



NDSS Action Alert (Reissued from May 10) – Senate Advocacy re: Senate ACA Task Force With U.S. Senators returning to Washington, DC this week from their Memorial Day recess, we expect them to increase their efforts to develop an alternative version of legislation (H.R. 1628) narrowly approved by the House of Representatives to repeal and begin replacing significant parts of the Affordable Care Act (ACA). As you know, the National Down Syndrome Society continues to have a number of serious concerns with the House-passed legislation, especially provisions that make changes to Medicaid and private health insurance plans that are detrimental to individuals with Down syndrome and their families. Earlier this month, Senate Majority Leader Mitch McConnell (R-KY) announced the establishment of a task force of U.S. Senators who will be tasked with developing an alternative version of legislation to repeal and replace ACA, these include:

Mitch McConnell (R-KY) @McConnellPress
John Cornyn (R-TX) @JohnCornyn
John Thune (R-SD)@SenJohnThune
John Barrasso (R-WY)@SenJohnBarrasso
Mike Enzi (R-WY) @SenatorEnzi
Orrin Hatch (R-UT)@SenOrrinHatch
Lamar Alexander (R-TN) @SenAlexander
Pat Toomey (R-PA) @SenToomey
Ted Cruz (R-TX) @SenTedCruz
Mike Lee (R-UT) @SenMikeLee
Tom Cotton (R-AR) @SenTomCotton
Cory Gardner (R-CO) @SenCoryGardner
Rob Portman (R-OH) @SenRobPortman

ACTION NEEDED: NDSS is grateful to those advocates who, in response to our May 10 action alert, have contacted their Senators, particular those advocates who live in the states represented by Senators above, to educate them on how changes to Medicaid and repeal of the ACA would directly impact you and your family. We urge you to continue to do so. Click [HERE](#) for a useful summary of the House-passed bill developed by the Kaiser Family Foundation.

Talking Points/Background:

Your U.S. Senators need to know how Medicaid and other reforms enacted as part of the ACA are needed to encourage people with Down syndrome to live and work in their communities, develop assets that reduce dependence on public benefits and avoid costly and segregated institutions. For example:

- If you or your family member with Down syndrome receives or is hoping to receive optional Medicaid services such as employment supports through Long-Term Services and Supports (LTSS) or Home and Community-Based Services (HCBS), let your Senators know why those programs are important to you and why they are put at risk by a provision in the House-passed bill that caps Medicaid payment to the states. Enactment of a per capita Medicaid spending cap threatens to halt the progress that has been made 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. To learn more about optional Medicaid services utilized by individuals with disabilities, click [HERE](#).



- Let your Senators know that individuals with Down syndrome have pre-existing and co-occurring medical conditions, and a provision in the House-passed bill would allow states to waive an ACA requirement prohibiting private insurance plans from charging more for pre-existing conditions. Such a waiver could undermine access to continuous health insurance coverage for people with Down syndrome, many of whom have conditions such as cognitive impairment, congenital heart defects, leukemia, obstructive sleep apnea, seizure disorders, neurobehavioral problems, pulmonary hypertension, thyroid diseases, celiac disease, gastrointestinal defects, Type 1 diabetes, immune system dysfunction, metabolic dysfunction and mental health disorders, to name a few.

- If you or your family member with Down syndrome depends on any of the 10 essential health benefits (EHBs) proscribed in the ACA, such as rehabilitative and habilitative services and devices, let your Senators know why these services are particularly important. The House-passed bill would allow states to apply for waivers to re-define EHBs for health insurance coverage offered in the individual or small group market. People with Down syndrome typically face delays in basic physical, cognitive, language, social and self-help skills, and 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. To learn more about optional Medicaid services utilized by individuals with disabilities, click [HERE](#).

NDSS is continuing to meet with key U.S. Senators and Congressional staff to outline these and other concerns with the House-passed legislation, and to advance health care reforms that will improve health outcomes, increase access to quality care, and create economic opportunity for all individuals with Down syndrome and other disabilities. Your continued active engagement in helping your Senators to understand why these programs are personally important to you and your family will further advance our efforts to ensure that cost-effective health insurance and supportive services will continue to be available. Please share feedback from your advocacy outreach and feedback with our team to help inform our ongoing meetings and discussions on Capitol Hill by sending us an email at:

policy@ndss.org.

For more information, please see NDSS' detailed U.S. House of Representatives letters: <http://www.ndss.org/Advocacy/Legislative-Agenda/Health-Care-Research/Affordable-Care-Act/>