

National Down Syndrome Congress

Congressional Public Policy Agenda for the 118th Congress (2023-2025)

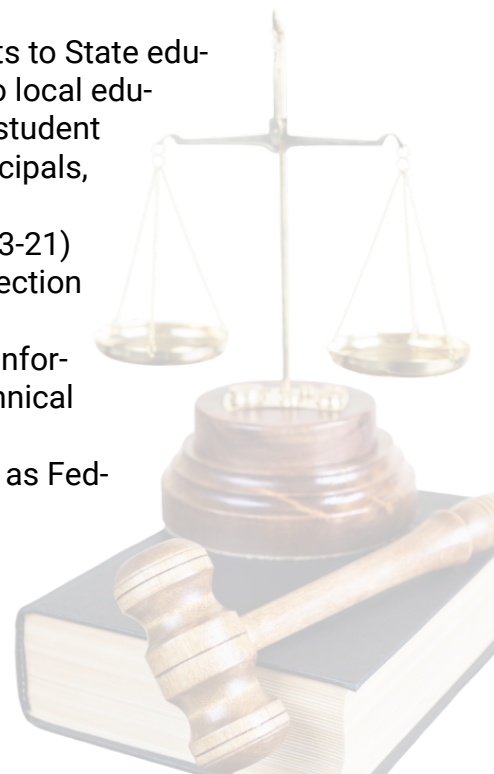
The National Down Syndrome Congress (NDSC) is the country's oldest national organization for people with Down syndrome, their families, and the professionals who work with them. We provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome, and work to create a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome. NDSC's Congressional public policy agenda is based upon the right of people with Down syndrome to live independent, self-determined lives in the community while receiving necessary supports. Our public policy agenda for the 118th Congress is as follows:

EDUCATION

NDSC believes that the education system must support people with Down syndrome to achieve their full potential. NDSC's [Position Statement on Inclusive Education](#) details NDSC's core tenets and approach to advocacy on education issues. To that end, NDSC's education public policy agenda for the 118th Congress is:

1. Increased funding for the Elementary and Secondary Education Act (ESEA) and Individuals with Disabilities Education Act (IDEA)

- A. Increase ESEA Title I, Part A funding which provides financial assistance for schools with high numbers or high percentages of children from low-income families to help ensure that all children meet challenging state academic standards.
- B. Increase ESEA Title II-A funding which provides formula grants to State educational agencies (SEAs), which then subgrant most funds to local educational agencies, to support activities designed to increase student achievement by improving the effectiveness of teachers, principals, and other school leaders.
- C. 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.
- D. Increase funding for the IDEA authorized parent training and information centers, community parent resource centers, and technical assistance for parent centers.
- E. Prohibit Federal funding for private school voucher programs as Federal dollars should remain in public schools.



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2. School and Student Safety

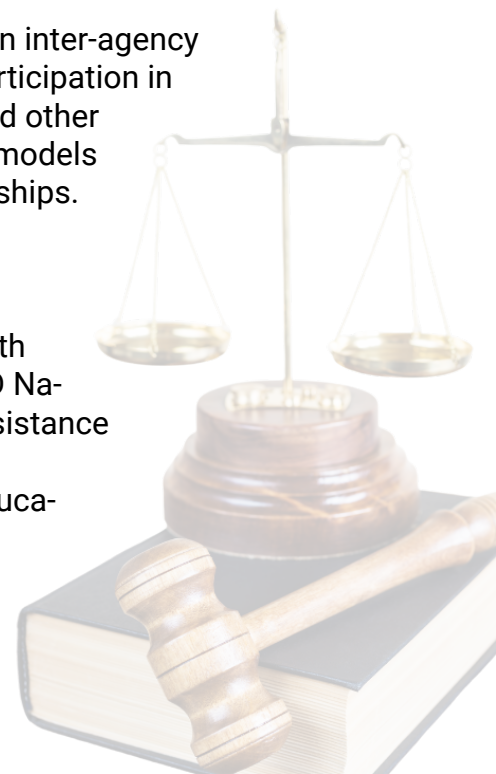
- A. Prohibit seclusion, mechanical restraints, chemical restraints, physical restraint that restricts breathing or is life threatening, and any form of aversive behavioral intervention, and require parental notification and follow-up meetings if a physical restraint occurs.
- B. Require states to collect and report data on the use of seclusion and restraint annually and make data about restraint and seclusion publicly available including data on the number of incidents, injuries, cases of death, and the demographic breakdown.
- C. Prohibit corporal punishment, or the act of inflicting physical pain as a form of discipline in schools.
- D. Prioritize funding for implementing evidence-based positive school climate programs such as School-wide Positive Behavioral Interventions and Supports, multi-tiered system of supports, and require school personnel to be trained in positive behavioral supports, elopement, and appropriate and safe behavioral interventions for crisis situations, and in the use of the Universal Design for Learning Framework.
- E. Prohibit the use of federal funds for school-based law enforcement and instead provide new grant funding to help schools hire more counselors, social workers, and other behavioral health personnel and implement services in schools that create positive and safe climates for all students.
- F. Address the disparate frequency and severity of disciplinary actions for students with disabilities, especially the harsher treatment of students of color, particularly Black students with disabilities.

