical complexities, and facilitating economic independence for people with Down syndrome. That’s because the caps are intended to slow the rate of federal health care spending, and will do so at the expense of optional Medicaid services such as employment supports through Long-Term Services and Supports (LTSS), and Home and Community-Based Services (HCBS).
- State Waivers of Essential Health Benefits (EHBs) –Among the 10 EHBs proscribed in the ACA are rehabilitative and habilitative services and devices. These services are particularly important for individuals with Down syndrome, who typically face delays in basic physical, cognitive, language, social and self-help skills. Their having access to early intervention and habilitative services is critical for achieving optimal health outcomes, improving skills and functioning for daily living, and becoming active and productive participants in their communities.

Individuals with Down syndrome are living longer than ever before. Today, as many as 80 percent of adults with Down syndrome reach the age of 60, and many live even longer. This necessitates access to affordable health care and long-term services and supports throughout an increased lifespan. Unless calibrated to account for both the complicated health care needs and supportive services that people with Down syndrome will face throughout their lifespan, the reforms adopted as part of H.R. 1628 will undermine the progress that has been made in promoting self-determination, independence, productivity, and integration and inclusion.

NDSS will continue to work with Congress and the Administration to ensure that any final health care reform legislation addresses these concerns, and advances the goal of improving health outcomes, increasing access to quality care, and advancing economic opportunity for all individuals with Down syndrome and other disabilities.