

The National Center on Birth Defects and Developmental Disabilities (NCBDDD)

Mission. The National Center on Birth Defects and Developmental Disabilities' (NCBDDD) mission is to promote the health of babies, children, and adults, and enhance the potential for full, productive living.

NCBDDD's work includes identifying the causes of and preventing birth defects and developmental disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities.

NCBDDD priorities:

- ▶ Develop and implement comprehensive research-to-practice initiatives that promote early identification, referral, and intervention for prioritized health conditions.
- ▶ Identify major new factors leading to healthy birth outcomes.
- ▶ Conduct research on the natural history of secondary conditions throughout the lifespan to identify promising interventions.
- ▶ Develop and implement a comprehensive research-to-practice initiative designed to promote preconception care services.
- ▶ Promote evidence-based strategies for optimal child development.

The External Partners Group is a coalition of government and private sector participants who work together to enhance the mission and activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in promoting child development; preventing birth defects and developmental disorders/disabilities; and enhancing the quality of life and preventing secondary conditions among people who are living with mental or physical disabilities, or a combination thereof.

For more information about the External Partners Group or its partner organizations, go to www.externalpartners.org

NCBDDD Organization. NCBDDD is comprised of three divisions with numerous programmatic areas of emphasis. The three divisions are:

- ▶ **Division of Birth Defects and Developmental Disabilities.** Birth defects affect about one in every 33 babies born in the United States each year. They are the leading cause of infant deaths, accounting for more than 20 percent of all infant deaths. Babies born with birth defects have a greater chance of illness and long-term disability than babies without birth defects. In early 1998, Congress passed the Birth Defects Prevention Act of 1998, which became Public Law 105-168. This bill authorized CDC to (1) collect, analyze, and make available data on birth defects; (2) operate regional centers for applied epidemiologic research on the prevention of birth defects; and (3) inform and educate the public about the prevention of birth defects.

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime.

- ▶ **Division of Blood Disorders.** CDC's Division of Blood Disorders works to prevent and reduce complications experienced by persons with certain hereditary blood disorders, such as hemophilia, von Willebrand disease, Thrombophilia, and Thalassemia.
- ▶ **Division of Human Development and Disability.** CDC's Human Development and Disability program is a population-based public health promotion program that focuses on issues related to human development and promotes the health of all people with disabilities.

CDC works, in collaboration with national, state, and local partners, to support optimal development for at-risk children and promote overall health for those individuals with disabilities. CDC supports surveillance, prevention, and intervention activities for a variety of programs within Human Development and Disability. They include programs for Disability and Health, Limb Loss, Spina Bifida, Tourette Syndrome, Muscular Dystrophy, Early Hearing Detection and Intervention, Fragile X, Special Olympics, and the Paralysis Resource Center.

Specific activities conducted by these programs include interventions for children at high risk for developmental problems; research on risk factors and measures of health, functioning, and disability among children and adults; newborn screenings to identify children with hearing loss and certain metabolic and genetic disorders; and development of programs within state health departments to provide infrastructure and support for the health promotion of people with disabilities.

IOM Disability Report. In April 2007, CDC provided primary funding for a report issued by the Institute of Medicine (IOM): *The Future of Disability in America*. Additional support came from the National Institute on Disability and Rehabilitation Research (NIDRR) and the National Center for Medical Rehabilitation Research (NCMRR). In the report, the IOM committee identified continuing gaps in disability science and proposed steps to strengthen the evidence base for public and private actions to reduce the impact of disability and related conditions on individuals and society in the United States. The new report builds on the 1991 IOM report, *Disability in America: Toward a National Agenda for Prevention*, and the 1996 report, *Enabling America*.