May 9, 2025

The Honorable Bill Cassidy, M.D.
455 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Bernie Sanders
332 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Susan Collins
413 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Patty Murray
154 Russell Senate Office Building
Washington, DC 20510

CC: Members of the Senate Health, Education, Labor, and Pensions (HELP) Committee and the Senate Appropriations Committees

RE: HHS Restructuring and Proposed Budget

Dear Chairman Cassidy, Ranking Member Sanders, Chairwoman Collins, and Ranking Member Murray:

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. We write today on behalf of our organization and the individuals and families we represent to express serious concerns about the Department of Health and Human Services' (HHS) restructuring plan and proposed Fiscal Year 2026 budget request. As currently drafted, these proposals could have significant unintended consequences for people with disabilities, including those with Down syndrome, by weakening and potentially dismantling critical protections, programs, and services they rely on to live full and independent lives.

The restructuring plan announced on March 27, 2025, would significantly alter the Administration for Community Living (ACL) and key disability-specific programs by dispersing their functions into broader HHS offices or phasing out funding for them altogether. This reorganization risks undermining decades of progress in ensuring that federal health and human services are responsive to the needs of people with disabilities.

Specifically, we are concerned that the restructuring diminishes the Administration for Community Living (ACL) by reassigning its essential disability programs elsewhere in

HHS, potentially diluting the visibility and prioritization of disability issues at the federal level. ACL was created in 2012 to bring 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. Reversing this structure and redistributing these core functions across multiple agencies could lead to greater fragmentation and reduced accessibility for the individuals these programs are designed to support. ACL was created with the intention of streamlining and creating efficiencies in the critical disability programs that HHS oversees. Dismantling this streamlined approach appears counterproductive to the Department's stated goal of achieving greater efficiency.

The pre-decisional Fiscal Year 2026 budget request which became available on April 16, 2025, raises several additional areas of concern related to eliminated or diminished funding for disability programs and services. These include:

- **Significant funding cuts for the National Institutes of Health (NIH).** The NIH conducts vital research to improve the health and wellbeing of millions of individuals with disabilities, including through the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Project, a NIH research initiative on critical health and quality-of-life needs for individuals with Down syndrome. Cuts to NIH funding and caps on indirect research costs could slow the momentum of the INCLUDE project and other vital research projects.

- **Eliminated funding for 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.

- **Eliminated funding for Head Start programs.** Head Start and Early Head Start are critical programs that 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. 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).

NDSS respectfully urges the Senate Health, Education, Labor, and Pensions (HELP) Committee, the House Energy and Commerce Committee, and the House and Senate Appropriations Committees to carefully review and reconsider these proposals and to ensure they do not unintentionally undermine the dedicated infrastructure within HHS that supports 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.

We stand ready to collaborate with you to ensure that any restructuring or budgetary changes continue to reflect the shared goals of inclusion, self-determination, and respect for the rights of people with disabilities.

Thank you for your attention to this important matter.

Sincerely,

Kandi Pick

Kandi Pickard

President and CEO
National Down Syndrome Society