

National Down Syndrome Congress: Impact of AHCA and Medicaid Restructuring on Down Syndrome Community Would be Devastating

May 25, 2017

The current attempts to drastically change the health care structure and Medicaid funding mechanism would be devastating for individuals with Down syndrome! NDSC's Governmental Affairs team is actively meeting with both Republicans and Democrats and their staffers to emphasize the potentially devastating consequences that provisions in the American Health Care Act (AHCA) would have on critical healthcare and services on which individuals with Down syndrome rely to live and work in the community through Medicaid waivers. NDSC has also prepared a glossary of key terms and concepts that are prominent in the national discussions around these issues. <http://www.ndscenter.org/wp-content/uploads/NDSC-explanation-key-AHCA-terms-5.25.17.pdf>

Status of AHCA and Next Steps

The American Health Care Act (AHCA) (H.R. 1628) was passed by the US House of Representatives by a vote of 217-213 on May 4, 2017. It repealed major parts of the Patient Protection and Affordable Care Act (also known as the Affordable Care Act – ACA or “Obamacare”) (P.L. 111-148) and replaced it with a new healthcare structure. It is now before the Senate for consideration.

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The Senate has put together a working group of US Senators who will be spearheading the effort to create an alternative version of the AHCA to repeal and replace the ACA. This task force has begun meeting and discussing key priorities and issues for its own version of a healthcare bill. Unfortunately, it appears that the Senate will not use the regular process that involves public committee hearings and meetings to amend/vote on approving and “reporting” a bill to the full Senate, so the transparency in this process will be lacking.

Once the Senate passes a healthcare bill it will go back to the House. If the House does not pass the Senate bill, then the House-passed bill will go to a “conference committee” of Representatives and Senators for approval then be approved by both the House and Senate

before heading to the President's desk for signature. There are reports that the House may have an "up or down" vote on the Senate bill and skip the lengthier process.

We are also hearing that the Senate is seriously considering a similar restructuring to Medicaid that would include block grants or per capita caps.

It is imperative that individuals with Down syndrome and their families reach out to their Senators, whether or not they are on the healthcare task force, to share their personal stories of how their lives have been impacted by the ACA and Medicaid. NDSC has prepared an Action Alert with sample talking points. <http://www.ndscenter.org/unite-against-ahca-sweeping-reforms-and-medicaid-restructuring/>

Medicaid Concerns

The national debate on health care is intertwined with a discussion of Medicaid, as the AHCA had proposed an \$834 billion cut to Medicaid over 10 years. Over 10 million people with disabilities, including a great many of those 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.

NDSC believes that the impact of any current or future proposals on Medicaid needs to be at the forefront of discussions that advocates have with elected officials. There is NO SCENARIO in which block grants and per capita caps will benefit the Down syndrome and broader disability community. Once the Medicaid funding program is restructured and the entitlement to Medicaid is removed, it will be a slippery slope downward and funding may continue to be cut with each subsequent Congress. NDSC urges advocates to align with the "#NoCapsNoCuts" message being promoted by most other national disability groups.

- ***Funding Model Shift Will Result in Massive Cuts to Medicaid:*** The AHCA relies on changing Medicaid from an entitlement system to either block grants or per capita caps, and NDSC is hearing that this proposal is also seriously being considered by the Senate. Under block grants, states would receive a fixed amount of federal funding for Medicaid that would not be based on enrollment, costs or program needs. There would be no guarantee of coverage, and states would be able to use waitlists or caps. Under a per capita cap system, federal funding to the states would be capped per enrollee and not based on health care costs and needs. It would increase based upon a pre-set formula or amount based on either an individual or subgroup of individuals. Under both block grants and per capita cap scenarios, federal funding will be limited and states will have to make up funding differences to accommodate their populations. As a result, states may 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."
- ***Cuts to Medicaid Funding Will Decrease Availability of Community-Based Services:*** 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 include home health services, transportation and supported employment services. LTSS are provided in both institutional and home and community-based settings (HCBS) through HCBS “waivers.” Although enrollment in current HCBS waiver programs can be capped by states resulting in long waiting lists, the waiver services are vital to facilitating access to employment and participation in the community for people with Down syndrome. If Medicaid funding shifts to a block grant or per capita cap model, it is likely that states will cut HCBS waiver programs to pay for the shortfall in federal funding. This is likely to result in some individuals with Down syndrome and other disabilities being institutionalized in order to receive appropriate care and supports that they formerly were able to receive at home or in the community. It will also negatively impact the employment of individuals with Down syndrome, whose job supports may be decreased or cut entirely.

- ***Cuts to Medicaid Funding Will Negatively Impact Education:*** 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 very 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.

Healthcare Concerns

People with Down syndrome must have access to high-quality, affordable healthcare in order to reach their full potential and meaningfully participate in their communities. NDSC strongly believes that the AHCA and similar proposals will turn back the clock to the years before the Affordable Care Act (ACA) when people with disabilities had very limited cost-effective and comprehensive options for health insurance.

- ***Individuals with Preexisting Conditions Will Have Few Choices and Pay More:*** Much debate centers on whether access to health coverage would be guaranteed for people with preexisting conditions. The AHCA passed with an amendment that would allow the states to seek a waiver from the requirement in the ACA prohibiting discrimination based on preexisting conditions and also allows them to waive the “essential benefits provisions” described below. Under the [MacArthur Amendment](#), states would be able to seek a waiver from the “community rating” provision in ACA

that have barred insurers from setting premiums based on health status. That means that insurers could increase premiums by unlimited amounts for people with medical complications associated with Down syndrome.

Even if coverage is not denied based on preexisting conditions, insurance rates for those with preexisting conditions will be increased so dramatically that it is likely to be cost-prohibitive for the affected individual to obtain, maintain or renew health insurance. Individuals with Down syndrome – particularly those who rely on private health insurance as their primary insurance or to fill-in insurance gaps – will likely be forced to join high-risk programs which will offer insurance to individuals with preexisting conditions at very high cost with limited coverage. The AHCA sought to address this problem by including funding of \$8 billion to subsidize high-risk pools, but this amount is woefully inadequate.

<https://www.americanprogress.org/issues/healthcare/news/2017/05/03/431827/upton-amendment-aca-repeal-bill-will-almost-no-effect/>)

- ***Essential Health Benefits May be Cut or Redefined:*** Essential Health Benefits (EHBs) are ten types of services that all health insurance plans must provide to comply with the ACA: (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 AHCA 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 will continue to keep the Down syndrome community informed about the health care and Medicaid reform issues as they progress. We encourage you to stay engaged by: (1) Signing up to receive to the NDSC E-News and action alerts at: <http://www.ndsccenter.org/stay-up-to-date-with-ndsc-news/> and (2) “Like” the NDSC Governmental Affairs Facebook page and (3) follow NDSC Governmental Affairs on Twitter @policyupdates.