

Rhode Island

Rhode Island Birth Defects Program (RIBDP)

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

Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Families

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2002

Organizational location: Department of Health (Center for Health Data and Analysis)

Population covered annually: 10,800

Statewide: Yes

Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws requires the development of a birth defects surveillance, reporting, and information system that will a) describe the occurrence of birth defects in children up to age five; b) detect trends of morbidity and mortality; and c) identify newborns and children with birth defects to intervene on a timely basis for treatment.

Legislation year enacted: 2003

Case Definition

Outcomes covered: All birth defects and genetic diseases

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)

Age: Birth up to 5 years

Residence: RI maternal residence

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment

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

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, RI has an integrated child health information system called KIDSNET, which links data from 10 programs including: Newborn Developmental Risk Screening, Newborn Bloodspot Screening, Newborn Hearing Screening, Home Visiting, Immunization, etc.

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics

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

Other sources: Physician reports

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 chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, All stillborn infants, All elective abortions, All infants in NICU or special care nursery, All prenatally diagnosed or suspected cases, Chart reviews are conducted for infants born at the regional perinatal center and the 4 other maternity hospitals who were identified with an ICD-9-CM code 740-759 and 760.71 or an ICD-10 Q code and other sentinel conditions

Conditions warranting chart review beyond the newborn period: 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.), 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

Data Collection Methods and Storage

Data collection: 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.)

Database collection and storage: Access, Oracle

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, 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), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, KIDSNET, hospital discharge data

System integration: Integrated into KIDSNET for web-based provider reporting

Funding

Funding source: 10% General state funds, 10% MCH funds, 80% CDC grant

Other

Web site: www.health.ri.gov/programs/birthdefects

Surveillance reports on file: 2020 Rhode Island Birth Defects Data Book

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