



Friends of NCBDDD

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

February 4, 2022

The Honorable Patty Murray
Chairwoman
Subcommittee on Labor, Health and
Human, Education, and Related Agency
Services
Senate Committee on Appropriations
Washington, DC 20515

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

The Honorable Roy Blunt
Ranking Member
Subcommittee on Labor, Health and
Human, Education, and Related Agencies
Services
Senate Committee on Appropriations
Washington, DC 20515

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and
Human, Education, and Related Agencies
Services
House Committee on Appropriations
Washington, DC 20515

Dear Chairwomen Murray and DeLauro, and Ranking Members Blunt and Cole:

The undersigned organizations are members of the Friends of the NCBDDD, a coalition of patient advocacy groups, public health professionals, and professional societies with a vested interest in advancing the health and well-being of our nation's most vulnerable populations by promoting and sustaining the public health initiatives and research activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD).

The Friends of NCBDDD are grateful for the support your subcommittees have given the Centers for Disease Control and Prevention (CDC) and NCBDDD. Despite support for CDC, NCBDDD has not received significant funding in recent years. We urge you to provide **at least \$186.8 million for the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD)** in the fiscal year (FY) 2022 Labor, Health and Human Services, Education and Related Agencies Appropriations bill and apply the increase across the full range of NCBDDD activities. This modest increase over the FY 2021 enacted level would allow for NCBDDD to increase support for programs to prevent birth defects and developmental disabilities and help people with disabilities and blood disorders live the healthiest life possible.

The NCBDDD funds vital surveillance, research, and prevention activities aimed at birth defects and developmental disabilities. According to the CDC Website, developmental disabilities are a group of conditions, including Attention Deficit Hyperactivity Disorder and Tourette Syndrome, due to an impairment in physical, learning, language, or behavior

areas. These conditions begin during the developmental period, may affect day-to-day functioning, and usually last throughout a person's lifetime. It also promotes health and well-being among people of all ages with disabilities and those with blood disorders.

NCBDDD's work impacts a broad cross section of the American public. Birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. Children with birth defects who survive often experience lifelong physical, movement, and cognitive disabilities. One in 6 children have one or more developmental disabilities or delays. Nearly \$400 billion in healthcare costs each year are associated with disabilities. Blood disorders - such as sickle cell disease, anemia, and hemophilia - affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status.

We are grateful that Congress has provided new resources to NCBDDD in recent years to address emerging issues. New funding in FY 2020 for the Surveillance for Emerging Threats to Mothers and Babies Network (SET-NET) is enabling select states and jurisdictions to continue important work begun during the Zika virus response to identify and address new threats including opiates and, now, COVID to maternal and child health.

SET-NET is an innovative data collection system that links maternal exposures during pregnancy to health outcomes for babies. Building on a mom-baby linked data collection approach developed in response to the Zika outbreak, SET-NET leverages existing data sources to enable CDC and health departments to detect the impact of new and emerging health threats on pregnant individuals and their babies. Findings from SET-NET help parents, health care providers, public health professionals, and policymakers take action to save lives, reduce risk, and improve the health of pregnant individuals and infants.

In contrast to these new initiatives, funding for most other NCBDDD activities has remained flat over the past four years, hindering the Center's ability to maintain and expand programming to support individuals and families impacted by birth defects, developmental disabilities, blood disorders and physical disability. Fourteen budget lines with no increase since 2017, including birth defects, Fetal Alcohol Spectrum Disorders, Autism, Early Hearing and Detection and Intervention, Fragile X, muscular dystrophy, and Tourette Syndrome. And all notable budget increases were associated with directive budget language.

The latest data from NCBDDD shows that the need for the Center's work is more important than ever:

- COVID-19 has increased both anxiety and isolation which can amplify conditions and co-occurring conditions covered by NCBDDD.
- Sickle cell disease (SCD) is the 3rd most common disorder identified by national newborn screening and was discovered a century ago. Yet, research efforts to understand disease progression, treatment, and impact have been stunted by a lack

of funding, and our knowledge of SCD is still limited. CDC's role is to implement surveillance programs and collect data that can be used to inform decisions at the state and federal levels to address the needs of the SCD population.

- One in 44 8-year-old children are now identified with autism spectrum disorder (ASD), up from 1 in 54 from the previous estimate in 2020. Important work from the NCBDDD has led to substantial progress in earlier detection of ASD, which allows children to gain access to services at a younger age, which in turn can help improve performance in school and increase quality of life.

NCBDDD represents people with conditions that have been historically overlooked and have resulted in health disparities due to systemic inequality. Data suggest that race and ethnicity, level of child impairment, and low family income are associated with delayed diagnosis of developmental disabilities and neuro-developmental disorders. Additionally, children living in low resource families, rural, and non-English speaking communities can face challenges in early identification, diagnosis, and access to early intervention services. Enhancing and expanding existing public health data systems can help inform and address health inequities in early identification and intervention.

Without the routine collection of disability status as a demographic category, documenting health inequities, and investigating the underlying contextual factors associated with disparities are impossible (and itself an inequity). Collecting these data is the first step in better preparing public health for addressing the needs of people with disabilities in future public health emergencies.

Fourteen budget lines have not increased since 2017, including birth defects, FASD, Autism, EHDI, Fragile X, muscular dystrophy, and Tourette Syndrome. And all notable budget increases were associated with directive budget language.

Established by the United States Congress in 2000 (P.L. 106-310), NCBDDD impacts the health of millions of our nation's citizens, including infants and children, people with disabilities, and people with blood disorders. It is the only CDC Center whose mission focuses on these populations. We urge you to **support a funding level of at least \$186.8 million for NCBDDD programs in FY 2022** to ensure NCBDDD can continue its vital work across its entire portfolio. For more information, please contact the chair of the Friends of NCBDDD, Sara Struwe (202-618-4747, sstruwe@sbaa.org).

Sincerely,

American Academy of Developmental Medicine and Dentistry
American Academy of Pediatrics,
Association of University Centers on Disabilities
Different Brains
Hemophilia Federation of America

March of Dimes

National Birth Defects Prevention Network

National Fragile X Foundation

National Task Group on Intellectual Disabilities and Dementia Practices

Society for Birth Defects Research and Prevention

Spina Bifida Association

Tourette Association of America