Partner Engagement Overview: NCBDDD Strategic Plan 2010

National Center on Birth Defects and Developmental Disabilities

December 15, 2010
Partner Engagement

Center Priorities
November 15

Division Priorities
December 15

Finalized Plan
Partner Input

- Changes in Health Care
- Strategy & Policy Intervention
- Glaring Omissions
- Prevention
NCBDDD Strategic Priorities

Prevent Major Birth Defects Due to Maternal Risk Factors

Prevent Death and Disability Associated with Deep Vein Thrombosis/Pulmonary Embolism

Reduce Disparities in Obesity and Other Health Indicators in Children, Youth and Adults with Disabilities
Core Public Health Strategies

Surveillance  Research  Prevention
Division Specific Priorities

Division of Human Development and Disability

Division of Blood Disorders

Division of Birth Defects and Developmental Disabilities
Partner Overview:
Division of Human Development & Disability
Strategic Plan 2010

National Center on Birth Defects and Developmental Disabilities

December 15, 2010
Vision: To serve as a national and international resource to promote optimal development, health, and well-being of children and people with disabilities.

Values: collaboration, respect, excellence, accountability, integrity, creativity

Multiple Funding lines

Life-course conceptual model
Life Course Model, Swanson, CDC
DHDD Approach

Define health broadly
ICF—Consider disability by *impact* not *diagnosis*;
*interaction* of environment and person

DHDD Public Health Services:

Interventions ↔ Data ↔ Policy/Advocacy

Criteria-based selection of priorities, approaches and projects
Technology to advance data, knowledge management, policy, research and interventions.
Priority 1: All newborns assessed for hearing loss and receive services

- **EHDI state data collection**
  - 1:3:6 with HRSA
  - 53 states a

- **EDHI data systems**
  - iEHDI feasibility study
  - EHRs—interoperable standards and procedures

- **EHDI research**
Priority 2: Reduce disparity in obesity and other health indicators in children, youth and adults with disabilities

- **Obesity:**
  - Inclusion in generic obesity programs
  - Disability-specific workgroup to determine prevalence, risk, interventions, implementation

- **Other Health Indicators**
  - Health status of adults with I/DD
  - Smoking, mental health, health care access
  - Emergency preparedness
Priority 3: Identify and Reduce Disparities in Health Care Access for Persons with Disabilities

- **Disability Surveillance Reporting System**
  - BRFSS data for all states on all variables

- **Complex Disabling Conditions**
  - Surveillance
  - Retrospective longitudinal studies
  - Prospective longitudinal method select conditions (SB, MD, FrX)

- **Disability & Health network of state programs**
  - Focused on key outcomes
  - Disability inclusion

- **HP2020**
Priority 4: Incorporate disability status into all relevant CDC surveys, programs and policies

- CDC-wide Disability & Health Workgroup
- Disability status inclusion in CDC surveys (PPACA)
- Disability inclusion in FOAs for programs and research
- Communication
DHDD Priority 5: Improve developmental outcomes of children

- Increase collaboration of child development expertise with complex disabling conditions
- Surveillance on select childhood conditions
- Implement Legacy for Children™ in Early Head Start
- Examine effects of Legacy into school years.
DHDD Infrastructure Priority

- Continued planning and plan implementation
- Strengthen collaboration with partners
  - National and international efforts
  - Public Health Resource and Practice Centers
- Infrastructure development to achieve priorities
  - Science and Surveillance
  - Policy, Advocacy, Communications
  - Interventions
Thank You!

For more information please contact Centers for Disease Control and Prevention

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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.
Partner Overview:
Division of Blood Disorders Strategic Plan 2010

National Center on Birth Defects and Developmental Disabilities

December 15, 2010
Division of Blood Disorders
History

- Some activities date back to the 1970s
- Initially focused on coagulation disorders
- Shifted to blood safety in the 1980s
- Expanded in the 1990s
- Most activities carried out from a clinical or laboratory perspective
Expanding to a population-based public health model

- Addresses public health challenges
- Includes:
  - Characterizing the problems
  - Conducting epidemiologic research
  - Developing and disseminating effective programs and policies
Division of Blood Disorders
Our Goals

- Establish blood disorders as a public health priority
- Understand the causes of and risk factors for blood disorders
- Understand and minimize occurrence and complications of blood disorders
- Develop and evaluate evidence-based interventions for blood disorders
- Ensure that people with or at risk for blood disorders have access to credible health information
Division of Blood Disorders
Outcomes We Hope to Achieve

- Improve the life expectancy of people with Sickle Cell Disease.
- Reduce the morbidity and mortality related to bleeding disorders in women.
- Reduce the incidence of deep vein thrombosis/pulmonary embolism, and prevent related mortality and serious morbidity.
- Prevent emerging morbidities of people with blood disorders.
Division of Blood Disorders
Our Priorities

- Prevent deep vein thrombosis and pulmonary embolism
- Prevent and control complications resulting from hemoglobinopathies
- Prevent and control complications resulting from bleeding disorders
Division of Blood Disorders
What We Will Do

Priority 1: Clotting disorders

- Population-based surveillance
- Awareness and education
- Use of evidence-based guidelines
Division of Blood Disorders
What We Will Do

Priority 2: Hemoglobinopathies

- Establish pilot surveillance
- Characterize the population
What We Will Do

Priority 3: Bleeding disorders

- Characterize the problem
- Conduct research
- Develop and implement effective interventions
Division of Blood Disorders
Moving Forward

- Expert advice to review and update current activities
- Partner input about the needs of the community
- Working together to serve the community
Thank You!

