STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

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Prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Acknowledgement: State birth defect program directors provided the information for this directory. Their names can be found under the “contact” section of each state profile.
Alabama Birth Defects Surveillance and Prevention Program (ABDSPPP)

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

**Partner:** Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 1995

**Earliest year of available data:** 1998

**Organizational location:** University


**Current legislation or rule:** none

**Case Definition**

**Outcomes covered:** Major birth defects and genetic disorders

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)

**Age:** up to one year after delivery


**Surveillance Methods**

**Case ascertainment:** Active case ascertainment

**Vital Records:** Birth certificates, Death certificates, Fetal death certificates

**Delivery hospitals:** Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Congenital Anomaly reporting form

**Pediatric & tertiary care hospitals:** Disease index or discharge index, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Congenital Anomaly reporting form

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counselling/clinical genetics facilities

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation, <2500 Gms, All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (ie seizure), GI condition (ie recurrent blockage), GU condition (ie recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

**Coding:** California's coding system based on BPA

**Data Collected**

**Infant/foetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report filled out by staff

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SPSS, Access, Excel pivot tables

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

**Data use and analysis:** Baseline rates, Rates by demographic and other variables, Time trends, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

**NOTE:** As of January 2009, the ABDSPP has suspended its birth defects surveillance activities

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Alaska

Alaska Birth Defects Registry (ABDR)

**Purpose**: Surveillance, Research

**Partner**: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups

**Program status**: Currently collecting data

**Start year**: 1996

**Earliest year of available data**: 1996

**Organizational location**: Department of Health (Maternal and Child Health; Women’s, Children’s and Family Health)

**Population covered annually**: 11,000

**Statewide**: Yes

**Current legislation or rule**: 7 AAC 27.012

**Legislation year enacted**: 1996

**Case Definition**

**Outcomes covered**: ICD-9 Codes 237.7, 243, 255.2, 277, 279, 282, 284.0, 331, 334, 335, 343, 359, 362.74, 389, 740-760, 760.71

**Pregnancy outcome**: Live births (all gestational ages and birth weights)

**Age**: birth to age six

**Residence**: in and out of state births to Alaska residents

**Surveillance Methods**

**Case ascertainment**: Population-based, Passive case ascertainment with case verification of selected conditions including FAS and NTDs

**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), MIMR (FIMR), public health nursing

**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-9 code.

**Pediatric & tertiary care hospitals**: Disease index or discharge index, Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.

**Third party payers**: Medicaid databases, Indian health services

**Other specialty facilities**: Genetic counseling/clinical genetics facilities

**Other sources**: Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period**: any chart with an ICD-9 code of 760.71 and other birth defects as selected for review by the ABDR Program Manager.

**Coding**: ICD-9-CM

**Data Collected**

**Infant/fetus**: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Birth defect diagnostic information

**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 storage/management**: Access

**Data Analysis**

**Data analysis software**: Epi-Info, SPSS, SAS, Access

**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, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Grant proposals, Education/public awareness, Prevention projects

**System Integration**

**System links**: Link case finding data to final birth file

**Funding**

**Funding Source**: 80% General state funds, 20% MCH funds

**Other**

**Web site**: www.epi.alaska.gov/mchepi/ABDR

**Surveillance reports on file**: see website

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

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

Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1986

Organizational location: Department of Health (Bureau of Public Health Statistics/Office of Health Registries)

Population covered annually: 98,507 in AZ to AZ residents in 2008

Statewide: Yes

Current legislation or rule: Statute- www.azleg.state.az.us/ars/36/00133.htm


Legislation year enacted: 1988

Case Definition

Outcomes covered: 44 categories (1986-2004); 32 categories (2005-Present) of major birth defects and genetic diseases, as defined by the BPA/MACDP codes

Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Terminations are not included in the electronic database. Stillbirths with a fetal death certificate can be of any gestational age or weight.

Age: Up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review (which occurs 2-4 years after the child's birth or fetal death), then the more precise diagnosis is used.

Residence: Cases are born in Arizona and have an Arizona abstract indicating mother's residence in AZ

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based

Vital Records: Birth certificates, Fetal death certificates

Other state registries: Programs for children with special needs

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Mothers charts for stillborns

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Mothers charts for stillborns

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases

Coding: CDC coding system based on BPA

Data Collected

Infant/etus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Maternal risk factors, Family history

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Access, Oracle

Data Analysis

Data analysis software: SAS, Access

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

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding

Funding Source: 27% General state funds, 11% MCH funds, 20% General screening revenues, 42% CDC grant

Other

Web site: http://www2.azdhs.gov/phs/phstats/bdr/index.htm

Surveillance reports on file: Same as Above

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

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

**Partner:** Local Health Departments, Universities, Hospitals, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 1980

**Earliest year of available data:** 1980

**Organizational location:** University, Arkansas Children's Hospital

**Population covered annually:** 41,000

**Statewide:** Yes

**Current legislation or rule:** Senate Bill Act 214

**Legislation year enacted:** 1985

**Case Definition**

**Outcomes covered:** Major structural birth defects

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)

**Age:** Two years after delivery

**Residence:** In and out of state births to state residents

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment, Population based

**Vital Records:** Birth certificates

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities

**Other sources:** Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with an ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, All stillborn infants

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** Locally modified BPA/CDC and NBDPS coding system

**Data Collected**

**Infants/foetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal diagnostic information, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SAS, Access, STATA

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

**System Integration**

**System links:** Link case finding data to final birth file

**Funding**

**Funding Source:** 100% General state funds

**Other**

**Web site:** http://arbirthdefectsresearch.uams.edu/

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

California
California Birth Defects Monitoring Program (CBDMP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: Department of Health; CDPH, University of California at San Francisco under contract with the California Department of Public Health
Population covered annually: 70,000
Statewide: No, The Program currently monitors a sampling of California births that are demographically similar to the state as a whole and whose birth defects rates and trends have been reflective of those throughout California. Furthermore, the Program has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.
Current legislation or rule: Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1996.
Legislation year enacted: 1982

Case Definition
Outcomes covered: Serious structural birth defects, primarily encompassed within ICD codes 740-759
Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, ≥20 weeks gestation), Elective terminations (less than 20 week gestation, 20 weeks gestation and greater)
Age: One year
Residence: In-state births to residents of 1 of 8 counties; does not include births in military hospitals.

