



September 4, 2018

The Honorable Joe Barton
The Honorable Kathy Castor
United States House of Representatives
Washington, D.C. 20515

Dear Congressman Barton and Congresswoman Castor:

On behalf of the National Down Syndrome Society, the leading human rights organization for all individuals with Down syndrome, I am writing to express our support for H.R. 3325, the "Advancing Care for Exceptional (ACE) Kids Act of 2017." We commend you for your leadership in sponsoring this legislation.

NDSS is the largest nonprofit organization dedicated to advocating for people with Down syndrome and their families at the federal, state and local levels of government. We are at the forefront of public policy efforts to improve the quality of healthcare provided to people with Down syndrome. H.R. 3325 is one such effort because it will improve the process by which children with Down syndrome who participate in the Medicaid program, and who also have other complex medical conditions, are able to obtain quality care and coordinated treatments.

According to the National Institutes of Health (NIH), at least one-half of all children with Down syndrome also have co-occurring conditions that contribute to the medical complexity of Trisomy 21. Leukemia and congenital heart disease are examples of common afflictions early in life that necessitate extensive medical intervention. Other common co-occurring conditions include obstructive sleep apnea, seizure disorders, neurobehavioral problems, pulmonary hypertension, thyroid diseases, celiac disease, gastrointestinal defects, Type 1 diabetes, immune system dysfunction, and metabolic dysfunction.

Because their complex medical conditions can be costly, many children with Down syndrome depend on state-based Medicaid programs. But they also require specialized care in centers of excellence, often times outside of their state, and Medicaid rules can limit access to coordinated care.

H.R. 3325 creates a mechanism for states to participate in a national framework for children with Down syndrome who also have other complex medical conditions, as well as other children with medical complexities and their families, to receive cost-effective and coordinated health care and support. This framework could significantly reduce the necessity for more extensive medical interventions later in life, thus improving the long-term financial viability of the Medicaid program.

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Thank you for your leadership and support on this important issue. NDSS welcomes the opportunity to work with you to advance this legislation.

Sincerely,

A handwritten signature in black ink, appearing to read "Sara Hart Weir". The signature is fluid and cursive, with the first name "Sara" being the most prominent.

Sara Hart Weir, MS
President & CEO
National Down Syndrome Society