

Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: Surveillance, Research, Referral to Services, Targeted prevention to higher risk populations.

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 2005

Earliest year of available data: 2006

Organizational location: Department of Health (Maternal and Child Health)

Population covered annually: 70,000

Statewide: Yes

Current legislation or rule: MS 144.2215-2219

Legislation year enacted: 2004

Case Definition

Outcomes covered: Pregnancy outcome: 1) Live birth; 2) Fetal death at => 20 wks in 2019 birth cohort Major structural and genetic defects diagnosed up to 1 year of age identified by CDC and NBDPN.

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Up to 1 year after delivery

Residence: In-state and out of state births to state residents

Surveillance Methods

Case ascertainment: Active Case Finding

Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Newborn CCHD screening

Delivery hospitals: Disease index or discharge index, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Other sources: Statewide de-identified hospital discharge dataset; Any case reported by local public health agency

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any birth certificate with a birth defect box checked, All stillborn infants, Any chart with an ICD10 Q00-Q99 or an ICD 10(P, Z, O) indicating stillbirths; All deaths prior to age 2 with a birth defect indicated as cause of death on death certificates, starting with 2009 births; Fetal death reports shared by Vital Records

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, etc.), Family history

Data Collection Methods and Storage

Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Remote access to medical records for large volume reporting facilities/systems

Database collection and storage: Web-based department-wide integrated disease surveillance database. Maven platform by Consilience Software.

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Education/public awareness, Prevention projects, Collaboration with Environmental Public Health Tracking Program

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Sharing of confirmed cases with key contacts at local public health agencies for service referral. LPH staff can log on to our the birth defects database to view relevant case information. In 2012, LPH began entering follow up and service/program updates into BDIS.

System integration: The Birth Defects Information System (BDIS) is integrated with Newborn Hearing program and Heritable Conditions. The databases share a model on the same platform, but they are managed separately. (This platform, Maven by Consilience Software, is also used by many infectious disease surveillance systems in MN and access is limited by disease/user role.) Additional integration with the Newborn CCHD Screening program takes place in 2017 as universal newborn CCHD screening is implemented.

Funding

Funding source: 76% General state funds, 24% CDC grant

Other

Web site:

<https://www.health.state.mn.us/people/childreneyouth/birthdefects/index.html>

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