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatricic logs, Postmortem/pathology logs, Surgery logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatricic logs, Postmortem/pathology logs, Surgery logs, Laboratory logs
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases, appr 0-0
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, GI condition (ie recurrent blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected
Infant/featus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: FoxPro

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, validity checks are done on all abstracts.
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Grant proposals, Education/public awareness

System Integration
System links: CBDMP links case finding data to final vital statistics birth and fetal death files
Funding
Funding Source: >95% Other federal funding (non-CDC grants), Some legislative special funds

Other
Web site: www.cdph.ca.gov/programs/CBDMP
Comments: Please send inquiries to mchinet@cdph.ca.gov.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Colorado

Colorado Responds to Children with Special Needs: Colorado (CRCN)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
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: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, less than 20 week limited to selected post-mortem pathology sites)
Age: Up to the 3rd birthday (up to the 10th birthday for fetal alcohol syndrome)
Residence: Events occurring in-state or out-of-state to Colorado residents

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics, selected postmortem pathology sites
Pediatric & tertiary care hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics, selected postmortem pathology sites
Other specialty facilities: Cytogenetic laboratories, Genetic counseling-clinical genetics facilities
Other sources: Physician reports, selected sites for fetal alcohol syndrome and muscular dystrophy

Case Ascertainment
Conditions warranting chart review in newborn period: Selected chart reviews for prenatal to age 3: for statistical trends monitoring (20 conditions - categories); selected death and fetal deaths; fetal alcohol syndrome (to age 10); active case ascertainment data sources (postmortem pathology and specialty clinics); quality control (selected procedures); and others as needed.
Coding: ICD-9-CM, extended code utilized to describe syndromes, further detail of a condition, and to specify status

Data Collected
Infant/etuses: 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, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications, Maternal risk factors
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 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.), 99% of data are collected in electronic format
Database storage/management: Access, Conversion to SQL

Data Analysis
Data analysis software: SAS, Access, ArcView (GIS software), Mapitude, SatScan
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness, ongoing quality control procedures for problematic conditions and situations; 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 investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic 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, Ongoing match to vital records files (birth, death, fetal death)

Funding
Funding Source: 26% General state funds, 31% Service fees, 43% CDC grant

Other
Web site: http://www.cdphe.state.co.us

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Connecticut
Connecticut Birth Defects Registry (CTBDR)

**Purpose:** Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, reporting for MCH Block Grant

**Partner:** Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 2002

**Earliest year of available data:** 2000

**Organizational location:** Department of Health (Maternal and Child Health)

**Population covered annually:** 43,000

**Statewide:** Yes

**Current legislation or rule:** Sec. 19a-56a. (Formerly Sec. 10a-132b), Birth defects surveillance program; Sec. 19a-54. (Formerly Sec. 19-21a), Registration of physically handicapped children; Sec. 19a-53. (Formerly Sec. 19-21), Reports of physical defects of children.

**Legislation year enacted:** Sec. 10a-132b: 1991; Sec. 19-21a: 1949 Sec. 19-21: 1949.

**Case Definition**

**Outcomes covered:** All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71

**Pregnancy outcome:** Live births (all gestational ages and birth weights) PDA ≥ 2500 gms birth weight.

**Age:** Up to one year after delivery for birth defects

**Residence:** In state births to state residents

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population based Vital Records: Birth certificates, Death certificates, Matched birth/death file, inpatient hospitalizations and emergency room visits

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

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Reports from health care professionals in newborn nurseries and NICUs

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, Reports from health care professionals in pediatric inpatient and outpatient services planned for future.

**Midwifery facilities:** Midwifery facilities

**Other sources:** Physician reports, Mandatory reporting by health care providers and facilities; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

**Case Ascertainment**

**Coding:** ICD-9-CM

**Data Collected**

**Infant/etus:** 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, Prenatal care, Pregnancy/delivery complications, Maternal risk factors

**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 storage/management:** Access, Oracle

**Data Analysis**

**Data analysis software:** SAS, Access, STATA, ArcGIS

**Quality assurance:** Validity checks, 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 investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Provider education

**System Integration**

**System links:** Link case finding data to final birth file

**Other**

**Web site:** http://www.ct.gov/dph/birthdefectsregistry

**Funding**

**Funding Source:** 100% MCH funds

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Delaware

Delaware Birth Defects Surveillance Project

Purpose: Surveillance, Referral to Prevention/Intervention
Partner: Hospitals, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: None yet
Organizational location: Department of Health and Social Services, Division of Public Health, Family Health Services
Population covered annually: 12,000
Statewide: Yes
Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects
Legislation year enacted: 1997

Case Definition
Outcomes covered: Birth Defects Registry - Selected birth defects for passive surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections, Autism
Pregnancy outcome: Live births (any gestation for live birth), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Birth to 5 years
Residence: In-state and out-of-state birth to state resident, and in-state birth to state non-resident.

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, hospital discharge records/data
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry
Delivery hospitals: Disease index or discharge index, Discharge summaries, Postmortem/pathology logs, High risk pregnancy
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Midwifery facilities: Midwifery facilities
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.)
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD-9-CM code 740-759, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codeable defect
Coding: ICD-9-CM, six-digit modified ICD-9 codes

Data Collected
Infant/infant: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnosis information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illness/conditions, Prenatal care, Pregnancy/delivery complications, Maternal risk factors
Father: Identification and demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Natus Medical Inc.

Data Analysis
Data analysis software: Natus Medical Inc.
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Clinical review, none at this time
Data use and analysis: Only became active in early 2010 with review of calendar year 2007

System Integration
System links: Link to Newborn Bloodspot and Hearing Screening System integration: Initial check into Newborn Bloodspot Screening records with a link which pulls info to Birth Defects Registry from Newborn Bloodspot Screening case management system.

Funding
Funding Source: 100% Genetic screening revenues

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District of Columbia

District of Columbia Birth Defects Surveillance and Prevention Program (DC BDSPP)

Program status: Interested in developing a surveillance program
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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Florida

Florida Birth Defects Registry (FBDR)

**Purpose:** Surveillance, Research, Educate health care professionals

**Partner:** Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, federal and state agencies

**Program status:** Currently collecting data

**Start year:** 1998

**Earliest year of available data:** 1998

**Organizational location:** Department of Health (Epidemiology/Environment), University

**Population covered annually:** 239,120 in 2007

**Statewide:** Yes

**Current legislation or rule:** Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added to the list in July 1999.

**Legislation year enacted:** 1999

**Case Definition**

**Outcomes covered:** Major structural malformations and selected genetic disorders

**Pregnancy outcome:** Live births

**Age:** Until age 1

**Residence:** Florida

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population based, FL has two CDC funded cooperative agreements which use active case ascertainment which is linked to the passive surveillance program.

