



## **NDSC Policy Positions for the 117<sup>th</sup> Congress (2021-2023)**

January 2021

The National Down Syndrome Congress (NDSC) is the country's oldest national non-profit, non-partisan organization that provides information, advocacy and support for people with Down syndrome, their families, and the professionals who work with them. NDSC's Policy & Advocacy Team is comprised of experienced, well-connected, and highly regarded national subject matter policy experts and leaders and is counseled by an engaged and experienced NDSC Public Policy Advisory Council, which represents a diversity of viewpoints and experiences.

NDSC engages with policymakers on a bipartisan basis and educates and empowers stakeholders to speak up for policies that will improve the lives of individuals with Down syndrome and their families. NDSC's policy positions and priorities are developed in consultation with the NDSC Policy Team, the Executive Director, the NDSC Public Policy Advisory Council and approved by the NDSC Board of Directors.

The NDSC Policy & Advocacy Team works across all policy areas listed in this document but with varying levels of leadership and engagement due to policy priorities, capacity, and resource limitations, as well as depending upon the urgency of a particular situation. ***NDSC has designated as its top tier priority areas of advocacy work: (1) COVID-19 Relief; (2) Education (both K-12 and Postsecondary); (3) Employment and (4) Medicaid Long-Term Services and Supports.*** NDSC's public policy positions (primarily listed alphabetically below) are based upon the assumption that people with Down syndrome want to live independent, self-determined lives in the community while receiving necessary supports, and that they have the right to do so.

### **COVID-19**

The COVID-19 pandemic has taken a huge toll on people with Down syndrome and their families. Since the COVID-19 pandemic began, NDSC has been advocating to protect the rights of individuals with disabilities and to obtain funding and resources to support them across many areas. NDSC will continue to advocate for COVID relief, including to:

1. Increase funding and resources for Medicaid Home and Community-based Services (HCBS) providers who are faltering and collapsing due to COVID-related closures. HCBS are vital to individuals with disabilities to help them maintain their independence and access the community;
2. Advocate to protect students with disabilities' rights under the Individuals with Disabilities Education Act (IDEA) throughout the COVID pandemic and request increased funding dedicated to IDEA implementation during virtual learning, as well as funding for educator and personnel shortages exacerbated by COVID;
3. Prevent COVID-related medical rationing schemes that discriminate against people with disabilities, to change hospital visitation policies so that people with disabilities can have a support person with them, and to prioritize people with Down syndrome in vaccine allocation; and
4. Expand safety net resources such as payment of COVID stimulus checks (dependent credit of \$500) to taxpayers who claim dependents over age 18 with disabilities, paid leave to caregivers of people with disabilities who need to stay home due to COVID, Supplemental Nutrition Assistance Program (SNAP) benefits (upon which many people with disabilities rely) to enable people to use benefits for online delivery and takeout to minimize COVID risk; and unemployment benefits to include part-time workers with disabilities who have been laid off due to COVID.

## **CIVIL RIGHTS**

People with Down syndrome are entitled to equal rights and full participation in society. NDSC works to preserve civil rights through vigilant enforcement of laws and regulations as well as to strongly oppose efforts that limit the rights of people with Down syndrome and other disabilities. NDSC's main civil rights priorities are to:

1. Protect the rights of individuals with Down syndrome in coalition with organizations working against forms of discrimination based on disability ethnicity, race, sex, gender identity and expression, sexual orientation, religion, familial status, age, language, national origin, genetic information, or any other protected status.
2. Protect and promote stronger enforcement of existing civil rights laws for people with disabilities, particularly the Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA), Every Student Succeeds Act (ESSA), the Rehabilitation Act, the Workforce Innovation Opportunity Act (WIOA) and Section 1557 of the Affordable Care Act.

