

Colorado

Colorado Responds to Children with Special Needs Section (CRCSN)

Purpose: Surveillance, 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

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1989

Organizational location: Department of Health (Vital Statistics, Center for Health and Environmental Data (CHED))

Population covered annually: 61,496 (2020)

Statewide: Yes

Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101.25-1.5-105

Legislation year enacted: 1985

Case Definition

Outcomes covered: Structural birth defects, fetal alcohol syndrome, selected genetic and metabolic disorders; muscular dystrophy; selected developmental disabilities; very low birth weight (less than 1500 grams); others with medical risk factors for developmental delay.

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

Age: Up to the 3rd birthday

Residence: Events occurring in-state- or out-of-state Colorado residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation

Vital records: Birth certificates, Death certificates, Fetal birth certificate

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Specialty outpatient clinics

Third party payers: Medicaid databases

Other specialty facilities: Cytogenetic laboratories

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Selected chart reviews for prenatal to age 3 (28 conditions), minimal active case ascertainment data sources

Coding: ICD-9-CM/ICD-10-CM, Program specific 'extended' code for added detail: 9CM and 10CM

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.), Gravidity/parity, Pregnancy/delivery complications, Family history

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

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.), Electronic scanning of printed records, Administrative (electronic) data sets

Database collection and storage: SQL-web based

Data Analysis

Data analysis software: Epi-Info, SAS, Access, Arcview (GIS software); Mapmarker, Tableau

Quality assurance: Re-abstraction of cases, Comparison/verification between multiple data sources, Timeliness, Records linkage and de-duplication

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, Time-space cluster analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Environmental Studies

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases

Funding

Funding source: 50% General state funds, 50% Service fees

Other

Web site: <http://www.cdphe.state.co.us>

Contacts

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	110 <i>4.2</i>	4 <i>0.6</i>	117 <i>3.6</i>	
Trisomy 13	27 <i>1.0</i>	10 <i>1.6</i>	74 <i>2.3</i>	
Trisomy 18	35 <i>1.3</i>	30 <i>4.8</i>	120 <i>3.7</i>	
Trisomy 21 (Down syndrome)	243 <i>9.2</i>	256 <i>40.6</i>	700 <i>21.5</i>	
Total live births	263,033	63,117	326,321	5

Notes

1. Data for this condition has enforced gestational age limits in more recent birth years.
2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
3. Data for this condition begin in 2016.
4. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
5. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.