



## Policy Priorities for the Down Syndrome Community July 2021

### *About Down Syndrome*

Down syndrome is the most common chromosomal condition in the United States. People with Down syndrome have a third copy of the 21<sup>st</sup> chromosome (trisomy 21). A common aspect of Down syndrome is an increased risk for certain medical conditions, as well as secondary neurobiological, behavioral and psychological conditions. Fortunately, many of these conditions are treatable, and most people with Down syndrome lead very healthy lives.

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 live meaningful, productive lives. They attend school and work, participate in decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways.

### *About NDSS*

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](http://www.ndss.org) or contact Ashley Helsing, NDSS Director of Government Relations, at [ahelsing@ndss.org](mailto:ahelsing@ndss.org) or (202) 766-2407.

### **1. The Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1235)**

Introduced by Congresswoman Jaime Herrera Beutler (R-WA) and Katie Porter (D-CA), the Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1235) prohibits discrimination by health care providers and entities associated with organ transplant against individuals seeking an organ transplant based on their disability. This legislation would uphold and enforce rights established in the Americans with Disabilities Act of 1990.

If passed, the Charlotte Woodward Organ Transplant Discrimination Prevention Act will ensure that a person's capacity to comply with post-transplant treatment requirements is not a significant

reason to deny them a transplant procedure. Furthermore, this bill requires that health care providers make policies, practices and procedures accessible to qualified recipients with disabilities.

The bill is named for Charlotte Woodward, an advocate with Down syndrome and member of the NDSS staff who received a life-saving heart transplant nearly nine years ago. Since then, she has advocated tirelessly to ensure others with Down syndrome and other disabilities have the same access to transplants.

***NDSS REQUEST:*** Please cosponsor H.R. 1235 and urge Senators to support the introduction of a companion bill in the Senate. To cosponsor, contact:

- Adrianna Lagorio with Rep. Jamie Herrera Beutler at [Adrianna.Lagorio@mail.house.gov](mailto:Adrianna.Lagorio@mail.house.gov) or at (202) 225-3536 or Jessica Seigel with Rep. Katie Porter at [jessica.seigel@mail.house.gov](mailto:jessica.seigel@mail.house.gov) or at (202) 225-5611.

## **2. Transformation to Competitive Integrated Employment Act (H.R. 2373/ S. 260)**

The Department of Labor (DOL) states that The Fair Labor Standards Act (FLSA) of 1938 establishes minimum wage, overtime pay, recordkeeping and youth employment standards affecting employees in the private sector and in Federal, State and local government ([U.S. Department of Labor](https://www.dol.gov)). Within this law, there is a provision called Section 14(c) that allows employers to pay people with disabilities less than the minimum wage (subminimum wage).

People with disabilities who are employed under the 14(c) certificates are trained to perform mundane tasks that do not build capacity or transfer into skills necessary to transition into other employment options. Thus, after entering these programs, people with disabilities remain in subsidized employment. This practice reinforces the misconception that people with disabilities are less productive and creates an artificial barrier to future employment opportunities.

H.R. 2373 will help pave the way for equality in the workplace for people with disabilities by moving them out of settings that do not prepare them for integrated employment and giving them access to acquiring meaningful skills and better employment.

***NDSS REQUEST:*** Please cosponsor (H.R. 2373) and urge Senators to support the introduction of a companion bill in the Senate. To cosponsor, contact:

- Phoebe Ball with Rep. Bobby Scott at [Phoebe.Ball@mail.house.gov](mailto:Phoebe.Ball@mail.house.gov) or 202-225-3725 or Kristin Flukey with Rep. McMorris Rodgers (R-WA) at [kristin.flukey@mail.house.gov](mailto:kristin.flukey@mail.house.gov) or (202) 225-2006.

## **3. Marriage Access for People with Special Abilities (MAPSA) Act (H.R. 761)**

The Marriage Access for People with Special Abilities Act (H.R. 761) ensures that marital status will not affect SSI or Medicaid benefits for those with intellectual or developmental disabilities (IDD). Under the current law, eligibility for SSI is determined using the incomes of both spouses. If passed, MAPSA will make sure eligibility is based only on an individual's income and not their spouse's.

NDSS supports this legislation because living with IDD is incredibly expensive, and there are few

economies of scale that can come about when two individuals with IDD 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 IDD cannot choose to be married without losing the necessities that allow them to function independently.

