

Birth Defects Reporting Fact Sheet

CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

Background

The Children and Youth with Special Health Needs program works to provide positive health outcomes for children and youth who have, or are at risk for, special health needs. The Birth Defects program is part of this effort to serve families better by assuring they receive appropriate services and identifying gaps.

The Birth Defects Information System (BDIS) was created in 2004 to establish and maintain an information system containing data on the cause, treatment, prevention, and cure of major birth defects (Minnesota Statute 144.2215-2219). Data are used to monitor trends of birth defects to detect emerging health concerns and identify affected populations. BDIS started in 2005 with babies born or treated in two counties and has since expanded statewide. In 2018, the statute was amended to include birth defects that result in stillbirth (also known as “fetal death”) to improve the response to emerging threats like Zika virus.

Birth defects reporting

Reporting birth defects records is required by Minnesota Statute 144.2216. The program primarily works with Health Information Management staff at hospitals, clinics and other institutions to receive reports and review medical records. Most health care facilities report using discharge and procedure codes for congenital anomalies, currently ICD-10-CM. The program supplements this reporting using birth, death, and fetal death certificates and other administrative sources. MDH abstractors review medical records for potential cases to ensure the child meets case definition.

Birth defects definitions

Conditions monitored and case definitions, including inclusion and exclusion criteria, follow the national guidelines provided by the Centers for Disease Control & Prevention (CDC) and National Birth Defects Prevention Network (NBDPN). Most are major structural and genetic defects, but some are less severe. These conditions affect many body systems, including:

- Cardiovascular
- Central Nervous System
- Eye
- Ear
- Orofacial
- Gastrointestinal
- Genitourinary
- Musculoskeletal
- Chromosomes or Genes

If a child meets the current case definition for a birth defect, case and diagnostic information is abstracted into BDIS. This may include, but is not limited to, personally identifiable information on the patient, information on tests and procedures conducted and results, diagnoses, referrals to other providers and services, and other pertinent information.

Data privacy

Information collected for the Birth Defects Information System are classified as private data on individuals (Minnesota Statute 144.2217). Minnesota Statute 144.2216, Subd. 4 provides parents or guardians the opportunity to “opt out” of including their personal identifying information after initial data collection. Once a confirmed birth defect diagnosis is collected into BDIS, MDH mails the parents or guardians a packet including the opt out option. If a parent or guardian submits an opt out form, the record is de-identified. The de-identified record remains in BDIS to ensure accuracy of prevalence rates for these rare conditions.

Results

- Prevalence estimates for nationally reportable birth defects are published annually in the [National Birth Defects Prevention Network Annual Report](https://nbdpn.org/publications/annual-reports-5/) (<https://nbdpn.org/publications/annual-reports-5/>).
- Analyses from BDIS are available through the [Minnesota Public Health Data Access Portal](https://data.web.health.state.mn.us/web/mndata/) (<https://data.web.health.state.mn.us/web/mndata/>).
- Additional analyses are added as more data become available.

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To obtain this information in a different format, call: 651-201-3650.