



June 4, 2026

The Honorable Tom Cole
Chair
House Appropriations Committee
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Committee
Washington, DC 20515

The Honorable Robert Aderholt
Chair
Subcommittee on Labor, Health and
Human Services, Education, and
Related Agencies
House Appropriations Committee
Washington, DC 20515

CC: Members of the House Appropriations Committee

RE: Fiscal Year 2027 Labor-HHS-Education Appropriations

Dear Chair Cole, Ranking Member DeLauro, and Chair Aderholt:

The National Down Syndrome Society's (NDSS) mission is to create a world where individuals with Down syndrome thrive. As the House and Senate Appropriations Committees consider the Fiscal Year (FY) 2027 Labor, Health and Human Services, Education, and Related Agencies appropriations measure, we urge you to prioritize funding for the key agencies and programs that support individuals with disabilities, including those with Down syndrome.

On behalf of our organization and the individuals and families we represent, we write in support of the following priorities:

Department of Health and Human Services – National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC)

The National Institutes of Health (NIH) conducts vital research to improve the health and wellbeing of individuals with disabilities, including through the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Project, a trans-NIH research initiative focused on critical health and quality-of-life needs

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for individuals with Down syndrome. INCLUDE and other initiatives at NIH support critical research into Alzheimer's disease, which is the number one cause of death for adults with Down syndrome. Individuals with Down syndrome have a higher than 90% lifetime risk for developing Alzheimer's disease; the age of onset is earlier and symptoms progress faster than in the general population.

Congress should provide robust and sustained funding for NIH, the INCLUDE Project, and Alzheimer's disease research activities at the Centers for Disease Control and Prevention (CDC) and across the federal government. Strong agency funding helps support important research areas that can improve the health and wellbeing of individuals with Down syndrome.

Department of Health and Human Services – Administration for Community Living (ACL)

The Administration for Community Living (ACL) was created in 2012 by bringing together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities. The creation of the ACL demonstrates an intentional effort to make disability and aging-related programs and services more efficient and effectively coordinated. We urge Congress to continue to fund ACL and its essential disability programs without structural changes.

In particular, we strongly recommend that the Committee fully fund key programs **such as Developmental Disabilities Councils (DD Councils), Protection and Advocacy agencies, University Centers for Excellence in Developmental Disabilities (UCEDDs), Aging and Disability Resource Centers (ADRCs), Voting Access for People with Disabilities, and the National Institute of Disability, Independent Living, and Rehabilitation Research (NIDILRR)**. These programs provide essential advocacy, legal protection, leadership development, research, training, and community support that improve the lives of millions of Americans with disabilities, and the families and caregivers who support them. Elimination of these programs could result in states losing a vital infrastructure for advancing self-determination, inclusion, and systems change for people with developmental disabilities, loss of legal protection and advocacy services for individuals with disabilities facing abuse, neglect, discrimination, or denial of services, and major cuts to disability research, training, technical assistance, and innovation in inclusive practices.

Department of Health and Human Services – Administration for Children and Families (ACF)

The Administration for Children and Families (ACF) oversees the Head Start and Early



Head Start programs, which ensure children with disabilities and developmental delays receive inclusive early education, health services, and family support. Head Start is required by law to ensure that at least 10% of enrolled children are children with disabilities, providing inclusive early education, health screenings, and developmental supports. We support continued funding for Head Start and Early Head Start, which help support the nation's commitment to inclusion under the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA).

Department of Health and Human Services – Office for Civil Rights (OCR)

The HHS Office for Civil Rights (OCR) enforces and ensures compliance with federal civil rights, conscience and religious freedom, and health information privacy and security laws. Increased funding is needed to support OCR and its efforts to prevent and address discrimination in the healthcare system, including discrimination on the basis of disability and discrimination in the organ transplant system.

Department of Education – Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA), administered by the Office of Special Education Programs (OSEP), guarantees a Free Appropriate Public Education for students with Down syndrome and other disabilities in the least restrictive environment. The grants administered to states under IDEA ensure that students have access to individualized instruction, accommodations, and relevant services, and must continue to remain in separate and distinct funding streams to preserve and protect the integrity of IDEA. We urge the committee to fund IDEA Part B Section 611 at no less than \$16.661 billion, consistent with the glidepath outlined in the bipartisan *IDEA Full Funding Act* (S. 1277 / H.R. 2598) to fulfill the federal government's commitment to funding 40% of average per pupil expenditure. Additionally, we urge the committee to fund the following IDEA programs in line with federal statute in separate funding streams at the following amounts:

- Part B Section 619 (preschool students): \$491 million
- Part C (infants and toddlers): \$632 million
- Part D, State Personnel Development: \$44.4 million
- Part D, Technical Assistance and Dissemination: \$36.2 million
- Part D, Personnel Preparation: \$135 million
- Part D, Parent Information Centers: \$38.15 million
- Part D, Media and Technology: \$36.7 million



The preservation of dedicated funding streams is essential to best support students with Down syndrome and other disabilities.

Department of Education – Office for Civil Rights (OCR)

The Office for Civil Rights (OCR) within the Department of Education is responsible for monitoring and investigating discrimination in public schools. To safeguard the rights of students with disabilities, we urge the committee to fund OCR at no less than \$163.8 million to ensure there is sufficient staff capacity to address and resolve any cases of non-compliance with Section 504, IDEA, or other civil rights laws.

Department of Education - Transition Programs for Students with Intellectual Disability (TPSIDs)

The Transition Programs for Students with Intellectual Disability (TPSID) program provides grants to institutions of higher education to create and expand high-quality, inclusive model comprehensive transition and postsecondary programs for students with intellectual disabilities. To ensure students with intellectual disabilities have access to meaningful university programs, we urge the committee to fund the Transition Programs for Students with Intellectual Disability (TPSID) Model Demonstrations, TPSID National Coordination Center (NCC), and Postsecondary Programs for Students with Intellectual Disabilities—National Technical Assistance and Dissemination Center (PPSID-NTAD) at no less than \$14.3 million.

NDSS respectfully urges the House Appropriations Committee to fund these agencies, programs, and services that support people with disabilities. It is essential that these programs are preserved and sufficiently resourced to uphold the principles of community living, integration, and equal opportunity for all Americans with disabilities.

Thank you for your attention to this important matter.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large loop at the end.

Kandi Pickard
President and CEO
National Down Syndrome Society