



# External Partners Group

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

## NCBDDD Health Disparities Basic Facts

*Numerous government reports from AHRQ to the IOM to the US Surgeon General have documented the disparities in access to health care services by racial and ethnic groups.*

*Many agencies have targeted cultural competence and overcoming ethnic and racial disparities in health services as national program objectives.*

- Disabilities are higher among individuals who are black (19.2%) and Hispanic (26.1%) than white (18.9%)
- African American youth are under represented in treatment for AD/HD compared with prevalence rates and compared with whites.
- Hispanic women have higher rates of neural tube defects (7.02 per 10,000) than women who are non Hispanic white (5.35 per 10,000) and non Hispanic black (4.70 per 10,000)
- On average, white children first received their autism diagnosis at 6.3 years of age, compared with 7.9 years for African-American children and 8.8 years for Latino children
- Sickle cell occurs in 1 in 500 African American births and 1 in 1,000 Hispanic births

## National Center for Birth Defects and Developmental Disabilities FY09 Appropriations Request

The External Partners Group (EPG) consists of over 200 organizations committed to supporting the Centers for Disease Control and Prevention's (CDC) National Center for Birth Defects and Developmental Disabilities (NCBDDD).

**The EPG supports an overall increase of \$20 million in new funding for the NCBDDD and included in that increase a \$5 million new program initiative to address the disparities faced by special populations served by NCBDDD.**

Health disparities are defined by differences in the presence of disease, health outcomes, or access to health care across groups of people. Individuals with intellectual and physical disabilities, or potentially disabling conditions (such as birth defects or blood disorders) are especially vulnerable to experiencing disparate health outcomes. Considered together, racial and ethnic minorities affected by these disabilities or conditions face even greater health disparities.

### **Suggested Report Language**

**The Committee understands that racial and ethnic disparities in health outcomes are complex and not fully understood. The Committee provides \$5 million for the NCBDDD to expand and coordinate research and develop public education campaigns on racial and ethnic disparities targeted at birth defects, enhancing the quality of life and preventing secondary conditions among people who are living with mental or physical disabilities.**

### **Critical Needs**

#### **Public Health Monitoring**

Public health monitoring is essential for understanding how often a condition and its complications or risk factors occurs in a population. The following critical monitoring needs have been identified related to NCBDDD issues:

- Expand public health monitoring in areas that include a higher percentage of racial and ethnic minorities to identify birth defects risk factors.
- Develop targeted studies for racial and ethnic minorities based on the developmental disability surveillance system in Atlanta.
- Expand national surveys to obtain state-level data on individuals with disabilities including race, ethnicity, severity and duration.
- Collect data to determine potential barriers to early identification and treatment among children with intellectual disabilities.

### **Public Health Research**

Public health research brings a unique perspective of studying health issues in large populations – not just among individuals or families who participate in clinic-based studies. The following critical research needs have been identified related to NCBDDD issues:

- Conduct applied research to identify promising interventions for those living with potentially disabling conditions, such as birth defects and blood disorders.
- Increase participation of minority populations in genetic research studies to include birth defects and blood disorders.
- Develop long term follow up studies to obtain data on early identification, treatment and referral to services for racial and ethnic minority children with intellectual disabilities.
- Conduct community-based intervention projects for women at high-risk of adverse pregnancy outcomes (e.g., women with intellectual disabilities, bleeding disorders, or chronic medical conditions)

### **Health Promotion**

Health promotion activities encourage healthy personal behaviors to reduce risk for complications and poor health outcomes through education and interventions. This includes increasing early identification and referral to services in order to enhance quality of life. The following critical health promotion needs have been identified related to NCBDDD issues:

- Refine promising health promotion interventions to address the special concerns of racial and ethnic minorities with disabilities, including and not limited to approaches to deal with cultural attitudes, stigma and misinformation about health.
- Develop culturally competent educational materials for healthcare providers, public health practitioners and the public on birth defects, intellectual disabilities, blood disorders and disabilities to promote early identification, treatment, and services.
- Conduct outreach with non-traditional organizations (e.g., faith-based groups and community organizations) and families, as well as advocacy organizations in order to reach minority and underserved populations in need of public health education and intervention.
- Enhance prevention strategies to reduce NTD rates among Hispanic women.

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