***NDSS REQUEST:*** Please cosponsor H.R. 761 in the House and urge Senators to support the introduction of a companion bill in the Senate. To cosponsor, contact:

- Jennifer Tyler with Rep. Katko (R-NY) at [jennifer.tyler@mail.house.gov](mailto:jennifer.tyler@mail.house.gov) or (202) 225-3701 or Natasha Silva with Rep. Keating (D-MA) at [natasha.silva@mail.house.gov](mailto:natasha.silva@mail.house.gov) or (202) 225-3111.

#### **4. ABLE Age Adjustment Act (H.R. 1219/S. 331)**

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 Section 529A tax-free savings accounts for individuals with disabilities and authorized states to develop their ABLE programs. As of January 2021, 43 states, and the District of Columbia, have developed ABLE programs in their states. There are about 82,000 ABLE accounts nationwide which have more than \$643 million in assets.

The ABLE Age Adjustment Act will further increase the breadth and reach of ABLE accounts. Similar legislation in the 115th Congress (H.R. 1874/ S. 817) and 116th Congress (H.R. 1814/S. 651) received significant bipartisan support. To be eligible for an ABLE Account, the onset of the disability must occur before the age of 26. If passed, H.R. 1874/S. 331 would increase the onset age to 46. This would allow six million more people with disabilities to open ABLE accounts. More access to accounts would increase the security of the ABLE program.

The original drafting of the ABLE Act did not have any age restriction. A review by the Congressional Budget Office (CBO) and the Joint Committee on Taxation (JCT) added the age limit of 26 to reduce the cost. Supporters of the program worked to address this inequity and the new proposed age limit of 46. Though still inequitable, it will help address the problem cost-effectively.

***NDSS REQUEST:*** Please cosponsor the ABLE Age Adjustment Act H.R. 1219/S. 331, which would raise the onset of disability age from 26 to 46 to be eligible for an ABLE Account. To cosponsor, contact:

- **Senate:** Michael Gamel-McCormick with Sen. Bob Casey (D-PA) at [michael\\_gamel-mccormick@aging.senate.gov](mailto:michael_gamel-mccormick@aging.senate.gov) or (202) 224-4193 or Kyle Christian with Sen. Moran at [kyle\\_christian@moran.senate.gov](mailto:kyle_christian@moran.senate.gov) or (202) 224-6521.
- **House:** Olivia Oo with Rep. Tony Cardenas at [olivia.oo@mail.house.gov](mailto:olivia.oo@mail.house.gov) or at (202) 225-6131 or Kristin Flukey with Rep. McMorris Rodgers (R-WA) at [kristin.flukey@mail.house.gov](mailto:kristin.flukey@mail.house.gov) or (202) 225-2006.

#### **5. Congressional Task Force on Down Syndrome**

In May 2015, the bipartisan Congressional Task Force on Down Syndrome formed as an expansion of the Congressional Down Syndrome Caucus. The Congressional Task Force on Down Syndrome

includes Members of the House and Senate. Formed in 2008, The Congressional Down Syndrome Caucus only included Members of the House.

The Task Force works to increase awareness in Congress about Down syndrome. It promotes bipartisan policies to educate legislators about issues important to individuals with Down syndrome and their families. Activities include letters to agency leaders, Member and staff briefings and sharing information about the value of people with Down syndrome.

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

- **House:** Kristin Flukey with Rep. McMorris Rodgers (R-WA) at [kristin.flukey@mail.house.gov](mailto:kristin.flukey@mail.house.gov) or (202) 225-2006 or Liam Steadman with Rep. Cheri Bustos at [liam.steadman@mail.house.gov](mailto:liam.steadman@mail.house.gov) or (202) 225-5905
- **Senate:** Michael Gamel-McCormick with Sen. Bob Casey (D-PA) at [michael\\_gamel-mccormick@aging.senate.gov](mailto:michael_gamel-mccormick@aging.senate.gov) or (202) 224-4193

## **6. 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 trans-NIH initiative to study trisomy 21. The goal is to improve the health and neurodevelopment of people with Down syndrome. The study also includes people in the general population with Alzheimer's disease/dementia, autism, cataracts, celiac disease, congenital heart disease and diabetes. The INCLUDE project launched in June 2018 in support of the Congressional directive.

The project applies expertise and resources from multiple NIH Institutes and Centers. It conducts targeted, high-risk, high-reward basic science studies on chromosome 21. Individuals with Down syndrome participate in existing clinical trials. On October 1, 2019, NIH announced it made 49 awards totaling \$22.2 million in funding for INCLUDE research. This will increase the total funding from FY2018 to an estimated \$59 million.

