

NCBDDD is CDC's lead National Center on disability and serves many highly vulnerable populations with pressing public health problems. The Center includes three divisions: the Division on Birth Defects and Developmental Disabilities; the Division on Human Development and Disability; and the Division on Blood Disorders. The Friends appreciates the subcommittee's support of the NCBDDD over the years and, while one of the smaller national Centers at CDC, the Center achieved a number of significant accomplishments during the past year, which can be found in the factsheet submitted as part of my testimony.

The Friends of NCBDDD (Friends) is a coalition of over 100 organizations that work together to enhance the mission and activities of NCBDDD. The "Friends" officially formed in 2002 and grew out of efforts to pass the Children's Health Act which authorized the NCBDDD. The Friends is dedicated to supporting the broad base work of the NCBDDD by disseminating information and educating all about the work of the Center. I have been personally involved with the Friends since its inception and its growth is a testament to the importance of NCBDDD's work. I am pleased to submit our view on what can be accomplished with increased federal funding for NCBDDD and respectfully recommend Congress support a \$20 million increase to NCBDDD's FY 2011 budget, which is a 14% increase over the FY 2010 level of \$143.539 million.

While these achievements are significant, the challenges facing NCBDDD are daunting given that at least 54 million Americans currently experience a disability and current projections indicate that the number of people living with birth defects, developmental disabilities and blood disorders will continue to increase over the next decade. Although the NCBDDD is dedicated to alleviating the health issues of these vulnerable populations, its budget has remained relatively flat since 2005. A \$20 million increase in NCBDDD's base funding is a sound public health investment that would be responsive to the anticipated trends in disability prevalence and would provide NCBDDD a degree of flexibility as it seeks to meet the needs of these vulnerable populations over the next decade. This increase could be used to support a variety of critical disability and health programs focused on:

- Enhancing Wellness and Prevention for children and adults with disabilities
- Reducing Health Disparities between children and adults with disabilities and the non-disabled population
- Providing Educational Materials to Consumers and their Families to Improve Medical Awareness
- Facilitating the Transition from Childhood to Adulthood for People with Disabilities
- Supporting Improved Global Health

Enhance Wellness and Prevention

NCBDDD is faced with the dual challenge researching why birth defects occur and how to prevent them as well as developing programs to enhance the wellness of those suffering from disabilities. With more than 4 million births annually in the United States, every woman needs accurate and clear health information about how to care for herself and if she is pregnant or planning to become pregnant she has additional

informational needs to assure the health of her unborn baby. Increased support is needed for CDC to continue their important research to learn more about what women can do even before they become pregnant to prevent birth defects and other developmental problems.

Another good example is NCBDDD's Early Hearing Detection and Intervention (EHDI) program. Identifying infants with hearing loss is known to be cost effective and early identification can improve the delivery and timeliness of healthcare services to infants and children with hearing loss and their families. The EHDI program currently screens 94% of the newborns in the United States but more can be done. Building on its existing state-based program, NCBDDD's EHDI program could be enhanced to ensure that its tracking and surveillance systems were taking advantage of existing data in electronic health records (EHR) to improve national data reporting and coding standards. If fully supported, it is possible that this nation could achieve \$2.6 billion in educational savings alone by reducing intervention costs through enhanced early detection.

Likewise, there is currently no comprehensive system for ensuring long term follow-up with children screened for potentially disabling or life-threatening conditions. NCBDDD could expand on its existing state-based relationships to develop systems for birth defects and developmental disabilities surveillance and research to identify interventions and track changes over time. Additional funding could help build state public health capacity for long-term follow-up and increase availability of data on conditions.

In a similar fashion, the mortality associated with Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE) is more than the combined total number of deaths from breast cancer, AIDS, and motor vehicles crashes. Pulmonary Embolism alone is the leading cause of preventable hospital deaths and maternal mortality in the United States. The estimated annual healthcare costs associated with DVT/PE range from \$2 to \$10 billion. While the burden and costs are high, there is a lack of consensus within the healthcare community on prevention, diagnosis, and management of DVT/PE. Additional funding could help establish a single set of standardized, evidence-based guidelines for early recognition, treatment and management of DVT/PE and increase provider, patient, and public awareness of DVT/PE through education materials.

Reduce Health Disparities

It is critical that NCBDDD be supported in their efforts to address the health disparities associated with people with disabilities (PWD). We know that approximately 54 million Americans live with a disability and that the burden of preventable health problems is higher with PWDs than people without disabilities. For example, people with disabilities suffer from increased smoking rates (62% of this population is more likely to smoke) and higher obesity rates (57% of this population has higher rates of obesity than non-disabled people). NCBDDD is well positioned to address these issues through existing programs that could be augmented with additional funding. An increase in its base funding could be used to expand existing state-based disability and health programs from 16 to 34 U.S. states and territories and reduce the impact of health disparities for PWDs by focusing on chronic disease prevention in these populations.

