

Background

What are birth defects?

Birth defects are structural changes present at birth that can affect almost any part or parts of the body (e.g., heart, brain, foot). They may affect how the body looks, works, or both. Birth defects range from mild to severe. They can cause physical, developmental, or medical problems and can significantly affect a child's quality of life or lead to premature death.

Why do we need birth defect surveillance, education, and intervention activities?

In the United States (US), birth defects are one of the leading causes of death for children under one year of age. It is estimated that one in every five infant deaths occurs due to birth defects.

According to the National Birth Defects Prevention Network (NBDPN), 1 in 33 infants is affected by one or more birth defects in the US. This translates into one infant born with a birth defect every four and a half minutes. Birth defects-associated hospitalizations have disproportionately high costs, accounting for 3% of all hospitalizations and 5% of total hospital costs. The estimated annual cost of birth defects-associated hospitalizations in the US was \$23 billion in 2013. Surveillance activities are important for tracking the occurrence of birth defects and identifying trends, developing and evaluating prevention programs, assisting families with referral for services, identifying potential risk factors, supporting epidemiological investigations, fostering collaborative studies, and shaping etiological hypotheses for follow-up research.

What is the Florida Birth Defects Registry (FBDR)?

The FBDR is a statewide, population-based surveillance system that is used to identify infants with birth defects born to Florida resident mothers. The FBDR utilizes and links multiple administrative datasets, including vital statistics and hospital discharge records, to identify any infant born after January 1, 1998 with a structural, genetic, or other specified birth outcome that can adversely affect the infant's health or development diagnosed within the first year of life.

The Department of Health (DOH) is the only agency in Florida with authority to create confidential disease registries in accordance with Section 381.0031, Florida Statute. Although information on birth defects can be found in multiple data sets, the FBDR is the only data source where data are combined with other demographic, clinical and maternal and child health information for analysis and reporting on the occurrence of birth defects in Florida.

What is done with the data the FBDR collects?

Data on trends, risk factors, costs, access to services, and effectiveness of prevention programs are analyzed and interpreted at the county and state levels for use by key stakeholders, including health policy leaders, county health departments, Healthy Start Coalitions, child health advocates, health care providers and researchers. Florida contributes substantially to various national collaborative projects with the NBDPN. The FBDR data help health policy leaders and child health advocates anticipate resource needs and secure funding for services. These data also help guide public health professionals in targeting areas and populations in which primary prevention activities would make the largest difference in the lives of infants and families.