



NATIONAL DOWN SYNDROME CONGRESS POLICY PRIORITIES 2018

Background

NDSC is a non-partisan, non-profit organization and carefully follows the Internal Revenue Service rules regarding advocacy. As such, we advocate on a bi-partisan basis and educate and empower stakeholders to speak up for policies that will improve the lives of individuals with Down syndrome and their families. Improvements in disability policy advocacy have come about with strong bipartisan support over the years. In recent years, NDSC and the disability community have experienced hard-won gains in education policy (for students with significant cognitive disabilities in the Every Student Succeeds Act and for Free Appropriate Public Education in the Individuals with Disabilities Education Act), passage of the Achieving a Better Life Experience Act, improvements in community living supports through Medicaid and employment policy under the Workforce Innovation Opportunity Act. These important statutes have been improved and aligned in a way that leads to employment and independent living, but there is still much work to be done. NDSC and the disability community also played a lead role in Congress rejecting legislation that would have dismantled health care protections and Medicaid in 2017. NDSC's advocacy focus has included education, health, employment, financial empowerment, and community living opportunities for individuals with Down syndrome.

Current Environment

With the focus of the current Administration and Congress on transferring policy and programmatic decisions to the states through block grants and other measures, NDSC will of necessity continue a major focus on protecting gains, defending against the erosion of civil and human rights, and protecting policies that benefit our stakeholders. While we are – and will continue to be -- involved in many uphill battles, it is important to advocate strongly on behalf of individuals with Down syndrome and their families and to educate and empower our stakeholders to advocate successfully. Even in those areas where we may not win a “battle”, Members of Congress and other policy makers take note of our advocacy efforts and are more cautious about the next policy battle. In addition to protecting gains, it is also important to continue to advocate for positive policy changes and potential solutions.

Strengths

The NDSC Policy & Advocacy Team is comprised of disability policy professionals who are experienced, well-connected, and highly regarded national subject matter policy experts and leaders. The Policy Team regularly consults with the engaged, experienced, and bipartisan NDSC Public Policy Advisory Council that represents a diversity of viewpoints and experiences. Recently, NDSC coalesced its large network of volunteer advocates across the country into the National Down Syndrome Advocacy Coalition (NDAC), a grassroots advocacy service that is designed to educate individuals with Down syndrome, their family members and other allies about policy issues and give them the advocacy tools, techniques and information they need to effectively engage with their legislators to advocate for change.

NDSC recognizes the value of joining our advocacy efforts with other disability and human rights groups in both informal and formal partnerships. Currently NDSC participates in the following coalitions: Consortium for

Citizens with Disabilities, Collaboration to Promote Self-Determination, National UDL Task Force, UDL Policy Council, ABLE National Resource Center and the Leadership Conference on Civil and Human Rights.

Policy Focus Areas

The NDSC Policy Team possesses significant subject matter expertise on K-12 and postsecondary education-related laws and policies. On education-related topics, NDSC is regularly consulted by Senior Hill staff, administrative agency staff, and other disability organizations. We work regularly with our coalition partners to implement our mutual policy priorities and vision.

EDUCATION

Every Student Succeeds Act (ESSA)

Goal: Retain critically important ESSA accountability.

NDSC works to retain critically important regulations and guidance and discourage waivers of the law.

Goal: Improve ESSA implementation through tools and technical assistance for stakeholders.

In states where there is a strong education advocacy presence, NDSC strives to keep these advocates informed about key ESSA issues in their state, as the issues come to our attention. NDSC also develops advocacy tools and information for use by stakeholders in any state.

Individuals with Disabilities Education Act (IDEA)

Goal: Retain IDEA protections.

NDSC works to retain current critically important regulations and guidance and develops reauthorization recommendations (but we are not encouraging reauthorization at this point).

Inclusion

Goal: Increase inclusive opportunities for students with Down syndrome and other cognitive disabilities.

NDSC participates as a liaison with the National Center on Inclusive Practices and Policies, which is focused on students with significant cognitive disabilities. We also have been promoting Dan Habib's film "Intelligent Lives" for policy purposes and to increase expectations for students with intellectual disabilities.

Universal Design for Learning (UDL)

Goal: Retain and improve positive language about UDL in the Higher Education Act (HEA).

NDSC takes the lead with the National UDL Task Force on HEA recommendations.