Additionally, there are certain disabling conditions that disproportionately impact minority populations in this country. For instance, the majority of the 100,000 people in the U.S. suffering from hemoglobinopathies like sickle cell disease (SCD) or thalassemia are African-American. Modest efforts to address the burden associated with sickle cell disease and thalassemia have already begun through an innovative collaboration between NCBDDD and NIH's National Heart, Lung and Blood Institute. In 2010, CDC and NHLBI partnered to establish the Registry and Surveillance System for Hemoglobinopathies (RuSH) in 6 states. Increased funding could also help expand the Registry and Surveillance System for Hemoglobinopathies (RuSH) from six to twelve states and permit CDC to capture 66% of the African-America population afflicted with SCD in the RuSH system.

Providing Educational Materials to Consumers and their Families to Improve Medical Awareness

The rare nature of many of the conditions falling within NCBDDD's areas of responsibility present the Center with the challenge of educating individuals, families, caregivers, providers, as well as the general public about these conditions. It is critical that NCBDDD have the resources necessary to educate them about these conditions in an effort to prevent or mitigate their impact and help people live full and productive lives. At the same time, these efforts can help avoid unnecessary and avoidable healthcare expenditures for the individuals, their families or caregivers, and society as a whole. NCBDDD has initiated efforts to address these issues but limited resources prevent the Center from maximizing their impact.

Currently in the United States, 13% of children have a developmental disability, which includes attention deficit/hyperactivity disorder, autism spectrum disorders, cerebral palsy, hearing loss, intellectual disabilities, vision loss, and others. Yet, less than 50% of developmental delays are identified before starting school, missing critical opportunities to intervene early and prevent the onset of negative health outcomes such as chronic diseases, smoking, drug use, and depression. This relatively late age of diagnosis is a reminder of how important it is to be aware of milestones that mark a child's development and to act early if a delay is suspected. Additional funding could be used to expand NCBDDD's Learn the Signs, Act Early Campaign, which provides families, educators, and healthcare providers with the training and materials they need to identify delays early and coordinate critical services at a time that maximize the impact on child's development.

Facilitating the Transition from Childhood to Adulthood for People with Disabilities

As medicine and science advance, people suffering from birth defects and disabilities are living longer and potentially, more productive lives. However, while scientific advancements have been rapid, the healthcare system often struggles to keep pace with the service needs of the PWD population. It is critical that we begin to dedicate resources to support the transition from childhood to adulthood for people with

disabilities. Again, NCBDDD has initiated efforts to address these issues but limited resources prevent the Center from maximizing their impact.

For instance, my organization established the National Resource Center on Attention Deficit/Hyperactivity Disorder (ADHD) which is the only national clearinghouse dedicated to sharing evidence-based information about identification, support, referral, and treatment for ADHD. Through support from NCBDDD, the Resource Center fields more than 12,000 inquiries and 1.1 million hits on its website each year; thereby providing important health and life information to children and adults with ADHD, as well as their families, caregivers, and other vital stakeholders.

In addition, NCBDDD has developed a web-based resource for parents and health professionals to guide the care and monitoring of children with Spina bifida across the life course. The resource contains a range of topics including health, self care, personal relationships, employment, income, and is expected to be launched late this year. Additional funding support would provide an opportunity to expand both its impact and reach.

Finally, thanks to recent medical advances, the diagnosis of a congenital heart defects (CHD) is no longer a death sentence and 90% of children with CHD survive to adulthood; resulting in an estimated one million adults currently living with CHD. These adults have significantly higher rates of health care utilization than their age-matched peers. With the potential rapid rise in the number of adults with CHD and their unknown health care needs, the corresponding increase in health care services could overwhelm the existing system. You and your colleagues in the House and Senate recognized the importance of this issue when you passed the Congenital Heart Futures Act as part of health reform. While this law gives CDC authority to act no funds were appropriated to fund these activities. An increase in funding at NCBDDD could be used to implement this important piece of legislation and help CDC better understand the disease burden and long-term outcomes in this population including the evaluation of evidence-based treatments. This expanded knowledge then can ensure individuals with CHD have the necessary information to lead healthier and productive lives in any life stage.

Supporting Improved Global Health

As alluded to throughout this testimony, this country has achieved some remarkable advances in birth defects prevention over the last 20-30 years. A noteworthy example is the prevention of neural tube defects (NTD) since mandatory flour fortification began in the United States in 1998. The Friends believe that NCBDDD is uniquely positioned to roll some of these advances out to the global community and have a significant impact on the health of children throughout the world. For instance, spina bifida and anencephaly, the most common forms of NTD, occur in an estimated 300,000 newborns worldwide. Data indicate that at least half the cases of NTDs could be prevented if women consumed sufficient amount of folic acid prior to and during early pregnancy. NCBDDD, in conjunction with its CDC partners and ministries of health, could implement a global folic acid fortification program in countries with the highest NTD burden, as a strategy for achieving similar results in other countries as those seen in our own.

In conclusion, the Friends of NCBDDD support NCDDD's mission of promoting the health of babies, children and adults and enhancing the potential for full, productive living for those with disabilities. Expanding NCBDDD's FY 2011 budget base by \$20 million will further enable it to have greater flexibility to expand upon the surveillance and research that are so vital to ensuring healthy birth outcomes, follow up and treatment for children with disabilities and ensure a smooth transition from childhood to adulthood. The Friends of NCBDDD therefore recommends that Congress provide a \$20 million increase to NCBDDD's FY 2011 budget. We submit a two page fact sheet of recent NCBDDD accomplishments to further support the far reaching impact of these programs.