**Vital Records:** Birth certificates

**Other state based registries:** Programs for children with special needs

**Delivery hospitals:** Disease index or discharge index

**Pediatric & tertiary care hospitals:** Disease index or discharge index

**Case Ascertainment**

**Coding:** ICD-9-CM

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weights, gestation, Apgars, etc.), Tests & procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors

**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 submitted by other agencies (hospitals, etc.)

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SPSS, SAS, Access, SQL

**Quality assurance:** Validity checks, Comparison/verification between multiple data sources

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, 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 environmental databases

**Funding**

**Funding Source:** 55% General state funds, 45% CDC grant

**Other**

**Web site:** www.fbdrg.org

**Surveillance reports on file:** Publications, procedure manuals, electronic case ascertainment database and educational materials

**Comments:** CDC/NCBDDD Cooperative Agreement for active surveillance for selected birth defects. CDC/NCEH Cooperative Agreement for Environmental Public Health Tracking for active surveillance of selected birth defects.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Georgia
Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Laboratories, Prenatal Diagnostic Providers
Program status: Currently collecting data
Start year: 1967
Earliest year of available data: 1968
Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities
Population covered annually: 51808
Statewide: No, Births to mothers residing within one of five central counties in the metropolitan Atlanta area of the state of Georgia
Current legislation or rule: State Laws Official Georgia Code Annotated (OCGA) 31-12-2

Case Definition
Outcomes covered: Major structural or genetic birth defects
Pregnancy outcome: Live births ≥20 weeks, Fetal deaths - stillbirths, spontaneous abortions, etc. ≥20 weeks gestation, Elective terminations (all gestational ages)
Age: Before 6 years of age
Residence: Births to mothers residing in one of five central metropolitan Atlanta counties

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, induction logs and miscarriage logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions i.e abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation, please specify., birth weight < 2500 grams and/or 20-36 weeks gestation, All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (ie seizure), GI condition (ie recurrent blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codeable defect
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web based, etc.)
Database storage/management: SQL Server

Data Analysis
Data analysis software: SPSS, SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Prevention projects, survival analysis

System Integration
System links: Link case finding data to final birth file, Link to environmental databases, National Death Index, Fetal death Records, Laboratory Records

Funding
Funding Source: 100% Other federal funding (non-CDC grants)

Other
Web site: http://www.cdc.gov/ncbddd/bd/macdcp.htm
Surveillance reports on file: MACDP 40th Anniversary.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Georgia

Georgia Birth Defects Reporting and Information System (GBDORIS)

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

**Partner:** Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 2003

**Earliest year of available data:** 2005

**Organizational location:** Department of Health (Maternal and Child Health)

**Population covered annually:** 150,000

**Statewide:** Yes

**Current legislation or rule:** Birth defects are reportable under State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3-2 which mandate the reporting of notifiable diseases and newborn hearing screening, and Chapters 290-5-3-.02 and 290-5-24 of the Rules of Department of Human Resources, which regulate the reporting of notifiable diseases and metabolic disorders.

**Legislation year enacted:** Updated in 2003

**Case Definition**

**Outcomes covered:** Major birth defects, genetic diseases, FAS and CP

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)

**Age:** up to 18 years of age

**Residence:** In and out of state births to state residents

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment

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

**Delivery hospitals:** Disease index or discharge index, Discharge summaries

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries

**Other specialty facilities:** Genetic counseling/clinical genetics facilities

**Other sources:** Physician reports

**Data Collected**

**Infants/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.)

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SAS, Access

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Capture-recapture analyses, Service delivery, Grant proposals, Education/public awareness, Prevention projects

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Hawaii
Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: Department of Health (Children with Special Health Needs Branch)
Population covered annually: 19,139 (average over past 3 years)
Statewide: Yes
Current legislation or rule: HRS §321-421 to 426; §324-41 to 44
Legislation year enacted: 2002

Case Definition
Outcomes covered: All outcomes identified on the ICD-9 and CDC/BPA codes for the 2010 NBDPN Annual Report as well as other adverse neonatal conditions, such as congenital infections, neonatal tumors, FAS, and specific chromosomal syndromes
Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages). Data collected on all elective medical terminations that were carried out because a screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect, and the parents elected not to bring the baby to term.
Age: Up to one year after delivery, except for Fetal Alcohol Syndrome, which can be diagnosed at any age
Residence: All in-state Hawaii births (resident and non-resident).

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Delivery hospitals: Disease index or discharge index, Discharge summaries
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other specialty facilities: Prenatal diagnostic facilities, Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases, Medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect, and parents elected not to bring baby to term, or mother spontaneously aborted.
Conditions warranting chart review beyond the newborn period: All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-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.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravity-parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Analysis
Data analysis software: Access, SQL Server 2000
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness, Prevention projects

Funding
Funding Source: Birth Defects Special Fund (state fund from marriage license fee)

Other
Additional information on file: HBPD informational brochure; copies of legislation; original and revised abstracting form; annual reports; HBPD data; quality assurance reports (completeness, accuracy, timeliness)

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Idaho

Program status: No surveillance program

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Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, State agency serving children with special healthcare needs
Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 180,000
Statewide: Yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)
Legislation year enacted: 1985

Case Definition
Outcomes covered: ICD-9-CM Codes 740.0 through 759.9; infants positive for controlled substances; serious congenital infections; congenital endocrine, metabolic or immune disorders; congenital blood disorders; other conditions such as retinopathy of prematurity, intrauterine growth retardation, FAS
Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: 2 years
Residence: In and out of state birth to state residents

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment
Vital Records: Birth certificates, Fetal death certificates
Other state based registries: Newborn metabolic screening prog.
Delivery hospitals: Disease index or discharge index, Discharge summaries, hospitals mandated to identify newborn cases and report to IDPH
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, hospitals mandated to report newborns discharged from any to the NICU or specialty units

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, <1500 grams
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA

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
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, Electronic file/report filled out by staff at facility, Electronic file/report submitted by other agencies
Database storage/management: Access, Mainframe

Data Analysis
Data analysis software: SAS, Access, Arc Map, JoinPoint & SaTScan
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Public Use Data

System Integration
System links: Link case finding data to final birth file
System integration: The APORS program data is incorporated into a data warehouse at the IL Dept. of Healthcare & Family Services.

