

Maine

Maine CDC Birth Defects Program (MBDP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Education

Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, March of Dimes, Maine Tracking Network

Program status: Currently collecting data

Start year: 1999

Earliest year of available data: 2003

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

Population covered annually: 12,000

Statewide: Yes

Current legislation or rule: 22 MRSA c. 1687

Legislation year enacted: 1999

Case Definition

Outcomes covered: Selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias and major heart defects

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Less than 20 weeks gestation, 20 weeks gestation and greater, Prenatally diagnosed at any gestation), Elective terminations (Prenatally diagnosed at any gestation)

Age: Through age 1

Residence: All in-state births to Maine residents

Surveillance Methods

Case ascertainment: Passive case ascertainment with active 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, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities

Other sources: Midwifery Facilities, Physician reports, Children with Special Health Needs

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), All stillborn infants, All infants in NICU or special care nursery, All prenatally diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Cardiovascular condition, Any infant with a codable defect

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.), 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

Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records

Database collection and storage: Oracle, Microsoft SQL Server

Data Analysis

Data analysis software: SAS

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

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other Maine state registries/databases, Link case finding data to final birth file

System integration: Newborn Hearing/ Newborn Bloodspot Screening Programs

Funding

Funding source: 100% MCH funds

Other

Web site:

<http://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/birth-defects/index.html>

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