

Birth Defects Registry

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Outline

- Overview of the Maternal and Child Health (MCH) Section Surveillance Activities
- Birth Outcomes Versus Birth Defects
- History of the Birth Conditions Program
- Strengths and Limitations of Registry Data
- Final Points

Maternal & Child Health Surveillance Activities

The Maternal and Child Health (MCH) Section is within the Bureau of Population Health and Community Services, Division of Public Health Services.

MCH Programs with Surveillance Activities

- Maternal Mortality
- The Newborn Screening Programs:
 - Early Hearing Detection & Intervention(EHDI)
 - Blood spot - Critical Congenital Heart Defects(CCHD)
 - Sudden Unexplained Infant Death and Sudden Death in the Youth (SUID & SDY)
 - Birth Conditions Program
- Injury Prevention
- Pregnancy Risk Assessment Monitoring System(PRAMS)

Birth Outcomes vs. Birth Defects

- **Birth Outcomes**

- Birth outcomes refers to measures such as gestation age and birth weight such as infants born preterm, or infants born at term with low birth weight. (1)
- Factors that contribute to adverse birth outcomes can include behavioral, social and environmental factors.

- (1) <https://ephtracking.cdc.gov/showRbMain>

Birth Defects

Birth defects are structural changes that are present in an infant at birth, which can affect any part of the body. They may affect how the body looks as in clubbed feet or how the body works as in heart defects. The defects can range from mild to severe. (2)

Birth Defects are Common, Costly and Critical

- Every 4 1/2 minutes, a baby is born with a birth defect in the United States, affecting 1 in every 33 babies born each year. (2)
 - Approximately 120,000 babies in the U.S annually. (2)
- Each year, total hospital costs for U.S. children and adults with birth defects exceed \$2.6 billion. (2)
- Birth defects cause 1 in every 5 deaths during the first year of life.(2)

(2) <https://www.cdc.gov/ncbddd/birthdefects/facts.html>

What Causes Birth Defects:

- Maternal factors may contribute to birth defects including substance use, certain medications, or certain infections .
- The relationship between environmental exposures and birth defects are not clear and more research needs to be conducted to understand these connections.

Important

- Causes of 65-80% of birth defects are unknown
- Some social, behavioral and environmental factors are linked with abnormal fetal development
- Surveillance systems monitor the prevalence of defects over time

History of the BCP

- Previous to the development of the BCP, birth defects data was documented through vital records and hospital discharge records.
- The BCP was created in 2003 and was located at the Geisel School of Medicine at Dartmouth.
- The program was funded by the CDC and collected birth defects data for the years 2003 to 2013. The BCP lost CDC funding in early 2016 and the program shuttered.
- The program gained limited CDC funding in late 2016 as part of the global Zika epidemic and was able to restart surveillance activities related to birth defects associated with Zika virus exposure in house under the MCH Section.
- Once Zika surveillance funding ended, MCH was able to fund the BCP through the MCH Block Grant.
- BCP is now operational and has re-started data collection beginning with the year 2018.
- Data is collected and de-identified data is reported to the CDC NBDPN over a rolling five (5) year period.

Stakeholders of the BCP

- CDC and NBDPN
- Families with babies born with a birth condition
- Healthcare service providers and hospitals
- Community organizations
- NH Department of Health and Human Services (DHHS)

Strengths and Limitations of Registry Data

Strengths

- Population-based, active birth defect surveillance system
- Monitors the occurrence of 45 birth defects that are recommended by the National Birth Defects Prevention Network(NBDPN) and the Centers for Disease Control and Prevention (CDC)
 - Accurate and complete surveillance within NH
 - Prevention and awareness activities
 - Currently social media is utilized to disseminate monthly messaging surrounding awareness months
- Connecting families to appropriate programs such as Bureau of Family Centered Services

Limitations

- Parents may opt out of the registry
- Cross Border state delivery information is often not available

Final Points

- Rare events
 - Statistical power
 - Reporting often focuses on counts instead of rates
 - Internal vs external analyses (e.g. mapping)
- Contribute de-identified to national data
 - Benefit to NH because studies that we could not do with NH data alone become possible
 - Also benefit from expertise
- PRAMS, Birth Certificate, Death Certificate, All-Payer Claims, Hospital Discharges
- Emerging/Potential Issues: e.g. Zika and COVID