Funding
Funding Source: 62% General state funds, 38% CDC grant

Other
Web site: www.idph.state.il.us/about/epi/apors.htm
Surveillance reports on file: Surveillance reports available on-line

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Indiana

Indiana Birth Defects & Problems Registry (IBDPR)

**Purpose:** Surveillance, Research, Referral to Services

**Partner:** Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 2002

**Earliest year of available data:** 2003 birth data is available in 2006

**Organizational location:** Department of Health (Epidemiology/Environment, Maternal and Child Health, State Health Data Center)

**Population covered annually:** 89,000

**Statewide:** Yes

**Current legislation or rule:** IC 16-38-4-7 Rule 410 IAC 21-3

**Legislation year enacted:** 2001

**Case Definition**

**Outcomes covered:** ICD-9-CM Codes 740-759.9, Fetal Alcohol Spectrum Disorder (760.71), Pervasive Developmental Disorder (299.0), fetal deaths, metabolic disorders & hearing loss from newborn screening, selected neoplasms, congenital blood disorders, and certain eye disorders.

**Pregnancy outcome:** Live births (all gestational ages and birth weights)

**Age:** Up to 5 years (FAS, autism); up to 3 years for all other birth defects

**Residence:** In- and out-of-state (as reported to IBDPR) births to state residents

**Surveillance Methods**

**Case ascertainment:** Combination of active and passive case ascertainment, Hospital based

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file

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

**Delivery hospitals:** Disease index or discharge index, Chart audits of 45 targeted birth defects

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Chart audits of 45 targeted birth defects

**Other specialty facilities:** Genetic counseling/clinical genetics facilities

**Other sources:** Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a selected list of ICD9-CM codes outside 740-759

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** ICD-9-CM and BPA

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**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.), ISDH Chart Auditors submit hospital chart audit information electronically through use of a laptop and a web-based portal to the Integrated Data System, which stores and integrates the data.

**Database storage/management:** Oracle

**Data Analysis**

**Data analysis software:** SAS, Oracle and ArcView GIS

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Needs assessment

**System Integration**

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

**System integration:** The database is linked with birth, death, newborn hearing screening, and newborn metabolic screening data.

**Funding**

**Funding Source:** 60% IBDPR fund obtained through birth certificate sales, 40% MCH funds

**Other**

**Web site:** www.birthdefects.in.gov

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Iowa

Iowa Registry for Congenital and Inherited Disorders (IRCID)

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

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1983

Earliest year of available data: 1983

Organizational location: University

Population covered annually: 37,831 avg 10 yr

Statewide: Yes

Current legislation or rule: Iowa Code 136A, Iowa Administrative Code 641-4.7


Case Definition

Outcomes covered: Major birth defects, Duchenne/Becker muscular dystrophy, Fetal deaths with and without birth defects, Newborn screening disorders

Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)

Age: 1 year

Residence: Maternal residence in Iowa at time of delivery

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based

Vital Records: Birth certificates, Death certificates, Fetal death certificates, Stillbirth Evaluation Protocol

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Iowa Perinatal Care Program

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

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

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports, Outpatient surgery facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases, Muscular dystrophy, All spontaneous abortions, All abortions not otherwise specified

Conditions warranting chart review beyond the newborn period: Facial dysmorphology or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestational age, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database storage/management: Access, Oracle, PC server

Data Analysis

Data analysis software: SPSS, SAS, Access, Oracle

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

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic 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 case finding data to final birth file, link to environmental databases. For specific studies, data may be linked with environmental databases or other state databases.

Funding

Funding Source: 44% General state funds, 56% CDC Grant

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Kansas

Birth Defects Information System (BDIS)

Purpose: Registry
Partner: Hospitals
Program status: Interested in developing a surveillance program
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Vital Statistics, Maternal and Child Health)
Population covered annually: 41,815 (Year 2008)
Statewide: Yes
Current legislation or rule: K.S.A. 65-1,241 through 65-1,246
Legislation year enacted: 2004

Case Definition
Outcomes covered: The outcome data below are available from Office of Vital Statistics. Live births and fetal deaths information are used as part of the birth defects reporting system. Thirteen anomalies (and "other" congenital anomalies) are listed on the birth certificate and are reported, however, these are not linked to ICD-9 codes. In addition to major birth defects, low birth weight and low Apgar scores are also reported to BDIS.
Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions (greater than 350 grams).
Age: Under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition.
Residence: In state and out of state births to Kansas residents and in-state births to out of state residents

Surveillance Methods
Case ascertainment: Passive case ascertainment, Population based
Vital Records: Birth certificates, Fetal death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance
Other sources: Physician reports

Case Ascertainment
Coding: ICD-9-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.)
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity
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 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.). In Kansas, birth defects (congenital anomalies) are collected through two data sources: birth certificates and the birth defects prevention program reporting form. The birth certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to the birth defects reporting system. Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into the birth defects reporting system.

Database storage/management: Mainframe

Data Analysis
Data analysis software: SAS
Quality assurance: Comparison/verification between multiple data sources, Office of Vital Statistics conducts verification on birth certificate data.

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Grant proposals, ad-hoc upon request

System Integration
System links: Link to other state registries/databases
System integration: Our program has a link with vital statistics records. BDIS uses the same data system (WebBFH) and shares information with Children and Youth with Special Health Care Needs Program (CYSHCN).

Funding
Funding source: 100% MCH funds.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention, Prevention of birth defects

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1998

Organizational location: Department for Public Health, Division of Maternal and Child Health, Early Childhood Development Branch

Population covered annually: 54,500

Statewide: Yes

Current legislation or rule: KRS 211.651-211.670

Legislation year enacted: 1992

Case Definition

Outcomes covered: Major birth defects, genetic diseases, fetal mortality

Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater). Other gestational age and/or birth weight criterion (20 weeks or 350 gms).

Age: Up to fifth birthday

Residence: All in-state births; out of state births to state residents

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, medical laboratory reporting mandated; outpatient reporting voluntary

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

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Specialty outpatient clinics, laboratory records

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, laboratory records

Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, local health departments

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (ie seizure), Cardiovascular condition, Any infant with a codable defect

Coding: ICD-9-CM, ICD-10 for Vital Statistics death data

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptopt, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, Mainframe

Data Analysis

Data analysis software: SAS, Access, Link Plus

Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic 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, IRB-approved research projects

System Integration

System links: Link case finding data to final birth file

System integration: True positives identified by newborn screening are integrated into the KBSR database.