3. Apprenticeships

- A. Reauthorize the National Apprenticeship Act to require that an inter-agency process be established to identify and address barriers to participation in apprenticeships by youth and adults with Down syndrome and other significant disabilities and identify and fund evidence-based models for such individuals to meaningfully participate in apprenticeships.

4. Inclusive Postsecondary Education

- A. Maintain funding for the Transition Programs for Students with Intellectual Disability (TPSID) Model Demonstrations & TPSID National Coordinating Center (NCC), and National Technical Assistance and Dissemination Center.
- B. If Congress develops legislation to reauthorize the Higher Educa-



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tion Act, then retain and update the provisions that authorize financial aid, TP-SID model programs, and the National Coordinating Center (NCC) for students with intellectual disabilities.

- C. Allow all students with disabilities to submit their Individualized Education Program (IEP), 504 Plan, or prior evaluation as documentation of their disability to obtain accommodations in college, so the students do not need to go to the expense and trouble of obtaining a new evaluation prior to attending a college or university.

EMPLOYMENT

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. To that end, NDSC's employment public policy agenda for the 118th Congress is:

1. Competitive Integrated Employment

- A. Support implementation of the Workforce Innovation and Opportunity Act (WIOA) which includes preserving the statutory definition of "Competitive Integrated Employment" (CIE) and supporting both regulatory and sub-regulatory guidance on CIE as currently issued by the U.S. Department of Education's Rehabilitation Services Administration.
- B. Promote and expand CIE opportunities that are meaningful for people with Down syndrome and radically transform segregated work settings and programs such as the AbilityOne program, facility-based congregate sheltered work, and congregate prevocational day services.
- C. Enact the recommendations to Congress included in the 2016 [report](#) published by the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities.
- D. Create incentives and build infrastructure for public and private sector employers to hire and/or reward retention of employees with Down syndrome and significant disabilities in CIE.

2. Phaseout of Subminimum Wage

- A. Pass legislation repealing Section 14(c) of the Fair Labor Standards Act (FLSA) which permits the payment of subminimum wages to



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people with disabilities. Any statutory repeal of Section 14(c) must include a multi-year phase out to avoid any job loss for workers employed under these certificates.

- B. As part of the phase out of Section 14(c), Congress should simultaneously provide significant federal investment in state systems-change and provider transformation efforts to reduce the reliance on facility-based congregate day and work services and increase the capacity of providers to offer supports that help individuals with disabilities pursue, secure, and sustain CIE.
- C. Require the U.S. Department of Labor to implement a moratorium on the issuance of new Section 14(c) certificates.

