



September 3, 2025

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 2026 Labor-HHS-Education Appropriations**

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

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. As the Appropriations Committee considers the Fiscal Year (FY) 2026 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 Senate Appropriations Committee 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)

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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 critical research into Alzheimer's disease, which is the number one cause of death for individuals 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.

Strong NIH funding helps support these important research areas, and any cuts could slow the momentum of vital research that can benefit individuals with Down syndrome.

### **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 demonstrates an intentional effort to make disability and aging related programs and services more efficient and effectively coordinated. We urge the House Appropriations Committee to fund ACL and its essential disability programs without structural changes, consistent with the Senate FY26 Labor-HHS bill.

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**

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 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 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, as included in the Senate FY26 Labor-HHS bill, is essential to best support students with Down syndrome and other 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 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.

**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 the first name "Kandi" and last name "Pickard" clearly legible.

Kandi Pickard  
President and CEO  
National Down Syndrome Society