



The National Down Syndrome Society (NDSS) is the leading human rights organization for all individuals with Down syndrome, and 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.

The following are some of the policy priorities that NDSS seeks to advance in Congress, and that have impacts throughout the lifespan of an individual with Down syndrome. For more information, please go to www.ndss.org or contact Ashley Helsing, NDSS Director of Government Relations, at ahelsing@ndss.org or (202) 766-2407.

1. Transformation to Competitive Employment Act (H.R. 873/S. 260)

The Transformation to Competitive Employment Act is bipartisan legislation designed to strengthen and enhance the disability employment service delivery systems throughout the states. The goal of the bill is to increase disability employment through expanding the infrastructure for providing services for competitive integrated employment and integrated services, while simultaneously phasing out Special Wage Certificates (SWCs) under Section 14(c) of the Fair Labor Standards Act.

NDSS strongly supports this legislation because it will help pave the way for equality in the workplace for people with Down syndrome and other disabilities, many of who work in settings that fail to prepare them for integrated employment in the mainstream economy. By phasing out the special wage certificates, this legislation will give people with disabilities access to the work and training environments that will allow them to acquire meaningful skills and better employment opportunities.

The phase-out period includes a systematic approach to expand capacity for competitive integrated employment, particularly for people transitioning out of sheltered workshops. Specifically, the bill authorizes \$300 million for two grant programs supporting competitive, integrated employment and a technical assistance center. One grant program will help states transition the business models of 14(c) certificate holders. The second will help current 14(c) certificate holders located in states that do not apply for the state grants to transition their business models. Technical assistance center will support all entities phasing out 14(c) to disseminate best practices and lessons learned on the transition from subminimum wage to competitive employment.

NDSS REQUEST: Please cosponsor the bipartisan Transformation to Competitive Employment Act (H.R. 873 in the House and S. 260 in the Senate). To do so, contact:

- **House:** Katherine McClelland with Rep. Bobby Scott at Katherine.mcclelland@mail.house.gov or 202-225-5031, or Kristin Flukey with Rep. McMorris Rodgers (R-WA) at kristin.flukey@mail.house.gov or at 202-225-2006.

- **Senate:** Michael Gamel-McCormick with Sen. Bob Casey (D-PA) at michael_gamel-mccormick@aging.senate.gov or 202-224-4193.

2. Marriage Access for People with Special Abilities (MAPSA) Act (H.R. 1529)

Bipartisan legislation was introduced on March 5, 2019, by Representatives John Katko (R-NY) and Bill Keating (D-MA) to address the unique challenges facing individuals with ID/DD who want to get married and who can reasonably be expected to remain on SSI for most of their adult life. The Marriage Access for People with Special Abilities (MAPSA) Act clarifies that SSI benefits for an individual with an intellectual or developmental disability (ID/DD) will not be affected by marital status. When determining SSI benefits for an individual with ID/DD, only their income and resources will be reviewed, and will not include those of their spouse.

NDSS supports this legislation because living with an ID/DD is incredibly expensive, and there are few economies of scale that can come about when two individuals with ID/DD wish to join and create one household. Each has unique personal care needs, medical expenses, job supports and other supportive services that allow them to function independently in their communities. As a result, most adults with ID/DD cannot choose to be married without losing the necessities that allow them to function independently.

NDSS REQUEST: Please cosponsor the bipartisan Marriage Access for People with Special Abilities Act (H.R. 1529 in the House) and urge Senators to support the introduction of a companion bill in the Senate. To do so, contact:

- **House:** Jennifer Wood with Rep. John Katko (R-NY) at jennifer.wood@mail.house.gov or 202-225-3701; or Michael Wertheimer with Rep. Bill Keating (D-MA) at michael.wertheimer@mail.house.gov or 202-225-3111.
- **Senate:** Senators are urged to support the introduction of a companion bill in the Senate.

3. Congressional Task Force on Down Syndrome

Established in May 2015, the bipartisan Congressional Task Force on Down Syndrome, which includes Members of the House and Senate, is an expansion of the Congressional Down Syndrome Caucus, which was originally formed in 2008 and only included Members of the House.

The Task Force works to increase awareness in Congress about Down syndrome, and to promote bipartisan policies that further the understanding of issues important to individuals with Down syndrome and their families. It does so through various means, including letters to agency leaders, Member and staff briefings on topics of interest, and the dissemination of information about the value and acceptance of people with Down syndrome.

The Task Force has four co-chairs: Senators Jerry Moran (R-KS) and Bob Casey (D-PA); and Representatives Cathy McMorris Rodgers (R-WA) and Cheri Bustos (D-IL).