Funding

Funding Source: 30% General state funds, 70% CDC grant

Other


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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Louisiana

Louisiana Birth Defects Monitoring Network (LBDAMN)

**Purpose:** Surveillance, Referral to Services

**Partner:** Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 2005

**Earliest year of available data:** 2005

**Organizational location:** Department of Health, Children's Special Health Services

**Population covered annually:** approx. 51,000 (2009)

**Statewide:** No, est. coverage 85% of births (2010)


**Legislation year enacted:** 2001

**Case Definition**

**Outcomes covered:** Major structural birth defects and selected genetic diseases

**Pregnancy outcome:** Live births

**Age:** Up to third birthday

**Residence:** In- and out-of-state births to state residents

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment, limited population-based (not statewide)

**Vital Records:** Birth certificates, Matched birth/death file

**Other state based registries:** Programs for children with special needs

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** CDC coding system based on BPA

**Data Collection**

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report filled out by staff

**Database storage/management:** Access, Excel

**Data Analysis**

**Data analysis software:** SPSS, SAS

**Quality assurance:** Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Education/public awareness, Prevention projects

**System Integration**

**System links:** Link case finding data to final birth file, link case finding data to infant death file

**Funding**

**Funding Source:** 55% CDC grant, 45% CSHCN funds

**Other**

**Web site:** http://www.dhh.louisiana.gov/offices/?ID=261

**Surveillance reports on file:** Louisiana Morbidity Report, May-June 2009, Vol 20, No 3

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Maine

Maine Birth Defects Program (MBDP)

**Purpose:** Surveillance, Referral to Services, Referral to Prevention/Intervention, Education

**Partner:** Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, March of Dimes

**Program status:** Currently collecting data

**Start year:** 1999

**Earliest year of available data:** 2003

**Organizational location:** Department of Health and Human Services, Children with Special Health Needs.

**Population covered annually:** 13,500

**Statewide:** Yes

**Current legislation or rule:** 22 MRSA c. 1687

**Legislation year enacted:** 1999

**Case Definition**

**Outcomes covered:** Selected major birth defects: NTD, clefts, gastrochisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias and major heart defects

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (prenatally diagnosed at any gestation)

**Age:** Through age one

**Residence:** All in-state births to Maine residents

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

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

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, Pediatric logs, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics

**Midwifery facilities:** Midwifery facilities

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

**Other sources:** Physician reports, Children with Special Health Needs

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

**Conditions warranting chart review beyond the newborn period:** Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codable defect

**Coding:** CDC coding system based on BPA, ICD-9-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.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** 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 storage/management:** Access, Citrix, University of Maine/Center for Excellence in Developmental Disabilities

**Child.dnk database system electronic abstraction record/hospital case reports/electronic submission of hospital discharge data.**

**Online hospital case report form.**

**Data Analysis**

**Data analysis software:** SAS, Stat-exact

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Needs assessment, Service delivery, Referral, Education/public awareness, Prevention projects

**System Integration**

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

**System integration:** Newborn Hearing/ Newborn Bloodspot Screening Programs

**Funding**

**Funding Source:** 85% MCH funds, 15% Maine Environmental Public Health Tracking grant

**Other**

**Web site:**

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State Birth Defects Surveillance Program Directory

Maryland
Maryland Birth Defects Reporting and Information System (BDRIS)

**Purpose:** Surveillance, Research, Referral to Services

**Partner:** Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 1983

**Earliest year of available data:** 1984

**Organizational location:** Department of Health (Family Health Administration, Office for Genetics & Children with Special Health Care Needs)

**Population covered annually:** 75,000

**Statewide:** Yes

**Current legislation or rule:** Health-General Article, Section 18-206; Annotated Code of Maryland

**Legislation year enacted:** 1982

**Case Definition**

**Outcomes covered:** Selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome until 2009, then all significant birth defects

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater or >=500 grams weight; reports accepted on fetal deaths <500 grams or <20 weeks gestation if sent to us). All gestational ages, reports accepted on terminations <500 grams or <20 weeks gestation if sent to us. BDRIS has no specific legal authority to collect information on terminations. Maryland does not require that any certificate be filed with Vital Records for a termination unless the body is transported for burial.

**Age:** Newborn

**Residence:** All in-state births

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population based, Multiple Source

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

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

**Delivery hospitals:** Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form

**Pediatric & tertiary care hospitals:** ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form

**Midwifery facilities:** Midwifery facilities

**Other specialty facilities:** Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All fetal death certificates

**Coding:** ICD-9-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.), Tests and procedures, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

**Father:** Identification information (name, address, date-of-birth, etc.), 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.)

**Database storage/management:** Access, Mainframe, Visual dBASE, SAS, ASCII files

**Data Analysis**

**Data analysis software:** SAS, Access

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation. Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic 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:** In the process of linkage with other state registries/databases

**System integration:** No

**Funding**

**Funding Source:** 100% General state funds

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

**Partner:** Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 1997

**Earliest year of available data:** 1999 for statewide data

**Organizational location:** Department of Public Health (Bureau of Family Health and Nutrition)

**Population covered annually:** 77,000

**Statewide:** Yes

**Current legislation or rule:** Massachusetts General Laws, Chapter 111, Section 67E. In 2002 the Massachusetts Legislature amended this statute, expanding the birth defects monitoring program. Regulations (105 CMR 302.000) were promulgated on February 6, 2009.

**Legislation year enacted:** 1963

**Case Definition**

**Outcomes covered:** Major structural birth defects and chromosomal anomalies of medical, surgical or cosmetic significance

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (>=20 weeks gestation or >=350 grams)

**Age:** Up to one year

**Residence:** In and out-of-state births to state residents

**Surveillance Methods**

**Case ascertainment:** Combination of active and passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Fetal death certificates

**Delivery hospitals:** Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs

**Pediatric & tertiary care hospitals:** Disease index or discharge index, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics

**Other sources:** Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, All stillborn infants, All neonatal deaths

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, All infant deaths (excluding prematurity), Auditory/hearing conditions, Any infant with a codable defect

**Coding:** CDC coding system based on BPA

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

**Father:** Identification information (name, address, date-of-birth, etc.), 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.), Electronic scanning of printed records, Data from printed Confidential Reporting and Abstracting Form is entered into electronic surveillance database.

