Friends of NCBDDD Quarterly Check-In

FY 2018 NCBDDD Budget Briefing

June 22, 2017
3:00 pm – 4:30 pm ET
Welcome

Becky Abbott
Chair, Friends of NCBDDDD
FY2018 President’s Budget Request for the National Center on Birth Defects and Developmental Disabilities

Coleen A. Boyle, PhD, MS hyg, Director
June 2017
The FY 2018 Request

FY 2018 President's Budget Request | $100 Million

- FY16 Enacted: $136M
- FY17 Enacted: $138M
- FY18 Request: $100M

Rounded funding levels up
The Process – 5 Steps

Completed
Step 1:
President releases a blueprint for the federal budget – March 16th
OMB releases the FY2018 President’s Budget Request – May 23rd

Next
Step 2: The House and Senate Pass Budget Resolutions
Step 3: House and Senate Subcommittees "Markup" Appropriation Bills
Step 4: The House and Senate Vote on Appropriations Bills and Reconcile Differences
Step 5: The President Signs Each Appropriations Bill and the Budget Becomes Law
Impact to NCBDDD

- Differences from FY17
  - Decreased by $37.5M
  - No specific lines listed
  - No PPHF request

- Impact on NCBDDD Programs
  - NCBDDD will focus on priority activities (CJ narrative)
  - At this level there would be significant implications to current portfolio
NCBDDD Next Steps

- Meet with Partners
- Meet with Congress
- Educate others on our unique role and public health impact
FY18 Budget Context

- Eliminate duplication
  - Critical to demonstrate unique role/contributions

- Focus on public health risk
  - Highest priority to core public health (monitor/surveillance, research, and intervention)

- Define roles: private versus public sector
  - Emphasis on appropriate roles and responsibilities
FY18 Budget Context – Example: Responding to Zika

- Eliminate duplication
  - CDC/NCBDDDD is the only government agency with the expertise in birth defects/Arboviruses; state emergency response capacity; and state surveillance to track CZIs in pregnancy; Use PH to connect moms/babies to services

- Focus on public health risk
  - Surveillance: tracking Zika’s impact in US and Territories
  - Research: focused on co-factors that amplify risk (opportunity for treatment in pregnancy); spectrum of CZS—more children may need services
  - Intervention: protecting pregnant women--travel guidance; protection from mosquito bites

- Define roles: private versus public sector
  - Private: expert clinical services; innovative diagnostics; routine large scale lab services
  - Public: Translating surveillance and research findings into clinical and lab guidance
FY18 Budget Context – Example: Improving Health for PWDs

- **Eliminate duplication**
  - CDC/NCBDDD: only Agency with a public health focus on PWDs; fund traditional PH partners (state/NGOs) and academic researchers; community level actions, tools and resource for protecting PWDs

- **Focus on public health risk**
  - Surveillance: Data for Action: Disability and Health (State) Data; Medicaid and NHIS-based analyses
  - Research: Testing disability-specific modifications to evidence-based ways to protect/promote health
  - Intervention: Integrating disability-specific program modifications to state/community prevention programs

- **Define roles: private versus public sector**
  - Private: Community and workplace health/fitness opportunities inclusive of PWDs; clinical sector trained to meet the needs of PWDs
  - Public: Champion; Data; Evaluation
NCBDDD Strategic Plan 2017-2022

A roadmap to a world where babies are born healthy, children reach their potential, and everyone thrives.

https://www.cdc.gov/ncbddd/aboutus/about-ncbddd.html
Questions

For more information, contact CDC
1-800-CDC-INFO (232-4636)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.
Discussion of 2017 Coalition Activities
Friends of NCBDDD 2017 Priorities

• Coalition management
  – Updating Friends website
  – Updating membership list
• Further engage the full membership of the Friends
  – Survey results
• Intensifying education efforts: policymakers, partners, and stakeholders
FY 2018 Budget Update