## **DIRECT SUPPORT PROFESSIONALS**

NDSC recognizes that a well-trained, fairly compensated direct support professional (DSP) workforce is essential to providing necessary supports and services to people with Down syndrome and other disabilities where they live and work. Unfortunately, the longtime DSP workforce crisis (low wages, high turnover, shortage) has been exacerbated by COVID-19. NDSC works to:

1. Ensure adequate funding so that DSPs are paid a living wage, including appropriate benefits, through Medicaid and other sources;
2. Implement programs aimed at the direct support labor market to address the workforce crisis such as recruitment, retention, training and supervision of DSPs to better serve individuals with disabilities; and
3. Classify DSPs as “essential workers” so that they receive all protections and benefits available to other healthcare workers, including access personal protective equipment (PPE) and priority in vaccine distribution.

## **EDUCATION**

NDSC believes that the education system must help people with Down syndrome to achieve their full potential and independence by having high expectations, integrated instruction by certified and effective teachers, inclusive classrooms, appropriate assessments, and positive behavioral supports to prepare students for postsecondary education, employment, and living as independently as possible in the community. NDSC’s [Position Statement on Inclusive Education](#) details NDSC’s core tenets and approach to advocacy on education issues. NDSC’s main education priorities are to maintain high expectations and accountability, encourage inclusion, and to preserve students’ rights. To that end, NDSC’s education public policy positions for the 117<sup>th</sup> Congress are:

### **1. *Every Student Succeeds Act (ESSA)***

- a. Full participation of students with disabilities in assessment, accountability systems, and reporting systems, including transparency about school performance for students with disabilities and state and local education agencies (LEAs) report cards;
- b. Required assessments that are aligned with the challenging state academic standards for the grade in which the student is enrolled;
- c. Proper implementation of the ESSA requirement that State Education Agencies should not exceed the 1% cap on the number of students with the most significant cognitive disabilities who take an alternate assessment aligned with alternate academic achievement standards; and
- d. Progress in the general education curriculum and an opportunity to complete the requirements of a regular high school diploma for students who take the alternate assessment; and
- e. Funding and full implementation of the early childhood provisions.

### **2. *Individuals with Disabilities Education Act (IDEA)***

- a. Monitoring and enforcement of the major components of IDEA, including free and appropriate public education (FAPE) in the least restrictive environment (LRE), due process, transition, and individualized education programs (IEPs);
- b. Change the Office of Special Education Program’s monitoring system so that it addresses LRE implementation by disability category and includes the academic progress of students who take alternate assessments, including changing how

annual determinations are made regarding whether states have met the requirements of IDEA;

- c. Preserve and implement the guarantee of a free and appropriate public education in the least restrictive environment;
- d. Fully fund IDEA Part B Section 611 (grants to states for ages 3-21) and provide increased funding for Part C early intervention, Section 619 preschool and Part D National Activities;
- e. Fully engage students and their parents or guardians as members of the IEP team;
- f. Better align key components of the pre-vocational provisions in the Workforce Innovation and Opportunity Act of 2014 (WIOA) with transition service requirements under IDEA;
- g. Promote Universal Design for Learning (UDL) in curriculum and educational practices so that instructional goals, methods, materials and assessments incorporate flexible approaches that can be customized and adjusted for individual needs; and
- h. In the event of an IDEA reauthorization, develop and advocate for robust recommendations to preserve and enhance the IEP rights of students with Down syndrome and their parents/guardians.

### **3. School Discipline**

- a. Prohibit all types of seclusion and certain types of restraint that compromise student health and safety, including corporal punishment, chemical, mechanical, and physical restraints, and require timely parental notification when incidents occur;
- b. Prioritize the use of Positive Behavioral Interventions and Supports, provide funding, and require school personnel to be trained in positive behavioral supports, elopement, and appropriate and safe behavioral interventions for crisis situations;
- c. Address the disparate frequency and severity of disciplinary actions for students with disabilities, especially the harsher treatment of students of color, particularly Black students; and
- d. Strengthen requirements for states to collect and report data on seclusion and restraint.