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SAS, Access, Excel

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects, 1) selected cases from surveillance are eligible for CDCs NBDPS 2) Down syndrome and cardiovascular defects used for CDC grant to determine prevalence, disparities, and cost of these defects; 3) contributed data to other surveillance research projects

**System Integration**

**System links:** Link case finding data to final birth file, 1) link case finding data to final fetal death file, 2) Massachusetts Pregnancy to Early Life Longitudinal (PELL) Linkage Project

**Funding**

**Funding Source:** 28% General state funds, 72% MCH funds

**Other**

**Web site:** http://www.mass.gov/dph/birthdefects

**Surveillance reports on file:** http://www.mass.gov/dph/birthdefects to view or download annual surveillance reports

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Michigan
Michigan Birth Defects Registry (MBDR)

**Purpose:** Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, incidence and mortality statistics

**Partner:** Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 1992

**Earliest year of available data:** 1992

**Organizational location:** Department of Health (Vital Statistics)

**Population covered annually:** 126,000

**Statewide:** Yes

**Current legislation or rule:** Public Act 236 of 1988

**Legislation year enacted:** 1988

**Case Definition**

**Outcomes covered:** Congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks or >400 grams)

**Age:** Up to two years after delivery

**Residence:** Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Combination of active and passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Fetal deaths since 2004 only

**Other state based registries:** Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry

**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, CSHCS

**Other specialty facilities:** Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a selected list of ICD9-CM codes outside 740-759. Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (ie seizure), GI condition (ie recurrent blockage), GU condition (ie recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Ocular conditions, Auditory/hearing conditions, Any infant with aodable defect

**Coding:** ICD-9-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.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors

**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 storage/management:** FoxPro

**Data Analysis**

**Data analysis software:** SPSS, Access, Fox-pro, Excel

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timelines

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic 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, CSHCS, WIC

**System integration:** No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

**Funding**

**Funding Source:** 20% CDC grant, 80% Vital records fees

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Minnesota Birth Defects Information System (BDIS)

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

**Partner:** Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 2005

**Earliest year of available data:** 2006

**Organizational location:** Department of Health (Maternal and Child Health)

**Population covered annually:** 73,000

**Statewide:** No, The statewide surveillance system will be phased in over a number of years. Data is currently being collected in the two largest counties in Minnesota (Hennepin and Ramsey counties). These two counties account for approximately 50 percent of the births.

**Current legislation or rule:** MS 144.2215-2219

**Legislation year enacted:** 2004

**Case Definition**

**Outcomes covered:** Major "reported birth defects" as defined by CDC and ICD-9 codes up to 1 year of age; age 6 for FAS

**Pregnancy outcome:** Live births (all gestational ages and birth weights)

**Age:** Up to 1 year after delivery

**Residence:** In-state data

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment, Combination of active and passive case ascertainment procedures. Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** Electronic file/report filled out by staff at facility (laptop, web-based, etc.), laptops encrypted and data loaded into web-based database

**Database storage/management:** Web-based department-wide integrated disease surveillance database

**Data Analysis**

**Data analysis software:** SAS

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness, physician review as needed;

**Data use and analysis:** Public health program evaluation, Baseline rates, Rates by demographic and other variables, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, collaboration with Environmental Public Health Tracking Program, phased-in statewide system expansion beginning in 2010; many of these listed above will be used when full data sets are available

**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

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

**Third party payers:** Medicaid databases, Health maintenance organization (HMOs)

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD-9-CM code 740-759, Any chart with a CDC/BPA code, Any chart with selected procedure codes, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive

**Coding:** CDC coding system based on BPA

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and

**System Integration**

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

**System integration:** Program plans to integrate with Newborn Screening/Hearing and collaborate with other regional programs

**Funding**

**Funding Source:** 80% General state funds, 20% CDC grant

**Other**

**Web site:** http://www.health.state.mn.us/divs/el/birthdefects

**Surveillance reports on file:** Annual reports: 2005-2009

**Additional information on file:** Folic Acid Guidelines for physicians

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Mississippi
Mississippi Birth Defects Registry (BDRS)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Title V Children with Special Health Care Needs
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health, Division of Genetic Services)
Population covered annually: 46,000
Statewide: Yes
Current legislation or rule: Section 41-21-205 of the Mississippi Code
Legislation year enacted: 1997

Case Definition
Outcomes covered: Live births and reportable fetal deaths with birth defects (fetal death of 20 completed weeks of gestation or more, or a weight of 350 grams or more) shall be reported.
Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater or 350 grams and greater).
Age: 0 to 21
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other sources: Physician reports, Community Health Centers

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.)

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 storage/management: Access

Data Analysis
Data analysis software: SPSS, SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Timeliness
Data use and analysis: Routine statistical monitoring, Education/public awareness

Funding
Funding Source: 100% Genetic screening revenues

Other
Web site: www.healthyms.com

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Missouri

Missouri Birth Defects Surveillance System

**Purpose:** Surveillance, Research

**Partner:** Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 1985

**Earliest year of available data:** 1980

**Organizational location:** Department of Health (Vital Statistics)

**Population covered annually:** 78,000

**Statewide:** Yes

**Case Definition**

**Outcomes covered:** ICD9 codes 740-759, plus genetic, metabolic, and other disorders

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), fetal death certificates are only source of data, surveillance of terminations currently limited to NTDs (expansion in progress)

**Age:** Up to one year after delivery

**Residence:** In- and out-of-state births to state residents

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

**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 sources:** Enrollment data, Missouri Dept. of Mental Health

**Case Ascertainment**

**Coding:** ICD-9-CM, ICD-10

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, ApGars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity-parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications

**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.)

**Database storage/management:** SAS (Unix)

**Data Analysis**

**Data analysis software:** SAS

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

**System Integration**

**System links:** Link case finding data to final birth file, Link to environmental databases

**Funding**

**Funding Source:** 50% MCH funds, 50% service fees

**Other**

**Web site:** [http://www.dhss.mo.gov/BirthDefectsRegistry/](http://www.dhss.mo.gov/BirthDefectsRegistry/)

**Surveillance reports on file:**

[http://www.dhss.mo.gov/BirthDefectsRegistry/Publications.html](http://www.dhss.mo.gov/BirthDefectsRegistry/Publications.html)

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Montana

Montana Birth Outcomes Monitoring System (MOBOS)

**Program status:** No surveillance program

**Start year:** 1999

**Earliest year of available data:** 2000

**Organizational location:** Department of Health (Maternal and Child Health)

**Current legislation or rule:** None

**Case Definition**

**Outcomes covered:** Major structural birth defects, chromosomal anomalies specified in the CDC 45 reportables for births occurring in calendar years 2000 through 2004. Registry suspended beginning with calendar year 2005 births due to loss of CDC funding

**Pregnancy outcome:** All gestational ages

**Comments:** Due to lack of funding, Montana is no longer performing active surveillance. Informal active/passive surveillance continues and linkages between ascertainment and services are in place and supported. Data and program linkages exist between newborn hearing screening, birth certificates, and newborn screening.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Nebraska
Nebraska Birth Defects Registry

Purpose: Surveillance, Research, We are in the process of exploring a program of referral to services and prevention programs.

