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 hyperbillirubinemia >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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DATA TABLES

New Jersey
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Anencephalus	9	4	15	0	0	30	
	0.4	***0.6***	***1.1***	***0.0***	***0.0***	***0.6***	
Anophthalmia/microphthalmia	20	6	14	3	0	45	
	0.9	***0.9***	***1.0***	***0.5***	***0.0***	***0.9***	
Anotia/microtia	23	4	56	19	0	104	
	1.0	***0.6***	***4.1***	***3.3***	***0.0***	***2.0***	
Aortic valve stenosis	29	3	13	2	0	48	
	1.3	***0.4***	***1.0***	***0.3***	***0.0***	***0.9***	
Atrial septal defect	700	636	687	200	2	2,267	
	30.7	***90.6***	***50.3***	***34.3***	***59.2***	***44.5***	
Atrioventricular septal defect (Endocardial cushion defect)	38	28	31	4	0	105	
	1.7	***4.0***	***2.3***	***0.7***	***0.0***	***2.1***	
Biliary atresia	11	1	2	6	0	21	
	0.5	***0.1***	***0.1***	***1.0***	***0.0***	***0.4***	
Bladder exstrophy	2	1	1	2	0	6	
	0.1	***0.1***	***0.1***	***0.3***	***0.0***	***0.1***	
Choanal atresia	28	2	13	0	0	46	
	1.2	***0.3***	***1.0***	***0.0***	***0.0***	***0.9***	
Cleft lip alone	60	12	32	11	0	117	
	2.6	***1.7***	***2.3***	***1.9***	***0.0***	***2.3***	
Cleft lip with cleft palate	91	30	93	17	0	237	
	4.0	***4.3***	***6.8***	***2.9***	***0.0***	***4.6***	
Cleft palate alone	113	25	75	25	0	257	
	5.0	***3.6***	***5.5***	***4.3***	***0.0***	***5.0***	
Cloacal exstrophy	39	7	20	10	0	79	
	1.7	***1.0***	***1.5***	***1.7***	***0.0***	***1.5***	
Clubfoot	269	107	182	62	0	636	
	11.8	***15.2***	***13.3***	***10.6***	***0.0***	***12.5***	
Coarctation of the aorta	69	18	52	8	0	153	
	3.0	***2.6***	***3.8***	***1.4***	***0.0***	***3.0***	
Common truncus (truncus arteriosus)	7	2	7	0	0	16	
	0.3	***0.3***	***0.5***	***0.0***	***0.0***	***0.3***	
Congenital cataract	24	13	36	9	0	88	
	1.1	***1.9***	***2.6***	***1.5***	***0.0***	***1.7***	
Congenital posterior urethral valves	29	22	19	9	0	82	1
	2.5	***6.2***	***2.7***	***3.0***	***0.0***	***3.1***	
Craniosynostosis	99	30	92	22	0	258	
	4.3	***4.3***	***6.7***	***3.8***	***0.0***	***5.1***	
Deletion 22q11.2	4	0	1	0	0	6	
	0.2	***0.0***	***0.1***	***0.0***	***0.0***	***0.1***	
Diaphragmatic hernia	38	7	34	13	0	95	
	1.7	***1.0***	***2.5***	***2.2***	***0.0***	***1.9***	
Double outlet right ventricle	11	12	11	3	0	38	
	0.5	***1.7***	***0.8***	***0.5***	***0.0***	***0.7***	
Ebstein anomaly	5	1	7	4	0	18	
	0.2	***0.1***	***0.5***	***0.7***	***0.0***	***0.4***	
Encephalocele	3	2	6	1	0	12	
	0.1	***0.3***	***0.4***	***0.2***	***0.0***	***0.2***	
Esophageal atresia/tracheoesophageal fistula	59	18	18	7	0	105	
	2.6	***2.6***	***1.3***	***1.2***	***0.0***	***2.1***	
Gastroschisis	28	16	40	1	0	86	
	1.2	***2.3***	***2.9***	***0.2***	***0.0***	***1.7***	
Holoprosencephaly	53	34	51	14	0	156	
	2.3	***4.8***	***3.7***	***2.4***	***0.0***	***3.1***	
Hypoplastic left heart syndrome	26	16	13	5	0	62	
	1.1	***2.3***	***1.0***	***0.9***	***0.0***	***1.2***	
Hypospadias	1,199	244	370	199	0	2,060	1
	102.7	***68.8***	***53.1***	***65.9***	***0.0***	***79.1***	
Interrupted aortic arch	8	2	2	1	0	13	
	0.4	***0.3***	***0.1***	***0.2***	***0.0***	***0.3***	