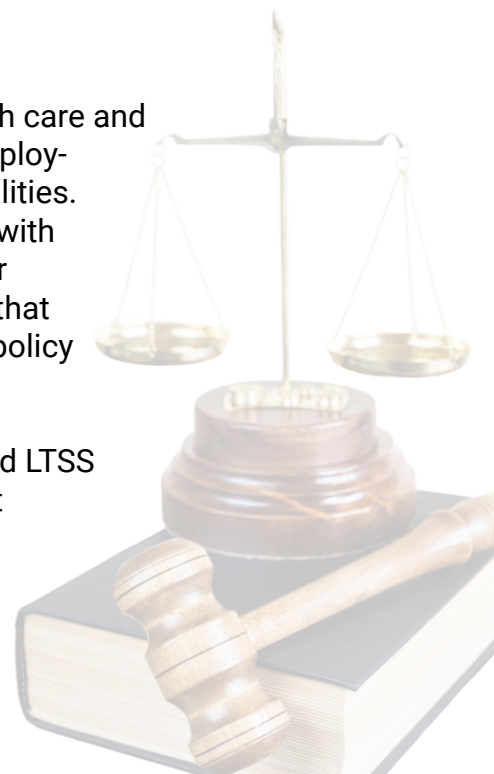
3. Pathways to Employment

- A. Expand apprenticeships and work-based learning experiences by facilitating the coordination of school-to-work transition programs (such as individualized Pre-Employment Transition Services), higher education, and community-based employers.
- B. Increase opportunities for self-employment and business ownership for people with Down syndrome including encouraging the U.S. Small Business Administration to add firms owned and controlled by persons with disabilities to the Small Business Administration's 8(a) Business Development program presumed eligibility list.
- C. Increase access to and capacity of supported and customized employment services funded through Medicaid, the U.S. Department of Education's Rehabilitation Services Administration, and other mechanisms.
- D. Provide oversight and support to better ensure that Federal Government agencies are meeting their workforce hiring goals as established under the Section 501 and 503 regulations of the Rehabilitation Act.

MEDICAID AND LONG-TERM SERVICES AND SUPPORTS

Medicaid is the single largest funding source of both acute health care and long term services and supports (LTSS) (both residential and employment supports) for people with Down syndrome and other disabilities. Over 10 million people with disabilities, including many of those with Down syndrome, qualify for Medicaid and rely on the program for their health care, employment and access to community life. To that end, NDSC's Medicaid Long-Term Services and Supports public policy agenda for the 118th Congress is:

- A. Maintain the entitlement to a full range of Medicaid health and LTSS for all eligible children and adults with disabilities and protect



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- against spending cuts, block granting, per capita caps and other attempts to curtail Medicaid benefits such as work requirements.
- B. Incentivize states to reduce and eventually eliminate Medicaid Home and Community-Based Services (HCBS) waitlists and incentivize states to exercise a broad range of services under Medicaid waiver programs, and ensure that the amount, duration, and scope of HCBS are provided based on individual needs identified through a person-centered planning process.
 - C. Provide necessary oversight and supports to states to ensure full implementation and enforcement of the HCBS Settings rule for both residential and non-residential services.
 - D. Remove the institutional bias in Medicaid LTSS and fund demonstration programs that assist people transitioning from institutions to community-based settings.
 - E. Preserve the Medicaid institutions for mental disease (IMD) exclusion rule which prohibits the federal government from providing federal Medicaid funds to states for services rendered to certain Medicaid-eligible individuals aged 21 through 64 who are patients in IMDs.
 - F. Facilitate portability of benefits so that Medicaid beneficiaries and their families are not disadvantaged or deprived by moving from one state to another.
 - G. Enact policies to promote a well-trained, fairly compensated direct support professional (DSP) workforce that is essential to providing necessary supports and services to people with Down syndrome and other disabilities where they live and work.
 - H. Pass legislation to require the Office of Management and Budget (OMB) to revise the Standard Occupational Classification (SOC) system to create a distinct classification for DSPs to better ensure sufficient training, support, clear expectations, and adequate compensation.