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Partner Overview: Division of Birth Defects and Developmental Disabilities Strategic Plan

National Center on Birth Defects and Developmental Disabilities
*Birth Defects*

- **1967:** The Metropolitan Atlanta Congenital Defects Program (MACDP)
- **1992:** State-based birth defect surveillance/The National Birth Defects Prevention Network (NBDPN)
- **1996:** National Birth Defects Prevention Study (NBDPS)

*Developmental Disabilities*

- **1984:** Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDS/MADDSP)
- **2000:** Autism and other Developmental Disabilities Monitoring Network (ADDM)
- **2001:** Study to Explore Early Development (SEED)
Division of Birth Defects and Developmental Disabilities
Current and Future

- **Vision**
  Healthy birth and optimal development for all children

- **Mission**
  To be the public health leader in preventing the occurrence or adverse consequences of birth defects, developmental disabilities, and pediatric genetic conditions through surveillance, research, and intervention programs
Division of Birth Defects and Developmental Disabilities

Our Priorities

• Enhance surveillance and research for autism and other developmental disabilities.

• Prevent congenital heart defects and other major birth defects associated with obesity, diabetes, and medications.

• Prevent alcohol-exposed pregnancy among reproductive age women.

• Eliminate all folic acid-preventable neural tube defects in the United States and globally.
Enhance surveillance and research for autism and other developmental disabilities to monitor changes in prevalence and contributing risk factors, and better inform policy and programs.
Enhance surveillance and research for autism and other developmental disabilities to monitor changes in prevalence and contributing risk factors, and better inform policy and programs.

Why is this important?

- Developmental disabilities affect approximately 13% of children younger than 18; about 1 in 110 children has an autism spectrum disorder (ASD).

- Average age of ASD diagnosis is 4.5 years of age.

- Total lifetime costs are substantial for children born with developmental disabilities and their families.
Enhance surveillance and research for autism and other developmental disabilities to monitor changes in prevalence and contributing risk factors, and better inform policy and programs.

**What can be done?**

1. Report prevalence of ASDs among 8-year-olds every two years and begin data collection among 4-year-olds.

2. Evaluate how changes in diagnosis and other system issues influence trends in prevalence.

3. Investigate the association of maternal risk factors (e.g., exogenous hormones, infections) with occurrence of ASDs to inform action for prevention or intervention.
Enhance surveillance and research for autism and other developmental disabilities to monitor changes in prevalence and contributing risk factors, and better inform policy and programs.

What can be done?

4. Assure that Learn the Signs. Act Early. campaign materials are relevant, effective and used by all organizations that serve parents and caregivers of young children.

5. Assure that effective strategies exist and are used by professional practice to reduce racial/ethnic disparities in identification of ASD and other developmental disabilities.
Prevent congenital heart defects and other major birth defects associated with obesity, diabetes and medications.
Prevent congenital heart defects and other major birth defects associated with obesity, diabetes and medications.

Why is this important?

- 1 out of every 33 children is born with a major birth defect; 1 out of every 100 children is born with a congenital heart defect.

- Costs are substantial with higher medical costs per year than other major childhood conditions, such as cancer.

- Some maternal risk factors have been identified: being obese or having uncontrolled diabetes prior to and during pregnancy; certain medications.
Prevent congenital heart defects and other major birth defects associated with obesity, diabetes and medications.

What can be done?

1. Disseminate safety information on medications used by reproductive-aged women and used during pregnancy.

2. Evaluate potential effect modifiers for diabetes and obesity.

3. Evaluate, disseminate, and implement programs to reduce birth defects and other adverse pregnancy outcomes.
Prevent alcohol-exposed pregnancy among reproductive age women to prevent fetal alcohol syndrome and other adverse effects of prenatal alcohol exposure.
Prevent alcohol-exposed pregnancy among reproductive age women to prevent fetal alcohol syndrome and other adverse effects of prenatal alcohol exposure.

### Why is this important?

- Prenatal alcohol exposure is a leading preventable cause of birth defects and developmental disabilities.
- Among pregnant women, 12% report alcohol use and 2% report binge drinking in the past month.
- Total lifetime costs are substantial for children born with FAS and FASDs.
Prevent alcohol-exposed pregnancy among reproductive age women to prevent fetal alcohol syndrome and other adverse effects of prenatal alcohol exposure.

**What can be done?**

1. Increase by 10% the percentage of primary health care providers who always screen for alcohol use and conduct brief interventions with women of reproductive age who screen positive for risky drinking.

2. Increase awareness of dangers of alcohol use during pregnancy among women and their health care providers.
Prevent alcohol-exposed pregnancy among reproductive age women to prevent fetal alcohol syndrome and other adverse effects of prenatal alcohol exposure.

What can be done?

3. Increase use of Project CHOICES among a wide range of service providers serving women at risk of an alcohol exposed pregnancy.

4. Use national data systems with data on alcohol use in women of childbearing age to influence clinical and public health policy on screening and brief intervention.
Eliminate all folic acid preventable neural tube defects in the United States and globally.
Eliminate all folic acid preventable neural tube defects in the United States and globally.

Why is this important?

- Neural tube defects (NTDs) are a significant cause of infant mortality and childhood morbidity globally.
- Globally, more than 300,000 infants are born with NTDs each year.
- Worldwide folic acid fortification could lead to the prevention of 150,000-210,000 NTDs per year.
Eliminate all folic acid-preventable neural tube defects in the United States and globally.

What can be done?

1. Use optimal blood folate concentration as a biomarker to evaluate the impact of fortification efforts.

2. Assure that the prevalence of NTDs among Hispanic women is not more than 10% higher than in non-Hispanic whites.

3. Increase number of countries fortifying highly consumed staples with folic acid (target 40% -- from 51 to 71).
Thank You!

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