

Mississippi

Mississippi Birth Defects Surveillance Registry (MBDSR)

Purpose: Surveillance, Referral to Services

Partner: Local Health Departments, Hospitals, Advocacy Groups, Title V Children with Special Healthcare Needs

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: Department of Health (Maternal and Child Health, Genetic Services Bureau)

Population covered annually: 38,000

Statewide: Yes

Current legislation or rule: Section 41-21-205 of the Mississippi Code of 1972

Legislation year enacted: 1997

Case Definition

Outcomes covered: The infant/fetus must have a reportable structural defect, newborn screening disorder, functional or metabolic disorder, genetically determined or a defect resulting from an environmental influence during embryonic or fetal life.

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

Age: Birth to 21 years

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation

Vital records: Matched birth/death file

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Discharge summaries

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

Other specialty facilities: Genetic counseling/clinic genetic facilities

Other sources: Physician reports

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.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Father: Demographic information (race/ethnicity, sex, etc.), 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 submitted by other agencies (hospitals, etc.)

Database collection and storage: Access, New web based program (in development)

Data Analysis

Data analysis software: SAS, Excel

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, 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, Epidemiological studies (using only program data), Referral, Education/public awareness

System Integration

System links: Link case finding data to final birth file

Funding

Funding source: 100% Genetic screening revenues

Other

Web site: www.HealthyMS.com

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