### **4. Federal Funds for Vouchers**

- a. As a general principle, Federal education funds must remain in public schools and must not be used for any voucher programs.
- b. If a voucher bill using federal funds is introduced, NDSC will consider whether that particular bill should be supported based on various factors, including the rights of students with disabilities.

### **5. Teacher Preparation and Training**

- a. Provide training opportunities for administrators, teachers, and specialized instructional support personnel to have the pre-service preparation and ongoing professional development to implement Positive Behavioral Interventions and Supports and Universal Design for Learning ([www.udlcenter.org](http://www.udlcenter.org))

- b. Train teachers and specialized instructional support personnel to facilitate the effective use of paraprofessionals and to provide the necessary accommodations, modifications, functional skills development, and other supports to ensure progress in the grade level general education curriculum alongside nondisabled peers.

#### **6. *Transition Services, Credentials, and Apprenticeships***

- a. Prepare students with Down syndrome for increased opportunities in inclusive postsecondary education and competitive integrated employment prior to leaving secondary school by ensuring students receive education and needed support in inclusive settings to attain the skills, abilities and knowledge in academics, social competence, independent living, self-advocacy, self-determination and career preparation to be successful in inclusive postsecondary settings. The development of job skills in secondary school should be accomplished through paid apprenticeships, work-based learning opportunities and other integrated job opportunities, for pay if possible;
- b. Promote the development of and funding for high-quality inclusive higher education opportunities;
- c. Do not preclude students with Down syndrome, including those who participate in alternate assessments, from attempting to meet the requirements of a regular high school diploma, and enable students with Down syndrome to receive a meaningful exit credential if they do not earn a regular diploma; and
- d. Execute a transition process that provides a smooth pathway to adult life.

#### **7. *Inclusive Postsecondary Education***

- a. In the event of a Higher Education Act reauthorization, retain and improve the ID provisions in the law, as recommended by the Inclusive Higher Education Committee;
- b. Encourage the U. S. Department of Education to correct misinformation provided on their website, in webinars, and to programs, on the definition of intellectual disability and requirements for Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSIDs);
- c. Increase funding for TPSIDs and the National Coordinating Center; and
- d. Increase the quality of inclusive postsecondary programs for students with ID through effective implementation of model accreditation standards and through providing information and technical assistance to students, families, and institutions of higher education.

### **EMPLOYMENT**

Although the vast majority of adults with Down syndrome are unemployed or under-employed, NDSC believes that employment should be an expected life activity for individuals with Down syndrome, and that individuals with Down syndrome should have the individual and systemic supports necessary to enable them to find, keep and succeed in careers in the community based on their preferences, interests, and strengths. NDSC's [Position Statement on](#)

[Employment](#) details NDSC’s employment policy agenda. NDSC is committed to advancing policies that:

**1. *Competitive Integrated Employment***

- a. Support implementation of the Workforce Innovation and Opportunity Act (WIOA), especially the definition of “Competitive Integrated Employment” (CIE);
- b. Increase employment opportunities in integrated, meaningful, community-based settings that contain the proportion of disabled people in the general population, pay all employees at least the minimum wage in their state, and offer benefits commensurate with their positions;
- c. Support “Employment First” policies, as defined by the US Department of Labor, as a strategy to align policies, service delivery practices, and reimbursement structures to commit to CIE as the priority option with respect to use of publicly-financed day and employment services for youth and adults with significant disabilities;
- d. Create incentives and build infrastructure for public and private sector employers to hire and/or reward retention of employees with Down syndrome in CIE;
- e. Expand employment training programs to provide more job development, placement, and coaching, skills training, and other services necessary to help find and maintain CIE for people with Down syndrome, with such services based on individual need and not subject to artificial timelines; and
- f. Fully implement the Medicaid Home and Community-Based Services (HCBS) waiver program and State Medicaid plan Section 1915(i) to promote CIE.