Partner: Hospitals, Nebraska Department of Health and Human Services and MCH

Program status: Currently collecting data

Start year: 1973

Earliest year of available data: 1973

Organizational location: Nebraska Department of Health and Human Services, Public Health, Office of Health Statistics

Population covered annually: Statewide, 27,000 births annually

Statewide: Yes


Legislation year enacted: 1972

Case Definition

Outcomes covered: All birth defects, exclusions according to CDC exclusion list

Pregnancy outcome: Live births (greater than 20 weeks and greater than 500 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Birth to 1 year

Residence: In-state and out-of-state birth to state resident.

Surveillance Methods

Case ascertainment: Passive case ascertainment

Vital Records: Birth certificates, Death certificates, Fetal death certificates

Delivery hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Nebraska Birth Defects Prevention Program Congenital Defects Case Record

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics, Nebraska Birth Defects Prevention Program Congenital Defects Case Record

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Coding: CDC coding system based on BPA

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, etc.), Gravidity/parity

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

Data Collection Methods and Storage

Data Collection: Hospitals enter defects electronically into our system. Our staff verifies and make sure all cases are linked to the birth record

Database storage/management: MS SQL server

Data Analysis

Data analysis software: SAS, Reports from Netsmart.

Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Case finding, data coding and entry.

Data use and analysis: Baseline rates, Monitoring outbreaks and cluster investigation, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Incidence rates, trend analysis, birth defect registry.

System Integration

System integration: Integrated with births, fetal deaths, deaths and hearing screening.

Funding

Funding Source: 100% MCH funds

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Nevada

Nevada Birth Outcomes Monitoring System (NBOMS)

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

**Partner:** Hospitals, Early Childhood Prevention Programs, Bureau of Child, Family, & Community Wellness

**Program status:** Currently collecting data

**Start year:** 2000

**Earliest year of available data:** 2005

**Organizational location:** Office of Health Statistics and Surveillance, Bureau of Health Statistics, Planning and Emergency Response, Nevada State Health Division. Early Childhood & Women’s Health Bureau of Child, Family and Community Wellness, Nevada State Health Division

**Population covered annually:** 39,186 in 2008

**Statewide:** Yes

**Current legislation or rule:** NRS 442.300 - 442.330 - Birth Defects Registry Legislation *** Regulation = NAC 442

**Legislation year enacted:** 1999

**Case Definition**

**Outcomes covered:** Major birth defects and genetic diseases

**Pregnancy outcome:** Live births (20 weeks of gestation and greater with all birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (20 weeks gestation and greater)

**Age:** Cover from 0-7 years of age

**Residence:** In-state births

**Surveillance Methods**

**Case ascertainment:** Combination of active and passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, hospital medical records, diagnostic/laboratory reports

**Other state based registries:** Newborn hearing screening program, Newborn metabolic screening program, Cancer registry

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries

**Third party payers:** Medicaid databases

**Other specialty facilities:** Genetic counseling/clinical genetics facilities

**Other sources:** Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any birth certificate with a birth defect box checked

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (ie seizure), GI condition (ie recurrent blockage), GU condition (ie recurrent infections), Cardiovascular condition, Any infant with a codable defect

**Coding:** ICD-9-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.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report filled out by staff

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SPSS, SAS, Access

**Quality assurance:** Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation. Time trends, Epidemiologic 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, Birth registry data is manually linked to birth defect data, but the actual databases are not linked.

**Funding**

**Funding Source:** 80% Service fees, 20% MCH Block Grant

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New Hampshire
New Hampshire Birth Conditions Program (NHBCP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 2003
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health), Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, Department of Environmental Services Bureau of Environmental Health, University
Population covered annually: 12,500
Statewide: Yes
Current legislation or rule: RSA 141-J, NH Administrative Rules He-P 3012
Legislation year enacted: 2008

Case Definition
Outcomes covered: All major birth defects and genetic diseases recommended by the CDC/NDBPN
Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)
Age: Currently collecting birth to age 2
Residence: All New Hampshire residents, those born in-state as well as out of state

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Fetal death certificates, Elective termination certificates, hospital ICD-9 codes for admissions, discharges and transports, fetal pathology reviews at Dartmouth Hitchcock Medical Center
Other state based registries: Programs for children with special needs, Newborn hearing screening program
Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, medical records abstraction of charts of selected ICD 9 Codes
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, cytogenetics laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling-clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, elective terminations that have confirmed birth conditions by autopsy or confirmed by clinical assessment
Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: CDC coding system based on BPA, ICD-9-CM
Data Collected
Infant/foetus: 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, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history
Father: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Oracle, AURIS, a web-based reporting system currently utilized by the NH DHHS Newborn Hearing Screening Program, has added a module to the currently operating system to meet the birth defects tracking requirements.

Data Analysis
Data analysis software: SPSS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Public health program evaluation, Baseline rates, Rates by demographic and other variables, Observed vs expected analyses, Service delivery, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases
System integration: Integrated into the NH DHHS Newborn Hearing Screening Program registry, a state-wide universal hearing program for all NH infants. This system also receives weekly uploads from the State’s Vital Records system that is then linked with the birth conditions and newborn screening data.

Funding
Funding Source: 100% CDC grant

Other
Web site: www.nhbcp.org

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New Jersey
Special Child Health Services Registry (SCHS Registry)

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

**Partner:** Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Neurodevelopmental Centers

**Program status:** Currently collecting data

**Start year:** 1928

**Earliest year of available data:** 1985

**Organizational location:** Department of Health & Senior Services - Special Child, Adult, and Early Intervention Services

**Population covered annually:** 114,000

**Statewide:** Yes


**Legislation year enacted:** 1983

**Case Definition**

**Outcomes covered:** All birth defects (structural, genetic, and biochemical), all Autism Spectrum Disorders, and severe hyperbilirubinemia, are required to be reported; all special needs and any condition which places a child at risk (prematurity, asthma, cancer, developmental delay) are also reported but not required.

