Legislative Priorities in the 114th US Congress

The National Down Syndrome Society (NDSS), founded in 1979, is the largest nonprofit in the United States dedicated to advocating for individuals with Down syndrome and their families. At NDSS, we envision a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. Our legislative priorities seek to promote these objectives throughout the lifespan of an individual with Down syndrome from birth through adulthood.

The NDSS Advocacy & Public Policy Center, located in Washington DC, works with Congress and federal agencies to develop and improve laws, regulations and other policies by executing a comprehensive legislative agenda supporting people with Down syndrome. Through its state-of-the-art national and statewide grassroots advocacy programs, NDSS works with self-advocates, parents and others to advocate for policies and initiatives on the local, state and national level to positively impact the lives of people with Down syndrome.

ECONOMIC SELF-SUFFICIENCY

ABLE to Work Act (S. 2702/H.R. 4795): Allows individuals and their families to save more money in an ABLE account if the beneficiary works and earns income. Specifically, an ABLE beneficiary who earns income from a job could save up to the Federal Poverty Level (currently at $11,770) beyond the existing $14,000 annual cap.

ABLE Financial Planning Act (H.R. 4794/S. 2703): Allows ABLE beneficiaries to roll over regular 529 accounts to 529A (ABLE) accounts up to the annual maximum contribution, and allows for a reverse-rollover if the beneficiary ceases to be disabled.

ABLE Age Adjustment Act (H.R. 4813/S. 2704): Raises the age of onset of disability from 26 to 46, which is halfway to retirement age.

Special Needs Trust Fairness & Medicaid Improvement Act (H.R. 670/S. 349): Enables individuals with disabilities to create their own special needs trusts (SNTs) without jeopardizing eligibility for means-tested benefits. This bill seeks to correct a drafting error in an earlier law (Omnibus Budget Reconciliation Act of 1993) that prevented competent individuals from establishing and controlling their own SNTs.

EMPLOYMENT

Transition to Independence Act (S. 1604): Creates a five-year Medicaid demonstration program in ten states. The program would give bonuses to the states for helping individuals with disabilities obtain integrated employment and for reducing subminimum wage work.

Transition to Integrated, Meaning Employment (TIME) Act (S. 2001/H.R. 188): Phases out, over three years, the Fair Labor Standards Act section 14(c), passed in 1938, which authorizes the Secretary of Labor to issue Special Wage Certificates to certain entities, permitting them to pay workers with disabilities subminimum wage (less than minimum wage).

EDUCATION

Every Student Succeeds Act (ESSA) (P.L. 114-95): Although the law has been enacted, NDSS continues to monitor state implementation and urges Members of Congress to support robust and meaningful federal regulation and oversight.
Strengthening Career and Technical Education for the 21st Century Act (H.R. 5587): a bill to reauthorize the Carl D. Perkins Career and Technical Education Act (P.L. 109-270), which provides funding for the nation’s career and technical education programs in secondary and post-secondary institutions which can be a key to success for individuals with Down syndrome preparing for life after secondary school.

COMMUNITY INTEGRATION
Disability Integration Act of 2015 (S. 2427): Would require states and insurance providers that pay for longterm services and supports (LTSS) to change their policies, provide community-based services first, and offer HCBS to people currently in institutions.

Kevin & Avonte’s Law (S. 2614/HR4919): Would enable Justice Department grants to be used by state and local law enforcement agencies to provide training programs designed to prevent elopement, as well as facilitate emergency protocols to track individuals who elope.

HEALTH CARE & RESEARCH
Accurate Education for Prenatal Screenings Act (H.R. 3441): Directs the Centers for Disease Control and Prevention (CDC) to develop, implement, and maintain programs to educate patients as well as health care providers on the purpose of cell-free DNA prenatal screenings, the reasons for such screenings, what conditions may be detected, as well as the risks, benefits, and alternatives to such screenings.

The Advancing Care for Exceptional (ACE) Kids Act of 2015 (S. 298/ H.R. 546): Addresses obstacles to the coordination of care in state-based Medicaid programs for children, such as those with Down syndrome, with complex medical conditions who see many different specialists, and may require care that takes them across state lines.

21st Century Cures Act (H.R. 6)/Senate Innovation Initiative: Modernizes the clinical and biomedical research process, from the discovery of clues in basic science, to streamlining the drug and device development process, to utilizing the power of digital medicine and social media at the treatment delivery phase.

The Congenital Heart Futures Reauthorization Act of 2015 (S. 2248/ H.R. 3952) – Would direct the CDC to enhance and expand their research and surveillance infrastructure for congenital heart disease, which is a very common health problem in individuals with Down syndrome.

NIH Funding for Down Syndrome Research: NDSS consistently urges the National Institutes of Health (NIH) to provide sufficient funding to advance the priorities identified in the agency’s Research Plan for Down syndrome.

For more information, please go to www.ndss.org or contact Heather Sachs, NDSS VP of Advocacy & Public Policy, at hsachs@ndss.org