

Connecticut

Connecticut Birth Defects Registry (CT BDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Reporting for MCH Block Grant
Partner: Local Health Departments, Hospitals, Advocacy Groups, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 37,000
Statewide: Yes
Current legislation or rule: Section 19a-53 (Formerly Sec. 19-21) of the general statutes was replaced (Effective October 1, 2017)
Legislation year enacted: 2017

Case Definition

Outcomes covered: All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71 (prior to ICD10 implementation still in the system although can no longer be selected). ICD10 codes include the entire Q series as well as some recommended by CDC in the provided crosswalk. Also Zika associated birth defects including those in ICD10 H series are included.
Pregnancy outcome: Livebirths (All gestational ages and birth weights, PDA = to 2500 gms birth weight)
Age: Up to one year after delivery for birth defects, but reported up to age 5
Residence: All in-state births are reported but reporting is done on in-state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, inpatient hospitalizations and emergency room visits
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, Reports from health care professionals in newborn nurseries and NICUs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Reports from health care professionals in pediatric inpatient and outpatient services planned for future
Other sources: Midwifery Facilities, Physician reports, Mandatory reporting by health care providers and facilities; CYSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment

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

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: Web based database

Data Analysis

Data analysis software: SAS, Access, Excel
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Time trends, Epidemiological studies (using only program data), Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Provider education

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: We are integrated with Newborn Screening and Early Hearing and Detection Intervention Program. Vital Records electronically imports in Maven Newborn Screening System (NSS). This database is also linked to Childhood Lead Program, Children with Special Health Care Needs and Family Wellness Healthy Start.

Other

Web site:
<https://portal.ct.gov/DPH/Family-Health/Birth-Defects-Registry/Connecticut-Birth-Defects-Registry>
Surveillance reports on file: NBDPN annual reports, state profiles

Contacts

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