



January 16, 2026

The Honorable John Thune
Majority Leader
U.S. Senate
S-230, The Capitol
Washington, DC 20510

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
H-232, The Capitol
Washington, DC 20515

The Honorable Chuck Schumer
Minority Leader
U.S. Senate
S-221, The Capitol
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
H-204, The Capitol
Washington, DC 20515

RE: Fiscal Year 2026 Labor-HHS-Education Appropriations

Dear Leader Thune, Speaker Johnson, Leader Schumer, and Leader Jeffries:

The National Down Syndrome Society's (NDSS) mission is to create a world where individuals with Down syndrome thrive. As Congress considers Fiscal Year (FY) 2026 spending legislation, including the Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill, we urge you to prioritize funding for key agencies and programs that support people with disabilities, including those with Down syndrome, and to follow the House and Senate Appropriations Committees in preserving dedicated funding streams in these areas.

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

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 for individuals with Down syndrome. INCLUDE and other initiatives at NIH support crucial 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,



and the age of onset is earlier and symptoms progress faster than in the general population. We urge you to support robust and expanded NIH funding to bolster these important research areas.

Department of Health and Human Services – Administration for Community Living

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 demonstrated an intentional effort to make disability and aging related programs and services more efficient and effectively coordinated. We strongly recommend that the final Labor-HHS measure fund ACL and its essential disability programs without structural changes that would compromise the integrity of ACL and the services it provides to the disability community.

In particular, we recommend that the Labor-HHS bill 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.

Department of Health and Human Services – Administration for Children and Families

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. Reductions in these programs would widen disparities, delay diagnoses and interventions, and risk undermining our nation's longstanding 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

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.

Department of Education – Individuals with Disabilities Education Act

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 Congress 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 to fulfill the federal government's commitment to funding 40% of average per pupil expenditure. Additionally, we request that Congress 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 these dedicated funding streams is essential to best support students with Down syndrome and other disabilities.

In addition, it is vital that federal special education funding and programs stay within the Department of Education in order for the federal government to fulfill its obligation to provide a free appropriate public education to students with disabilities.

Department of Education – Office for Civil Rights

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 Congress 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.



NDSS respectfully requests swift passage of a final FY 2026 Labor-HHS bill that funds 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