

Indiana

Indiana Birth Defects & Problems Registry (IBDPR)

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

Partner: Hospitals, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 2003 birth data is available in 2006

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

Population covered annually: 83,000

Statewide: Yes

Current legislation or rule: IC 16-38-4-7Rule 410 IAC 21-3

Legislation year enacted: 2001

Case Definition

Outcomes covered: Major birth defects, genetic disease, fetal alcohol syndrome, neonatal abstinence syndrome, pervasive developmental disorders, metabolic disorders, hearing loss, congenital blood disorders, and certain eye disorders.

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, We only capture if mom had a past stillbirth or spontaneous abortion, not for the current child. For spontaneous abortions we quantify it as less than 20 weeks gestation, and for stillbirth we quantify it as 20 weeks gestation or greater. Data is not delineated by birth outcome.)

Age: 0-3 for core, recommended, and extended conditions; up to 5 years for FAS; up to age 8 with Autism Spectrum Disorders

Residence: In- and out-of-state (as reported to IBDPR) births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation, case confirmation for hospital discharge data; w/o case confirmation for direct physician reporting

Vital records: Birth certificates, Death certificates

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Developmental Disabilities Surveillance

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries

Other specialty facilities: Genetic counseling/clinic genetic facilities

Other sources: Midwifery Facilities, Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99. Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease). We collect all cases with codes Q00-Q99, but only perform chart reviews on core, recommended, extended NBDPN conditions, plus FAS, NAS, and Autism Spectrum Disorder.

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, Prenatal care, Pregnancy/delivery complications

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: Oracle

Data Analysis

Data analysis software: SAS, SQL, Excel

Quality assurance: Double-checking of assigned codes, Data/hospital audits, Review by IBDPR staff, non-clinician

Data use and analysis: Routine statistical monitoring, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, The birth defects registry is linked to other program databases (see below).

System integration: The database is linked with birth, death, newborn hearing screening, newborn metabolic, and pulse oximetry screening data.

Funding

Funding source: 14% Service fees, 86% Genetic screening revenues

Other

Web site: www.birthdefects.in.gov

Surveillance reports on file: Progress Report to the Indiana Legislature

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