Goal: Increase implementation of UDL in districts and schools.

NDSC works to increase constituent knowledge and understanding of UDL and its impact on education activities. We also take the lead with UDL Policy Council to encourage states and districts to implement UDL as part of their ESSA plans and to develop and promote UDL credentialing for education personnel and certification of education technology products and education entities (e.g. school districts, schools).

Expanding Inclusive Postsecondary Education (PSE)

Goal: Retain and improve provisions in the Higher Education Act (HEA) that allow financial aid and authorize model programs and a national coordinating center for students with ID.

NDSC takes the lead in this advocacy effort through the role of Co-chair of the Committee to Promote Inclusive Higher for Students with Intellectual Disabilities (ID). We work closely with other national organizations and are in continuous contact with Congressional staff and U.S. Department of Education high-level officials, and

utilize grassroots advocacy, to encourage Congress to reauthorize and improve the ID provisions in the final Higher Education Act reauthorization bill.

Goal: Increase access to inclusive postsecondary opportunities for students with Down syndrome and other intellectual disabilities.

NDSC regularly communicates with high-level U.S. Department of Education (ED) and Capitol Hill staff to advocate for improvements to current ED guidelines that restrict the use of vocational rehabilitation and IDEA funds for students with ID in postsecondary programs. Additionally, we provide technical assistance and training to parents, program staff and others on postsecondary options, access, and funding.

Goal: Increase the quality of Postsecondary Education Programs through model standards.

As Chair of the National Coordinating Center Accreditation Workgroup, NDSC works to include policies and practices beneficial to students with Down syndrome and their families in the development and use of model accreditation standards for Postsecondary Education programs.

MEDICAID/EMPLOYMENT

NDSC recognizes that most people with Down syndrome currently do – or will in the future -- rely upon Medicaid for their health care, employment and access to community life. In addition to covering medical care, state Medicaid programs cover a wide range of services and supports for people with disabilities. The potential loss of these services through funding cuts and restructuring will be devastating to the Down syndrome community. NDSC actively works in collaboration with the Consortium for Citizens with Disabilities, the Collaboration to Promote Self-Determination and other groups to protect Medicaid.

Medicaid: Long Term Services and Supports, Employment Supports

Goal: Maintain current infrastructure framework of Medicaid and protect against cuts, block granting, and per capita caps.

Goal: Maintain long term services funded by Medicaid, particularly Home and Community Based Services (HCBS) waivers that fund employment and residential supports. (The primary source of long-term employment support is Medicaid.)

Goal: Increase public awareness of the importance of Home and Community Based Services and utilizing self-directed services with necessary safeguards.

Employment

With needed supports and services, primarily provided through Medicaid, people with disabilities have shown they can successfully work in jobs alongside their peers without disabilities. NDSC is committed to advancing policies that have been shown to help people work. This includes increasing access to supported employment services funded through Medicaid, providing job training, increasing opportunities for apprenticeship and work-based learning experiences in higher education, and addressing transportation barriers. Serving in a leadership role as Vice President of the Collaboration to Promote Self-Determination, NDSC works collaboratively with other disability groups on employment issues for people with disabilities.

Goal: Retain Workforce Innovation Opportunity Act law, especially the definition of “competitive integrated employment” and the rule not allowing schools to contract with sheltered workshops.

Goal: Expand opportunities regarding apprenticeships as a pathway to employment for people with disabilities.

OTHER PRIORITIES

The NDSC Policy & Advocacy Team also works closely with our coalition partners on the following priorities.

Transition Services

Goal: Improved transition services, including opportunities for paid work and college access, while still eligible for IDEA services (typically ages 18 through 21).

Health Care

Goal: 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.

ABLE Act

Goal: Increase the availability of ABLE accounts. Monitor legislative developments with the ABLE Act and influence the development of ABLE-related regulatory guidance.

Health Care State Bills

Goal: Monitor state bills relating to Down syndrome information, termination based on Down syndrome, and nondiscrimination in organ transplantation.

Housing

Goal: Increase supply of affordable, accessible housing, and eliminate housing discrimination.

Research Funding

Goal: Expanded funding for Down syndrome research and scientific study to improve the quality of life of people with Down syndrome and enable them to achieve their full potential.

Transportation

Goal: Increase supply of affordable, reliable transportation, and eliminate discrimination in transportation.