NDSS REQUEST: Please join the Congressional Task Force on Down Syndrome. To do so, please contact:

- **Senate:** Michael Gamel-McCormick with Sen. Bob Casey (D-PA) at michael_gamel-mccormick@aging.senate.gov or 202-224-4193, or Kyle Christian with Sen. Moran (R-KS) at kyle_christian@moran.senate.gov or 202-224-6521.
- **House:** Kristin Flukey with Rep. McMorris Rodgers (R-WA) at kristin.flukey@mail.house.gov or 202-225-2006 or Liam Steadman, with Rep. Cheri Bustos, at Liam.Steadman@mail.house.gov or 202-225-5905.

4. Advancing Care for Exceptional (ACE) Kids Act - PASSED!

The ACE Kids Act 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) Research Plan on Down Syndrome, 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 outside of their state. Unfortunately, current Medicaid rules can limit access to coordinated care and restrict options to receive medical treatment by out-of-state specialists. This legislation could significantly reduce the necessity for more extensive medical interventions later in life, thus improving the long-term financial viability of the Medicaid program.

5. Funding for the Investigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) project at NIH

As part of the Consolidated Appropriations Act of 2018 (H.R. 1625), Congress directed the NIH Director to develop a new trans-NIH initiative to study trisomy 21, with the aim of yielding scientific discoveries to improve the health and neurodevelopment of individuals with Down syndrome and typical individuals at risk for Alzheimer's disease/dementia, autism, cataracts, celiac disease, congenital heart disease and diabetes. The INCLUDE project was launched in June 2018 in support of the Congressional directive.

Applying the expertise and resources from multiple NIH Institutes and Centers, the INCLUDE project will conduct targeted, high-risk, high-reward basic science studies on chromosome 21; assemble a large study population of individuals with Down syndrome; and include individuals with Down syndrome in existing clinical trials. On October 1, NIH announced it made 49 awards totaling \$22.2

million in funding for INCLUDE research, bolstering total funding for Down syndrome research in FY2018 to an estimated \$59 million.

Fully funding the INCLUDE project will allow NIH to not only expand its current efforts on Down syndrome and commonly co-occurring conditions in individuals with Down syndrome that are also seen in the general population, but to build an integrated effort across NIH that will be truly transformative in these areas.

NDSS REQUEST: *Urge the House and Senate Appropriations Subcommittees on Labor, Health and Human Services to support full funding of the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) project at the National Institutes of Health (NIH).*

6. ABLE Age Adjustment Act (H.R. 1814/ S. 651)

The Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act (Public Law 113-295) was signed into law on December 19, 2014. The ABLE Act established of Section 529A tax-free savings accounts for individuals with disabilities and authorized states to develop their own ABLE programs. Currently, 42 states, including the District of Columbia, have developed ABLE programs in their states. There are now approximately 35,000 ABLE accounts nationwide which have more than \$171 million of assets under management.

ABLE Age Adjustment Act has been reintroduced to further increase the breadth and reach of ABLE accounts. Similar legislation was introduced in the 115th Congress (S. 817 and H.R. 1874), with significant bipartisan support. It would increase the eligibility threshold for ABLE accounts for onset of disability from up to age 26 to up to age 46. This would allow approximately 6 million more individuals to open ABLE accounts and increase the long-term stability and viability of the ABLE program.

As introduced, the original ABLE Act did not have any age restriction. After review by the Congressional Budget Office (CBO) and the Joint Committee on Taxation (JCT), the age limitation of 26 was added to reduce the cost associated with the enactment of the ABLE Act. However, supporters of the program vowed to work address this inequity, and the new proposed age limit of 46, while still inequitable, is an effort to address the problem in a cost-effective manner.

NDSS REQUEST: *Please cosponsor the ABLE Age Adjustment Act, which would raise the onset of disability from age 26 to 46 to be eligible for an ABLE Account. To do so, contact:*

- **Senate:** Michael Gamel-McCormick with Sen. Bob Casey (D-PA) at michael_gamel-mccormick@aging.senate.gov or 202-224-4193.
- **House:** Kristin Flukey with Rep. McMorris Rodgers (R-WA) at kristin.flukey@mail.house.gov or 202-225-2006.

7. Disability Employment Incentive Act (S. 255)

People with disabilities face many workplace barriers that make it more difficult for them to obtain and retain employment. The Disability Employment Incentive Act would provide additional incentives to small and large employers through the Work Opportunity Tax Credit, the Disability Access Credit, and the Architectural and Transportation Barrier Tax Credit to encourage the hiring and retention of individuals with disabilities as members of their workforce.

NDSS supports this legislation because it will facilitate efforts to encourage businesses to invest in hiring people with Down syndrome and increasing the number of opportunities for individuals with Down syndrome to work in meaningful and competitive employment settings. Employees with Down syndrome should be fully integrated physically, functionally and socially in the workplace, and given the necessary supports for success. Further, employers should recognize the value of employees with Down syndrome as an integral part of their workforce and provide accommodations that include them in their recruitment and hiring efforts.

