Friends of NCBDDD
In Support of the National Center on Birth Defects and Developmental Disabilities

June 24, 2025

The Honorable Shelley Moore Capito
Chair
Senate Appropriations Subcommittee on
Labor, Health and Human Services,
Education & Related Agencies
Washington DC 20510

The Honorable Tammy Baldwin
Ranking Member
Senate Appropriations Subcommittee on
Labor, Health and Human Services,
Education & Related Agencies
Washington, DC 20510

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

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee on
Labor, Health and Human Services,
Education & Related Agencies
Washington, DC 20515

Dear Chair Capito, Ranking Member Baldwin, Chair Aderholt, and Ranking Member DeLauro:

As organizations dedicated to improving the health of all people living with disabilities and birth conditions, we strongly urge you to adhere to Congress' initial intent in establishing the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and reject the Administration's proposal, as outlined in its FY 26 Congressional Justification, to merge NCBDDD, along with other health agencies and programs, into the Administration for a Healthy America (AHA).

We also ask that you maintain full funding levels for the following programs despite the Administration's request to reduce:

- Public Health Approaches to Blood Disorders
- Fetal alcohol syndrome
- Autism
- Neonatal Abstinence Syndrome
- Disability Health
- Tourette Syndrome
- Muscular Dystrophy
- Spina Bifida
- Cerebral Palsy
- Congenital Heart Failure

NCBDDD at the Centers for Disease Control and Prevention (CDC) was established in April 2001 as a result of the passage of the Children's Health Bill of 2000 (P.L. 106-310). NCBDDD promotes the health of babies, children, and adults; and enhances the potential for full, productive living. The Center's work includes identifying the causes of birth defects and developmental disabilities, helping children develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities.

According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. NCBDDD seeks to advance the health and well-being of the nation's most underserved populations, including infants, children, and individuals with birth conditions and developmental disabilities. Although NCBDDD's efforts are broad and far-reaching, the center's important work has continued to identify potential risk factors for birth defects, to collect data on children with intellectual and developmental disabilities, to protect the health of people with blood disorders, to use genomic and family health history information to prevent disease and protect health throughout the lifespan, and to improve the health of the 1 in 4 U.S. adults with a disability.

The Center's epidemiological work and research covers various conditions and topics including, but not limited to: fetal alcohol syndrome, infant health, autism, attention deficit hyperactivity disorder, congenital heart defects, Cerebral Palsy, Fragile X, Spina Bifida, sickle cell disease, Tourette Syndrome, and hemophilia.

As a result of the Center's work, infants with permanent hearing loss are being identified early through Early Hearing Detection and Intervention (EHDI), individuals with Tourette Syndrome can be diagnosed and treated earlier, and far fewer babies are born with a neural tube birth defect due to national folic acid fortification. NCBDDD is also responsible for reporting the prevalence number of children in the United States with or at risk for autism, which is currently 1 in 31 for children ages 4-8. Their data helps health care providers, schools, public health agencies, and policy makers make evidence-based decisions to support these children. Their data also improves health and well-being for families with children with rare disorders across the lifespan.

NCBDDD is also home to the Surveillance for Emerging Threats to Mothers and Babies Network (SET-NET), the first-ever preparedness and response data surveillance network that enables CDC to understand the impact of infections and exposures during pregnancy and any potential impacts on maternal health and that of the baby.

NCBDDD provides critical support for our partners, decision makers, state, local, and tribal public health professionals, and the American public. Our concern is that this proposal could undermine the mission of and programs at the Center and place an undue burden on the already significantly reduced staff. As a result, these drastic changes would have a long-term negative impact on the disability community.

Since its inception, the Center has enjoyed strong bipartisan support and has played a major role in helping to improve the lives of one of our nation's most vulnerable populations through research, education, and scientific breakthroughs. Therefore, we ask that you please reject the Administration's proposal and continue to support NCBDDD as Congress has over the last 20 years.

We appreciate your consideration of our request. For additional information on NCBDDD, please contact Jay Nichols with Tourette Association of America at jay.nichols@tourette.org.

Sincerely,

The Friends of NCBDDD
American Academy of Developmental Medicine and Dentistry
American Academy of Pediatrics
Association of Maternal & Child Health Programs
Cerebral Palsy Foundation
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Golisano Institute for Developmental Disability Nursing, St. John Fisher University
Lakeshore Foundation
March of Dimes
National CMV Foundation
People Advocating for Optimal Health
Prevent Blindness
Spina Bifida Association
Tourette Association of America