

Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: Surveillance, Research

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: 1996

Earliest year of available data: 1996

Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health)

Population covered annually: 9,500

Statewide: Yes

Current legislation or rule: 7 AAC 27.012

Legislation year enacted: 1996

Case Definition

Outcomes covered: Selected major birth defects based on ICD-10-CM code list

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

Age: Birth to third birthday

Residence: In and out of state births to Alaska residents

Surveillance Methods

Case ascertainment: Passive case-finding with limited case confirmation

Vital records: Birth certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Genetics clinics, specialty clinics (heart, cleft lip/palate, neurodevelopmental), Maternal Child Death Review (MCDR), public health nursing, Alaska Dept. of Behavioral Health (AKAIMS)

Delivery hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.

Pediatric & tertiary care hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.

Third party payers: Medicaid databases, Indian health services, Private health insurers

Other specialty facilities: Genetic counseling/clinic genetic facilities

Other sources: Physician reports, Alaska Health Information Exchange, AK AIMS (Alaska Dept. of Behavioral Health)

Case Ascertainment

Conditions warranting chart review in newborn period: All Codes included in the current NBDPN list of birth defects listing (see: http://www.nbdpn.org/docs/Appendix_3_1_BirthDefectsDescriptions2015.pdf) are sampled for review. Other collected conditions/codes will be sampled and reviewed based upon incoming requests and/or need.

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 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: Access

Data Analysis

Data analysis software: R

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Needs assessment, Grant proposals, Education/public awareness

System Integration

System links: Link case finding data to final birth file

System integration: No.

Funding

Funding source: 20% General state funds, 80% MCH funds

Other

Web site:

<http://www.dhss.alaska.gov/dph/wcfh/Pages/mchebi/abdr/default.aspx>

Surveillance reports on file:

Http://www.dhss.alaska.gov/dph/wcfh/Pages/mchebi/abdr/Data_Reports.aspx

Additional information on file: 1)

http://dhss.alaska.gov/dph/wcfh/Documents/mchebi/abdr/Data%20Analysis%20Methods_v2.1.pdf2)

http://dhss.alaska.gov/dph/wcfh/Documents/mchebi/abdr/Data%20Collection%20Methods_v2.1.pdf

Contacts

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