

New Jersey
Special Child Health Services Registry (SCHS Registry)

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

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators, Neurodevelopmental Centers; Federally Qualified Health Care Centers; State Parent Advocacy Network; AAP NJ Chapter; all three (3) NJ MCH Consortia

Program status: Currently collecting data

Start year: 1928

Earliest year of available data: 1985

Organizational location: Department of Health (Family Health Services/Special Child Health and Early Intervention Services)

Population covered annually: ~100,000

Statewide: Yes

Current legislation or rule: NJSA 26:8-40.2 et seq., NJAC 8:20 - Amended: 1990, 1991, 1992, 2005, Readopted: 2010, Rule Amendments Adopted: 2009; Readopted: 2010

Legislation year enacted: 1983

Case Definition

Outcomes covered: All birth defects (structural, genetic, and biochemical), all Autism Spectrum Disorders, severe hyperbilirubinemia >25mg/dL, and failed pulse oximetry are mandated to be reported; all special needs and any condition which places a child at risk (e.g. prematurity, asthma, developmental delay) are also reported, but not mandated.

Pregnancy outcome: Livebirths (All gestational ages and birth weights)

Age: Mandated reporting of birth defects diagnosed through age 5, voluntary reporting of birth defects diagnosed > age 6 and all children diagnosed with Special Needs conditions who are 22 years or younger. Autism mandated up to 22 years.

Residence: All NJ residents born in or out of state

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation, staff reach out to reporters to verify rule out diagnoses, pending diagnoses, and other questionable diagnoses

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, Autism Registry

Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, Quality assurance visit consisting of chart review of 3 month period -staff of BDR does not actively look at logs and discharge summaries but depends on staff of various hospitals and agencies to do same.

Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Laboratory logs, quality assurance visit consisting of chart review of 3 month period

Third party payers: Universal billing database is used for quality assurance activities

Other sources: Midwifery Facilities, Physician reports, Special Child Health Services county-based Case Management Units, parents, medical examiners, Autism diagnosticians and treatment centers

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, Chart reviews are conducted on infants/children with mandated conditions that are in the 3 month audit window

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: 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.)

Database collection and storage: SAS; PostgreSQL

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness, Merge registry with birth certificate registry and the death certificate registry

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), 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 state registries/databases, Link case finding data to final birth file, link to hearing screening registry

System integration: Autism Registry is fully integrated. Newborns having failed Pulse Oximetry Screening are integrated with Registry. Newborn hearing screening registry provides direct report to the SCHS Registry. Metabolic screening program provides direct report to SCHS Registry. Special Child Health Services county-based Case Management Referral System is included in the Registry.

Funding

Funding source: 90% MCH funds, 10% CDC grant

Other

Web site: <http://www.nj.gov/health/fhs/bdr/>

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