- Proposed $37.56 million (27 percent) cut to NCBDDD budget
  - Doesn’t account for Zika supplemental funding
- The President proposes and Congress disposes, but...
  - Very tough fiscal environment (sequestration, veterans’ health care)
- Congress is behind schedule – only 100 days until end of the fiscal year and only about 40 of those are working days
Education & Advocacy Strategy

- Hill Meetings and Targeted Outreach
  - Advocacy Day on Capitol Hill – Thursday, June 29
  - Zika briefing: Thursday, July 13
  - Highlighting NCBDDD research and activities
  - Sign-on Letter: COMPLETE

- Administration Outreach

- Grassroots Activation
  - Grassroots Toolkit

- Grasstops Activation – How can you help?
Questions & Discussion
New Educational Materials from NCBDDD

• Impact Statements by Center Activity
• Thematic Area Fact Sheets
• State Funding Profiles
• Disability & Health State Profiles
CDC Contributions to National Advances in Autism

CDC delivers:
- Actionable Information: CDC’s surveillance data provide the nation’s clearest picture of the real impact of autism on families and communities and aim to the foundation for national, state, and local policy and planning.
- A path to understanding: CDC is actively searching for autism causes or risk or protective factors by conducting the largest epidemiologic study of autism in the U.S. and
- Tools to aid early identification: CDC supports parents, early education, and healthcare providers to promote early identification through free, online products, making it easier to identify autism and developmental delays early and encourage entry into services when services can help the most.
- CDC works with other federal agencies to expand the impact nationally by providing:

  - Essential data on the characteristics of those affected by autism to guide states and communities in responding to this urgent public health needs of parents and families impacted by autism; and
  - Training to help the Health Resources and Services Administration and others educate physicians about how to diagnose and manage autism and help to administer for Children and families and others: early identification and developmental delays early and encourage entry into services when services can help the most.

Impact Statements by Center Activity

CDC’s autism program provides gold standard prevalence estimates, key information about characteristics of children who have autism, and identifies risk factors for autism:

- CDC’s surveillance program (SAEM) in annual funding reports that about 1 in 68 children has autism.
- About 10% of children with autism also have Down syndrome, fragile X syndrome, or tuberous sclerosis.
- CDC conducts the largest ongoing study of risk factors for autism in the United States (SAEM in annual funding).

CDC’s data shed light on the challenges that families affected by autism face:

- CDC analyzes show that parenting a child with autism is associated with high stress and that cost of care are staggering. Total costs per year for children with autism are estimated to be between $11.3 billion to $161.8 billion, which represents a significant economic burden on medical care, social education, and lost wages for parents.
- Behavioral interventions alone can cost $44,000-$58,000 per year.

- Most children who have autism are not diagnosed until after age 4, even though many can be identified before age 2. Developmental monitoring and screening are important to help children get access to services early, during the most critical developmental period, and reduce the need for more costly interventions over time.

CDC has helped to establish autism as an urgent public health priority:

- The Interagency Autism Coordinating Committee develops an annual National Strategic Plan for autism research.
- The Autism Congressional Caucus, which includes over 120 members, promotes autism research and improved care.
- Funding for research conducted at national, state, and local levels has increased (NH funding alone increased from $5.6 million in FY 2010 to $109 million in FY 2012).
- Many states have established autism councils, which advise state agencies and legislatures on the needs of children and families affected by autism.

Highlighting CDC’s Autism Portfolio Would Have A Disastrous Impact:

- 26 years of investment provides gold standard prevalence estimates and information about the severity of disorder in children with autism, used by state and local health and social service agencies to plan for services, will be abruptly discontinued. Insurmountable burden associated with early identification and planning for services will not be guided by the key information need to target children and communities most at need for services.
- Loss of funding for CDC’s unique multisite research study on risk factors for autism, the largest ongoing study of autism, would halt progress toward understanding causes and identifying ways to prevent autism—a lifelong condition that is estimated to cost the United States between $11.3 billion - $161.8 billion per year. The study has already yielded critical information about the spectrum of behaviors and characteristics of children with autism and has contributed to understanding risk factors, including fertility treatments and maternal chronic medical conditions such as diabetes and hypertension. Without continued funding and collection of comprehensive data, the future impact of the research will be significantly diminished.

