

## North Dakota

### North Dakota Birth Defects Monitoring System (NDBDMS)

**Purpose:** Surveillance

**Partner:** Advocacy Groups, Division of Special Health Services.

**Program status:** Currently collecting data

**Start year:** 2002

**Earliest year of available data:** 1994

**Organizational location:** Department of Health (Office of the State Epidemiologist.)

**Population covered annually:** 10,051-This data is for CY 2020.

**Statewide:** Yes

**Current legislation or rule:** North Dakota Century Code:1. 23-41-04.

Birth report of child with special health care needs made to department. Within three days after the birth in this state of a child born with a visible congenital deformity, the licensed maternity hospital or home in which the child was born, or the legally qualified physician or other person in attendance at the birth of the child outside of a maternity hospital, shall furnish the department a report concerning the child with the information required by the department.2. 23-41-05. Birth report of child with special health care needs - Use - Confidential. The information contained in the report furnished to the department under section 23-39-04 concerning a child with a visible congenital deformity may be used by the department for the care and treatment of the child pursuant to this chapter. The report is confidential and is solely for the use of the department in the performance of its duties. The report is not open to public inspection nor considered a public record.

**Legislation year enacted:** 1941

#### Case Definition

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

**Age:** 12 months or within the year of birth.

**Residence:** In-state birth/s to state resident.

#### Surveillance Methods

**Case ascertainment:** Passive case-finding without case confirmation

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

**Other state based registries:** Programs for children with special needs

**Pediatric & tertiary care hospitals:** Contracted clinics conducted by Special Health Services.

**Other sources:** Physician Reports from contracted clinics conducted by Special Health Services.

#### 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, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)

**Coding:** ICD-9-CM/ICD-10-CM

#### 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, 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.), Demographic information (race/ethnicity, sex, etc.)

#### 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.)

**Database collection and storage:** Access, Excel and SPSS

#### Data Analysis

**Data analysis software:** SPSS, Access

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Needs assessment, Education/public awareness, The NDBDMS has stopped surveillance since 2015. This due to lack of Medicaid paid claims data. Medicaid claims data was the major source of birth defects information.

#### System Integration

**System links:** Link case finding data to final birth file

#### Funding

**Funding source:** 100% Other (State Systems Development Initiative (SSDI))

#### Other

**Web site:** <http://www.ndhealth.gov/cshs/>

**Surveillance reports on file:** North Dakota Birth Defects Monitoring System Summary Report 2001-2005 North Dakota Birth Defects Monitoring System Summary Report 1995-1999

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