**2. *Phaseout of Subminimum Wage***

- a. Build infrastructure and supports needed to phase out the issuance of subminimum wage certificates under Section 14(c) of the Fair Labor Standards Act while increasing opportunities for competitive, meaningful, integrated employment and putting in place safeguards to protect the interests of any people affected by this shift;
- b. Expand training and technical assistance to community rehabilitation providers to transition from the use of subminimum wages and segregated environments.

**3. *Pathways to Employment***

- a. Expand opportunities regarding apprenticeships and work-based learning experiences by facilitating the coordination of school-to-work transition programs, higher education, and community-based employers;
- b. Facilitate opportunities for self-employment and business ownership;
- c. Increase access to and capacity of supported and customized employment services funded through Medicaid and other mechanisms;
- d. Support training opportunities to support inclusive meaningful, employment opportunities in the community and be flexible enough to foster collaboration and braiding of employment-related funds;
- e. Increase the number of people with disabilities employed by the federal government and federal contractors; and

- f. Minimize transportation barriers to employment.

## **FAMILY SUPPORT**

Families play a key role in supporting people with Down syndrome, many of whom live at home. These families often receive few services and lose jobs and income as they try to meet the needs of their disabled family member. NDSC advocates to:

1. Support federal initiatives and legislation such as the Lifespan Respite Care Act that recognize the vital role of families and the need for comprehensive and affordable family supports;
2. Provide paid family and medical leave and job protections such as under the Family Medical Leave Act to workers who need to care for a disabled family member;
3. Provide a caregiver tax credit to assist families with out-of-pocket costs for disability-related expenses.

## **FINANCIAL SECURITY AND POVERTY BENEFITS**

NDSC works to promote public policy aimed at increasing the financial security of all individuals with Down syndrome and their families. Because of the disproportionate number of people with disabilities (and particularly people of color with disabilities) living in poverty, NDSC advocates for public policy that enhances savings opportunities and bolsters means-tested public benefits programs. NDSC advocates to:

### ***1. ABLÉ Accounts & Special Needs Trusts***

- a. Ensure full implementation of the Achieving a Better Life Experience (ABLE) Act and increase the availability of ABLE accounts and the sustainability of the ABLE program by expanding eligibility to those who have onset of disability after age 25.
- b. Preserve and improve upon laws and policies regarding Special Needs Trusts and other investment vehicles that will help individuals with disabilities and their families with financial planning.

### ***2. Poverty Assistance***

- a. Increase benefits and flexibility to the Supplemental Nutrition Assistance Program (SNAP), particularly regarding online purchasing and grocery delivery services
- b. Support the Temporary Assistance for Need Families (TANF) program to provide funds to needy families for income assistance, childcare, education and job training, transportation and a variety of other needs.

## **HEALTH CARE**

People with Down syndrome must have timely access to high quality, comprehensive, accessible, affordable, and individualized health care services to improve and maintain health and functioning. NDSC's healthcare priorities are to:

1. Preserve key tenets of the Affordable Care Act that eliminate denial in coverage or charge higher rates based upon pre-existing conditions, prohibit annual and lifetime caps, and cover essential health benefits such as rehabilitative and habilitative services;
2. Ensure that all people with Down syndrome and their families have access to affordable prescription drugs that meet their individual health care needs;
3. Protect existing health care entitlements under Medicare and Medicaid and make improvements to these programs, such as eliminating Medicare's 2-year waiting period and increasing provider reimbursement rates;
4. Address and reduce health care disparities experienced by people with Down syndrome, particularly people of color who have Down syndrome; and
5. Ensure that people with Down syndrome and other disabilities are treated fairly and given equal access to medical treatments, including organ transplants, vaccinations and in crisis of care standards.