- Improvements in state and local level early identification systems to identify and encourage entry into services for over 1 million children with autism would be diminished. Science shows early intervention products to improve outcomes for children with autism.
- Loss of the research investment needed to address the challenges facing adolescents with autism as they transition into adulthood. In the next decade, over half a million youth with autism will enter adulthood.
- Parents, providers, and early childhood programs across the nation could no longer rely on resources from CDC to help track typical child development and ensure autism and other developmental disabilities are identified early and families are connected to services. CDC’s orders of over 400,000 items each month from autism’s most useful tools to support the development of data and tools for support the development of data and tools.
- The response to the Zika virus would be negatively impacted. U.S. states and territories use CDC’s tools and resources to target the development of data and tools.
- Approximately 250 state, local, federal, and commercial contracts would be eliminated.
Friends of NCBDDD
In Support of the National Center on Birth Defects and Developmental Disabilities

Thematic Area
Fact Sheets

PROTECTING PEOPLE

1 in 76 Americans are born with a blood disorder.

People with blood disorders are living longer than ever before, but with far too many medical complications that could be prevented. These conditions are serious, sometimes fatal, health consequences and cost our healthcare systems billions of dollars every year. CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD) invests in activities that increase understanding of blood disorders, advance medical care and treatments, and improve outcomes for all people with blood disorders.

How NCBDDD makes a difference

Hemophilia Treatment Centers – NCBDDD worked with funded partners to implement the Community Counts project in hemophilia treatment facilities across the country, following the model of the successful National Surveillance of 10,000 Hemophiliacs (1998-2002). Community Counts is a comprehensive, population-based surveillance system for children with hemophilia. In 2016, 31 states reported surveillance data, providing critical information to healthcare providers, researchers, and public health officials. Community Counts also monitors patient care and provides education and support to families.

Public Health Approaches for Blood Disorders – NCBDDD recognizes the need to develop evidence-based guidelines for healthcare providers. In response, NCBDDD has developed two guidelines: “Guideline for the Diagnosis and Management of Childhood Idiopathic Thrombocytopenic Purpura” and “Guideline for the Prevention and Management of Acute Care Hemorrhagic Events in Children with Hemophilia.” These guidelines provide guidance for healthcare providers on how to diagnose and manage blood disorders in children.

Hemophilia – NCBDDD supports biomedical research as part of the Community Counts project by funding projects that focus on improving the lives of people living with hemophilia. NCBDDD funds research projects that explore new treatments for hemophilia, provide better care for people with hemophilia, and improve the quality of life for people with hemophilia.

Thrombocytopenia – Thrombocytopenia is a group of genetic red blood cell disorders that cause anemia by preventing the production of red blood cells. As a result, people with thrombocytopenia may be at risk for bleeding complications. NCBDDD supports research projects that focus on understanding the mechanisms of thrombocytopenia and developing new treatments for this disorder.

2016 Successes

Community Counts
Community Counts is a public health monitoring program funded by NCBDDD. The project’s goal is to gather and share information about common health issues, medical complications, and causes of death that affect people with bleeding disorders cared for in Hemophilia Treatment Centers in the United States. Community Counts aims to continue the work of the Universal Data Collection System, which ended in 2011.

Hemoglobinopathy Screening Primer
NCBDDD and the Association of Public Health Laboratories worked with experts on newborn screening. The Primer includes new findings on the prevalence of hemoglobinopathies and provides guidelines for the implementation of newborn screening programs.