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). Many people with Down syndrome and their families rely upon benefits from one or both of these programs for financial assistance and as an avenue to obtain health insurance such as Medicaid through SSI and/or Medicare through SSDI. NDSC's social security public policy agenda for the 118th Congress is:

- A. Preserve both SSI and SSDI benefits and remove barriers to inde-



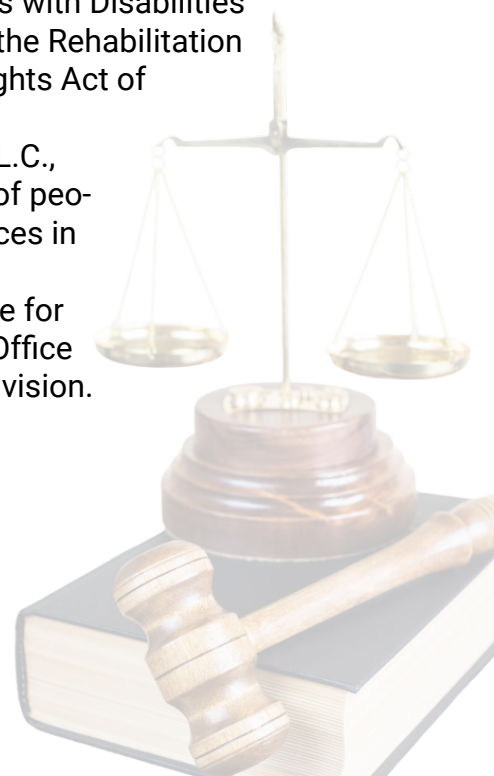
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- pendence, community integration, savings, work, marriage, and assistance or support by families for people with Down syndrome and other disabilities.
- B. Substantially increase both the countable income limit and the asset limit for SSI to at least the level it would have been had it been indexed for inflation since inception.
 - C. 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.
 - D. Eliminate the five-month waiting period to receive SSDI benefits.
 - E. Eliminate work disincentives for individuals who are eligible for the Disabled Adult Child (DAC) benefit so they can attempt work without worrying that they will lose their SSDI benefit if they can no longer work.
 - F. Exclude retirement accounts from countable resources for purposes of SSI eligibility.
 - G. Preserve and improve upon laws and policies regarding ABLE Accounts and Special Needs Trusts and other investment vehicles that will help individuals with disabilities and their families with financial planning.
 - H. Increase funding for the Social Security Administration to minimize delays in accessing benefits, processing times for claims, and improved customer service.

CIVIL RIGHTS AND RACIAL EQUITY

People with Down syndrome are entitled to equal rights, freedom from discrimination, and full participation in society as guaranteed by civil rights laws. NDSC works to preserve civil rights and opposes efforts that limit the rights of all people with Down syndrome and other disabilities. To that end, NDSC's civil rights and racial equity public policy agenda for the 118th Congress is:

- A. Protect and promote stronger enforcement of existing civil rights laws for people with disabilities, including but not limited to the Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act of 1973, Section 1557 of the Affordable Care Act, Civil Rights Act of 1964, and Title IX of the Education Amendments of 1972.
- B. Ensure that the Supreme Court's landmark case *Olmstead v. L.C.*, which ruled that the ADA prohibits unnecessary segregation of people with disabilities, who have a right to live and receive services in the most integrated setting appropriate, is preserved.
- C. Increase funding for the U.S. Department of Education's Office for Civil Rights, U.S. Department of Health and Human Services Office for Civil Rights, and U.S. Department of Justice Civil Rights Division.



FAMILY SUPPORT

Families play a key role in supporting people with Down syndrome, many of whom live at home. For many families, supporting their loved one comes at an enormous cost both financially and emotionally. Family caregivers can be negatively impacted supporting a disabled family member through lost wages, time spent out of the workforce, and from out of pocket expenses incurred to ensure their family member's needs are met. NDSC's family support public policy agenda for the 118th Congress is:

1. As recommended in the [2022 National Strategy to Support Family Caregivers](#):

- A. Increase funding for caregiver support services under the National Family Caregiver Support Program (NFCSP), the Lifespan Respite Program, and the Alzheimer's Disease Program Initiative (ADPI).
- B. Include a broader definition of "family" to include grandparent and kin caregivers.
- C. Include family caregiver out-of-pocket care expenses (products and services) as medical expenses eligible for tax credits.
- D. Introduce a range of incentives to encourage employers to adopt caregiver-friendly practices, including tax incentives.
- E. Develop tax deductions for paying for home and community-based services (HCBS), including by family members who are not claiming the care recipient as a dependent.
- F. Allow family caregivers who leave the workforce for caregiving to accrue Social Security credits to qualify for Social Security benefits.
- G. Allow kin and grandparent caregivers who have primary responsibility for a child to claim the federal Child Tax Credit.

HEALTHCARE

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 health-care public policy agenda for the 118th Congress is:

- A. Appropriate funding for the Prenatally and Postnatally Diagnosed Conditions Awareness Act to ensure that new and expectant parents learning about a prenatal or postnatal diagnosis, such as Down syndrome, will be provided with up-to-date, scientific information regarding life expectancy, clinical course, intellectual and functional development and prenatal and postnatal treatment options.



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- B. Preserve key tenets of the Affordable Care Act which prohibit 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.
- C. Ensure that all people with Down syndrome and their families have access to affordable prescription drugs that meet their individual health care needs.
- D. Eliminate Medicare's 2-year waiting period and increase provider reimbursement rates in Medicaid and Medicare.
- E. Address and reduce health care disparities experienced by people with Down syndrome, particularly people of color who have Down syndrome.
- F. 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

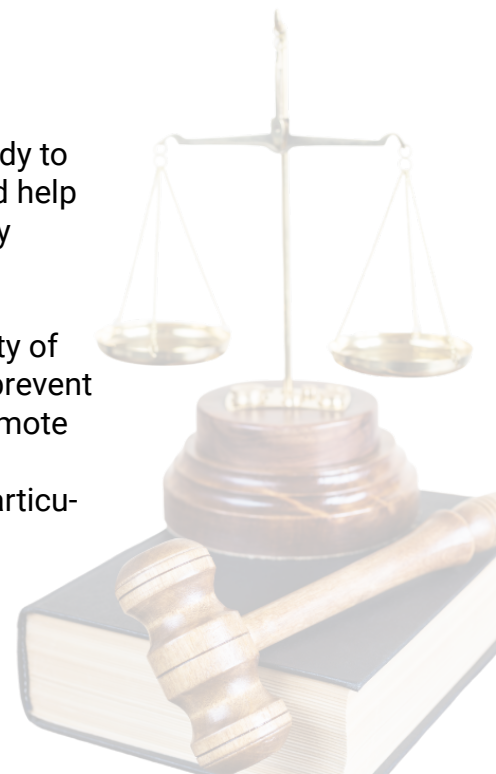
People with Down syndrome, like all Americans, have a right to live in their own homes, in the community. Adults should control where and with whom they live, have the freedom to choose their daily routines and activities, and they should have opportunities to rent or buy their own homes. NDSC's [Position Statement on Housing and Community Living](#) details the principles that guide our advocacy in this area. NDSC's housing public policy agenda for the 118th Congress is:

- A. 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.
- B. Address the need for safe, affordable and accessible housing.
- C. Eliminate barriers that prevent people with Down syndrome and other disabilities from renting or buying their own homes.

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's research public policy agenda for the 118th Congress is:

- A. Increase funding for programs 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.
- B. Increase participation of people with Down syndrome, and particu-



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larly people of color who have Down syndrome, in research studies.

TRANSPORTATION

Transportation provides a critical means for people with disabilities to access employment, education, health care, and community life. NDSC's transportation public policy agenda for the 118th Congress is:

- A. Preserve and strengthen laws that prohibit discrimination in transportation and increase the supply of affordable, reliable, and accessible transportation.
- B. Integrate the principles of universal design into the development of new transportation devices and projects to ensure greater mobility for people with disabilities.

Please direct all question and/or comments to Cyrus Huncharek, NDSC Policy & Advocacy Director at cyrus@ndsccenter.org.