Fully funding the INCLUDE project is critical. It will allow NIH to expand its efforts on Down syndrome and the co-occurring conditions people with Down syndrome experience that are also found in the general population. In addition, it is building an integrated effort across NIH that will be truly transformative.

***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 NIH.*

## **7. Disability Employment Incentive Act (H.R. 3765/ S. 630)**

People with disabilities face barriers that make it difficult 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. This will encourage the hiring and retention of people with disabilities in the workforce.

NDSS supports this legislation because it will facilitate efforts to encourage businesses to invest in hiring people with disabilities, including Down syndrome. It will increase the number of opportunities for people with Down syndrome to work in meaningful and competitive employment settings. Employees with Down syndrome should be fully integrated in the workplace and have the necessary supports for success. 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 S. 630 and support the introduction of a companion bill to the S. 630 in the House. To cosponsor, contact:

- Michael Gamel-McCormick with Sen. Bob Casey (D-PA) at [michael\\_gamel-mccormick@aging.senate.gov](mailto:michael_gamel-mccormick@aging.senate.gov) or (202) 224-4193.

## **8. Disability Integration Act**

The Supreme Court's 1999 decision in *Olmstead v. L.C.* stated that the unnecessary segregation of individuals with disabilities is a violation of the Americans with Disabilities Act (ADA) of 1990. Despite this, many states have failed to implement integration.

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

NDSS supports this legislation because people with disabilities want to live the same kind of lives as other Americans. They want to get an education, work, find someone to share their lives with and have a family. For individuals who are in institutions, this isn't possible.

***NDSS REQUEST:*** Please support the reintroduction of this legislation in the House and Senate.

## **9. Access to Inclusive Postsecondary Education Opportunities**

Students with Down syndrome often face significant challenges when transitioning out of the K-12 education system. Whether they choose to continue their education at an institution of higher education or through career and technical education or an apprenticeship, they encounter systems that stand in stark contrast to the supports required under the Individuals with Disabilities Education Act (IDEA).

As Congress continues to contemplate various methods to amend the Higher Education Act, National Apprenticeship Act and other laws related to postsecondary transition, NDSS works to ensure that the structures put in place will support students with Down syndrome and other disabilities, not stand in their way. We are especially mindful of how potential changes to Titles I,

IV, and VII of the Higher Education Act would impact the Down syndrome community.

***NDSS Request:*** Retain and improve Higher Education Act programs dedicated to students with intellectual disabilities; remove barriers to entry, including those related to disclosure of disability, financial aid eligibility and wellness supports. Improve overall inclusiveness of Registered Apprenticeships to be more closely aligned with IDEA and updated priorities in Perkins V.

## **10. Inclusion, Equity and Disability Justice in School Safety Initiatives**

Even before the COVID-19 pandemic redefined the parameters of school safety, students with disabilities encountered practices that produce discriminatory outcomes or, at best, disparate impacts. Non-inclusive emergency preparedness, the use of restraint and seclusion, inequitably applied discipline procedures and a pervasive lack of understanding about disability manifestation among staff all continue to put students with Down syndrome and other disabilities at risk at school. We must stop imperiling our students.

As Congress works to address these issues – in addition to its work shaping COVID-19 safety procedures – NDSS is advocating for policies rooted in the civil right of individuals to be safe at school. We look forward to reviewing the *Keeping All Students Safe Act*, which we have supported in prior Congresses, and whose reintroduction we anticipate this year.

***NDSS Request:*** Account for the right of students with disabilities to be safe in any and all legislation related to student safety; support legislation that effectively curtails the harmful use of restraint and seclusion in our nation's schools.

## **11. Educator Preparation, Support and Professional Development**

Educational outcomes for students are inextricably linked with professional development for all educators – classroom teachers, school administrators, paraprofessionals, specialized instructional support personnel and non-instructional staff. For students with Down syndrome and other disabilities, whose legal rights include the provision of special education services, the importance of a well-instructed, well-supported staff is only more critical. But the legal framework of professional development for educators is a patchwork of various federal laws, state implementation and local deployment of resources. This lack of coordination ultimately results in a system where educators are too often under-prepared and under-supported, contributing to high attrition throughout the field.

As Congress weighs appropriations strategies and potential amendments to the Higher Education Act, the Every Student Succeeds Act, the Individuals with Disabilities Education Act and other laws that impact educator preparation and support, NDSS is working to ensure that all educators have the resources and training to support the students with disabilities they serve, informed by evidence-based best practices.

***NDSS Request:*** Support legislation that improves both pre-service and in-service professional development and support for all educators.