Priorities for the future

- Understanding burden: Harness new tools to analyze electronic health records, state-wide monitoring systems, and existing healthcare databases to understand the populations affected by blood clots and hemoglobinopathies.
- Improving prevention: Work with partners to promote better treatment and follow-up care options for people affected with blood disorders.
- Empowering people to participate and learn: Create tools and awareness campaigns to teach Americans about the power they have to prevent blood disorder complications and to find the right healthcare providers.
- Reducing health disparities: Connect vulnerable populations affected by blood disorders with healthcare centers and support systems to ensure access to consistent and high-quality care.

1 IN 10 PEOPLE WITH A BLOOD CLOT WILL DIE IF IT MOVES TO THE LUNGS

Healthcare costs associated with blood clots in the U.S. are $10 billion
Friends of NCBDDD
In Support of the National Center on Birth Defects and Developmental Disabilities

State Funding Profiles

CDC’s National Center on Birth Defects and Developmental Disabilities

MARYLAND

HELPING CHILDREN live to the fullest by understanding developmental disabilities

Slightly more than 1 in 10 (11.3%) parents in Maryland have a child diagnosed with an intellectual disability (ID) or autism. NCBDDD funds the national resource on ADHD based in Maryland to offer support and resources for families in Maryland and across the United States.

In Maryland, 1 in 60 children was identified as having autism spectrum disorder. Johns Hopkins University (JHU) is a key collaborator in CDC’s efforts to better understand the factors that might increase the risk for autism spectrum disorder. NCBDDD funds JHU to support autism tracking and monitoring throughout the state and collaborate on the Study to Explore Early Development.

In the most recent year with available data (2014), NCBDDD’s Early Hearing Detection and Intervention program in Maryland successfully tested 95.1% (70,304) of newborn babies for hearing loss and identified 69 babies who were deaf or hard of hearing. These babies and their families will benefit from services that will keep their learning on par with their hearing peers.

PROTECTING PEOPLE and preventing complications of blood disorders

NCBDDD’s work to protect the people of Maryland is broad-ranging, from ensuring that state preparedness plans protect children and those living with a disability to supporting best practices for blood clot prevention being implemented throughout the state. The Stop the Clot, Spread the Word™ campaign raises awareness of the risks, signs, and symptoms of blood clots (venous thromboembolism). JHU was named a Hospital Associated Venous Thromboembolism (VA-ITE) Champion by NCBDDD for their innovative and effective ways to prevent IMAeVTE in hospitals. NCBDDD also supports one hemophilia treatment center in Maryland through a national program.

IMPROVING HEALTH of people with disabilities

More than 1 in 5 (20.7%) of American adults live with a disability. NCBDDD helps to ensure that individuals with a disability in Maryland have the same opportunity for good health as those without a disability. Programs funded by NCBDDD are being designed and implemented to improve the health of people with disabilities in Maryland.

Annual Program Funding

NCBDDD is directly funding Johns Hopkins University ($1,497,313)

- Maryland Department of Health and Mental Hygiene ($475,453)
- National Blood Clot Alliance ($361,045)
- Children and Adults with Attention Deficit-Hyperactivity Disorder ($505,000)

“We have accomplished a lot together, but there is more work to be done.”

Graham A. Eddy, PhD, MPH
Disability & Health State Profiles
Thank You!

• A big thank you to Dr. Coleen Boyle, Adriane Griffen, Anna Costalas, Sascha Chaney, Marian Wiley, and AcademyHealth

• Next Quarterly Call: Thursday, September 28 at 3:00 pm

• Send feedback to Becky Abbott (rabbott@marchofdimes.org)
Next Steps and Action Items

• Contact Becky Abbott to sign-up for June 29th Advocacy Day and/or to be added to Advocacy Coalition email list (rabbott@marchofdimes.org)

• Review grassroots toolkit when disseminated and consider engaging

• REMINDER: Keep the Friends updated on the work of your organization!
  – Monthly newsletter: content due the 10th of each month to acostalas@aucd.org
  – Listserv: anyone can post to the listserv (friendsncbddd@lyrisvs.aucd.org)