New Jersey
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Limb deficiencies (reduction defects)	71	27	49	10	0	159	
	3.1	***3.8***	***3.6***	***1.7***	***0.0***	***3.1***	
Omphalocele	13	33	15	6	0	70	
	0.6	***4.7***	***1.1***	***1.0***	***0.0***	***1.4***	
Pulmonary valve atresia and stenosis	106	91	134	25	0	381	
	4.6	***13.0***	***9.8***	***4.3***	***0.0***	***7.5***	
Pulmonary valve atresia	4	5	11	2	0	25	
	0.2	***0.7***	***0.8***	***0.3***	***0.0***	***0.5***	
Rectal and large intestinal atresia/stenosis	57	19	51	23	0	157	
	2.5	***2.7***	***3.7***	***3.9***	***0.0***	***3.1***	
Renal agenesis/hypoplasia	142	33	85	25	0	292	
	6.2	***4.7***	***6.2***	***4.3***	***0.0***	***5.7***	
Single ventricle	1	2	4	3	0	10	
	0.1	***0.4***	***0.4***	***0.6***	***0.0***	***0.2***	
Small intestinal atresia/stenosis	52	21	59	9	0	144	
	2.3	***3.0***	***4.3***	***1.5***	***0.0***	***2.8***	
Spina bifida without anencephalus	25	10	38	9	0	91	
	1.1	***1.4***	***2.8***	***1.5***	***0.0***	***1.8***	
Tetralogy of Fallot	62	23	52	17	0	161	
	2.7	***3.3***	***3.8***	***2.9***	***0.0***	***3.2***	
Total anomalous pulmonary venous connection	16	6	15	10	0	49	
	0.7	***0.9***	***1.1***	***1.7***	***0.0***	***1.0***	
Transposition of the great arteries (TGA)	29	8	24	5	0	71	
	1.3	***1.1***	***1.8***	***0.9***	***0.0***	***1.4***	
Dextro-transposition of great arteries (d-TGA)	20	5	13	4	0	45	
	0.9	***0.7***	***1.0***	***0.7***	***0.0***	***0.9***	
Tricuspid valve atresia and stenosis	7	9	13	3	0	32	
	0.3	***1.3***	***1.0***	***0.5***	***0.0***	***0.6***	
Trisomy 13	11	5	11	0	0	28	
	0.5	***0.7***	***0.8***	***0.0***	***0.0***	***0.5***	
Trisomy 18	12	12	18	3	0	46	
	0.5	***1.7***	***1.3***	***0.5***	***0.0***	***0.9***	
Trisomy 21 (Down syndrome)	192	82	248	30	0	571	
	8.4	***11.7***	***18.1***	***5.1***	***0.0***	***11.2***	
Turner syndrome	20	1	14	2	0	39	2
	1.8	***0.3***	***2.1***	***0.7***	***0.0***	***1.6***	
Ventricular septal defect	1,090	361	781	235	3	2,533	3
	47.8	***51.4***	***57.2***	***40.3***	***88.8***	***49.7***	
Total live births	**228,222**	**70,203**	**136,643**	**58,363**	**338**	**509,721**	**4**
Male live births	**116,761**	**35,485**	**69,676**	**30,194**	**167**	**260,553**	
Female live births	**111,460**	**34,713**	**66,966**	**28,169**	**171**	**249,161**	

New Jersey
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	81	5	86	
	2.1	***0.4***	***1.7***	
Trisomy 13	16	12	28	
	0.4	***1.0***	***0.5***	
Trisomy 18	20	25	46	
	0.5	***2.0***	***0.9***	
Trisomy 21 (Down syndrome)	237	318	571	
	6.1	***26.0***	***11.2***	
Total live births	**387,525**	**122,191**	**509,721**	**4**

Notes
1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
2. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
3. Data for this condition only include confirmed cases.
4. Data for total live births include unknown gender.

General comments
*Data for totals include unknown and/or other.