NDSS REQUEST: Please cosponsor the Disability Employment Incentive Act (S. 255 in the Senate) and urge Representatives to support the introduction of a companion bill in the House. To do so, contact:

- **Senate:** Michael Gamel-McCormick with Sen. Bob Casey (D-PA) at michael_gamel-mccormick@aging.senate.gov or 202-224-4193.
- **House:** Representatives are urged to support the introduction of a companion bill in the House.

8. Disability Integration Act (H.R. 555/S. 117)

The Supreme Court's 1999 decision in *Olmstead v. L.C.* put states on notice that unnecessary segregation of individuals with disabilities is a violation of the Americans with Disabilities Act (ADA) of 1990. Unfortunately, many states have failed to implement this integration mandate by failing to provide community-based services to people with disabilities.

The Disability Integration Act (DIA) is bipartisan legislation that would address the fundamental issue that people who need Long Term Services and Supports (LTSS) are forced into institutions and losing their basic civil rights. The legislation seeks to end the institutional bias and provide people with disabilities home and community-based services (HCBS) as an alternative to institutionalization.

NDSS supports this legislation because individuals with Down syndrome and other disabilities want to live the same kind of lives most other Americans take for granted. They want to get an education, work, find someone to share our lives with and have a family. For individuals who are locked away in institutions, this isn't possible.

NDSS REQUEST: Please cosponsor the bipartisan Disability Integration Act (H.R. 555 in the House and S. 117 in the Senate) to affirm the rights of people with disabilities to have the real choice to live in the community. To do so, contact:

- **Senate:** Matt Fuentes with Senator Charles Schumer (D-NY) at matthew_fuentes@schumer.senate.gov 202-224-6542.

- **House:** Amy Bos with Rep. Jim Sensenbrenner (R-WI) at amy.bos@mail.house.gov or 202-225-5201.

9. Higher Education Act Reauthorization

Congress is in the process of considering a major rewrite of the Higher Education Act (HEA), which was last comprehensively reauthorized in 2008 by the Higher Education Opportunity Act. That legislation included important new provisions that allow students with intellectual disabilities to access certain forms of federal financial aid (grants and work-study jobs) if the student meets the definition of "intellectual disability" and is enrolled in a Comprehensive Transition and Postsecondary Program for Students with Intellectual Disabilities (CTP). The law also authorized Transition and Postsecondary Programs for Students with Intellectual Disability (TPSIDs) to create high-quality model programs and a National Coordinating Center (NCC) to provide technical assistance, evaluate the TPSIDS, and recommend program standards.

Forty years of advancement in K-12 policy and practice – spurred by the implementation of the Individuals with Disabilities Education Act (IDEA) – has improved access to the general curriculum, classroom inclusion, and academic achievement of students with disabilities. Yet, higher education policy has not kept pace with K-12 system improvements, resulting in a lack of higher education and competitive integrated employment options for individuals with disabilities. It is important that HEA reauthorization legislation maintain the 2008 reforms while enacted new reforms that would eliminate additional barriers to student participation in higher education programs.

NDSS REQUEST: *Retain and improve higher education programs for students with intellectual disabilities so they have access to financial aid and inclusive college programs that lead to competitive, integrated paid employment.*

10. Keeping All Students Safe Act

Restraint and seclusion practices used in public schools have killed, injured, and traumatized students. They are disproportionately used on students with disabilities. In 2016, the Department of Education released figures that showed that, although students with disabilities make up 12% of all public school students, they account for 67% of students subjected to restraint or seclusion. The disproportionate use of these techniques on students with disabilities violates their right to nondiscrimination in accessing education.

Although many states are taking stronger actions to pass laws prohibiting seclusion and limiting restraint, at least 11 states have no policy protecting children from these practices. In many states, parents are never even notified their child is placed in seclusion or had restraint imposed.

The Keeping All Students Safe Act is legislation that was introduced at the end of the 115th Congress (H.R. 7124 in the House and S. 3626 in the Senate) that would make it illegal for any school receiving federal funds to seclude a child, prohibit schools from physically restraining children, except when necessary to protect students and staff, and better equip school personnel with the training they need to address challenging behavior with evidence-based proactive strategies.

NDSS REQUEST: *When reintroduced, please cosponsor the Keeping All Students Safe Act to prevent the harmful use of restraint and seclusion in our nation's schools.*

About Down Syndrome

Down syndrome is the most common chromosomal condition in the United States. People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of them also have secondary neurobiological, behavioral and psychological conditions, such as Autism spectrum disorders. However, many of these conditions are now treatable, so most people with Down syndrome lead healthy lives. They attend school and work, participate in decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways.

All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses. Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to lead fulfilling and productive lives.