## **HOUSING**

People with Down syndrome, like all Americans, have a right to live in their own homes, in the community. Adults should control where and with whom they live, have the freedom to choose their daily routines and activities, and they should have opportunities to rent or buy their own homes. NDSC's [Position Statement on Housing and Community Living](#) details the principles that guide our advocacy in this area. NDSC is committed to advancing policies that:

1. Increase funding for, and protect the integrity of, US Department of Housing and Urban Development (HUD) programs such as the Section 811 Supportive Housing for Persons with Disabilities program;
2. Address the need for safe, affordable and accessible housing; and
3. Remove barriers that prevent people with Down syndrome and other disabilities from renting or buying their own homes.

## **MEDICAID & LONG TERM SUPPORTS AND SERVICES**

Medicaid is the single largest funding source of both acute health care and long term supports and services (LTSS) (both residential and employment supports) for people with Down syndrome and other disabilities. Over 10 million people with disabilities, including those with Down syndrome, rely upon Medicaid for their health care, employment and access to community life. NDSC's priorities are to:

1. Maintain the individual entitlement to a full range of Medicaid health and LTSS for all eligible children and adults with disabilities and protect against cuts, block granting, per capita caps and other attempts to curtail Medicaid benefits such as work requirements;
2. Eliminate the waitlists and fully implement the Medicaid Home and Community Based Settings (HCBS) waiver program for both residential and employment benefits, and ensure



that the amount, duration, and scope of HCBS are provided based on individual needs identified through a person-centered planning process;

3. Remove the institutional bias and support demonstration programs like Money Follows the Person which provides funding for transition from institutions to community-based settings;
4. Provide necessary supports to states to ensure full implementation and enforcement of the HCBS Settings rule for both residential and non-residential services; and
5. Facilitate portability of benefits so that Medicaid beneficiaries and their families are not disadvantaged or deprived by moving from one state to another.

## **RESEARCH**

NDSC recognizes the vast benefits of research and scientific study to improve the quality of life for all people with Down syndrome and help them to achieve their full potential. NDSC supports the work of other national Down syndrome organizations in their advocacy for research funding for Down syndrome, IDD in general and other co-occurring conditions such as autism and Alzheimer's disease. NDSC's policy priorities are to:

1. Provide funding for all relevant agencies designed to improve the quality of life for people with Down syndrome across the lifespan and prevent the causes and effects of co-occurring conditions and to promote the translation of research findings into practice; and
2. Increase participation of people with Down syndrome, and particularly people of color who have Down syndrome, in research studies.

## **SOCIAL SECURITY**

Supplemental Security Income (SSI) provides minimum basic financial assistance to the elderly and people with disabilities with very limited income and resources, and Social Security Disability Insurance (SSDI) supports individuals who are disabled and have a qualifying work history, either through their own employment or a family member (spouse or parent). People with Down syndrome and their families rely upon benefits from one or both of these programs for financial assistance and as a gateway to obtain health insurance through Medicaid (SSI) and/or Medicare (SSDI). NDSC advocates for policies that:

1. Ensure the adequacy of SSI and SSDI benefits and remove barriers to independence, community integration, savings, work, marriage, and assistance or support by families;
2. Substantially increase both the countable income limit and the resource limit for SSI to at least the level it would have been had it been indexed for inflation since inception;
3. Increase the SSDI's and SSI's Substantial Gainful Activity (SGA) level at least to the level used for SSDI for people who are blind; and
4. Adequately fund the Social Security Administration to minimize delays in accessing benefits and processing times for claims.

## **TRANSPORTATION**

Transportation provides a critical means for people with disabilities to access employment, education, health care, and community life. NDSC advocates for policies that:

1. Eliminate discrimination in transportation and increase the supply of affordable, reliable, and accessible transportation; and
2. Integrate the principles of universal design into the development of new transportation devices and projects to ensure greater mobility for people with disabilities.

For questions about these policy positions, please contact Heather Sachs, NDSC Policy & Advocacy Director, [heather@ndscenter.org](mailto:heather@ndscenter.org)