**Pregnancy outcome:** Live births (all gestational ages & birth wts)

**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

**Residence:** All NJ residents, in and out of state

**Surveillance Methods**

**Case ascertainment:** Combination of active & passive case ascertainment, Population based

**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

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization labs, Specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization labs, Specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period

**Midwifery facilities:** Midwifery facilities

**Third party payers:** Universal Billing database is used for Quality Assurance activities

**Other specialty facilities:** Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

**Other sources:** 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 ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, All neonatal deaths, all death certificates for < 3 year of age

**Conditions warranting chart review beyond the newborn period:** GI condition (ie recurrent blockage), GU condition (ie recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codable defect

**Coding:** ICD-9-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 and 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.), implementation of a web-based reporting ongoing since July 1, 2009

**Database storage/management:** Mainframe, SAS

**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, Epidemiologic 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:** Newborn hearing screening registry provides direct report to SCHS Registry. Metabolic screening program provides direct report to SCHS Registry

**Funding**

**Funding Source:** 85% MCH funds, 10% CDC grant, 5% Genetic screening revenues

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

New Mexico

New Mexico Birth Defects Prevention and Surveillance System (NM BDPASS)

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

**Partner:** Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Private providers

**Program status:** Currently collecting data

**Start year:** 1995

**Earliest year of available data:** 1995

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

**Population covered annually:** 29,000

**Statewide:** Yes

**Current legislation or rule:** In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regulations.

**Legislation year enacted:** January 1, 2000

**Case Definition**

**Outcomes covered:** 740-760.71, Currently focused on major birth defects of interest to Environmental Public Health Tracking.

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)

**Age:** birth through age 4 years

**Residence:** Births to New Mexico residents.

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Fetal death certificates

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

**Delivery hospitals:** Disease index or discharge index, medical chart review

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Specialty outpatient clinics, Specialty outpatient clinics, including neurosurgery, plastic surgery, pediatric surgical specialists, prenatal diagnostic providers

**Third party payers:** Medicaid databases, Health maintenance organization (HMOs), Indian health services, Childrens Medical Services (CMS)

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), 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. Any birth certificate with a birth defect box checked, charts with a list of other ICD9-CM codes selected by CMS

**Coding:** CDC coding system based on BPA, ICD-9-CM, ICD10 for deaths

**Data Collected**

**Infant data:** 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.)

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report filled out by staff, Electronic file/report submitted by other agencies (hospitals, etc.)

**Database storage/management:** Stata and a web-based system, ChallengerSoft

**Data Analysis**

**Data analysis software:** Stata

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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 environmental databases, Link to death file

**Funding**

**Funding Source:** 100% CDC grant. At this point, the only funding for birth defects surveillance is from Environmental Public Health Tracking grant. We are actively seeking resources to support this effort.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

New York

New York State Congenital Malformations Registry (CMR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Community outreach and education
Partner: Universities, Hospitals, Early Childhood Prevention Programs, March Of Dimes
Program status: Currently collecting data
Start year: 1982
Earliest year of available data: 1983
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 250,000 - 300,000
Statewide: Yes
Current legislation or rule: Public Health Law Art. 2, Title II, Sect 225(3)(t) and Art. 2 Title I, sect 206(1)(j): Codes, Rules and Regulations, Chap 1, State Sanitary Code, part 22.3
Legislation year enacted: 1982

Case Definition
Outcomes covered: Major malformations - a detailed list is available upon request
Pregnancy outcome: Live births (all gestational ages and birth weights)
Age: 2 years
Residence: In-state and out-of-state birth to state resident; in-state birth to nonresident; all children born in or residing in New York, up to age 2

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment, Population based
Other state based registries: NYS Dept. of Health statewide hospital discharge database
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Other specialty facilities: Cytogenetic laboratories
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Charts with major malformations - a detailed list is available upon request
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-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.), Tests and procedures, 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: Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Sybase

Data Analysis
Data analysis software: SAS, Access, JAVA
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic 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 environmental databases

Funding
Funding Source: 19% General state funds, 8% MCH funds, 39% CDC grant, 3% Genetic screening revenues, 39% Other federal funding (non-CDC grants)

Other
Web site: http://www.health.state.ny.us/diseases/congenital_malformations/cmrhome.htm
Surveillance reports on file: Reports for 1983-2006

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North Carolina
North Carolina Birth Defects Monitoring Program (NCBDMP)

**Purpose:** Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Education, Advocacy

**Partner:** Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 1987

**Earliest year of available data:** 1989

**Organizational location:** Department of Health, State Center for Health Statistics

**Population covered annually:** 130,000

**Statewide:** Yes

**Current legislation or rule:** NCGS 130A-131

**Legislation year enacted:** 1995

**Case Definition**

**Outcomes covered:** Major birth defects

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (all gestational ages)

**Age:** Up to one year after delivery

**Residence:** NC resident births, in-state and out-of-state occurrence

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

**Other state based registries:** Programs for children with special needs

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

**Third party payers:** Medicaid databases

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any birth certificate with a birth defect box checked, All stillborn infants, All prenatal diagnosed or suspected cases

**Conditions warranting chart review beyond the newborn period:** Any infant with a code able defect

**Coding:** CDC coding system based on BPA

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** 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 storage/management:** Access, Mainframe, SAS

**Data Analysis**

**Data analysis software:** SPSS, SAS, Access

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

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation. Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, advocacy

**System Integration**

**System links:** Link to other state registries/databases, Link case finding data to final birth file, Vital Statistics, Medicaid Paid Claims, MCH Program Data

**Funding**

**Funding Source:** 80% General state funds, 20% CDC grant

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

North Dakota
North Dakota Birth Defects Monitoring System (ND-BDMS)

Purpose: Surveillance
Partner: Universities, March of Dimes
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 1994
Organizational location: Department of Health (Vital Statistics, Maternal and Child Health, Children's Special Health Services)
Population covered annually: 8974
Statewide: Yes
Current legislation or rule: North Dakota Century code 23-41
Legislation year enacted: 1941

Case Definition
Outcomes covered: Selected birth defects (NTDs, congenital heart defects, cleft lip and palate, chromosomal anomalies) and other risk factors that may lead to health and developmental problems
Pregnancy outcome: Live births (all gestational ages and birth weights; numbers collected and reported via Vital Records), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater; numbers collected and reported via Vital Records), Elective terminations (less than 20 week gestation, 20 weeks gestation and greater; numbers collected and reported via Vital Records)
Age: Newborn period
Residence: In-state resident births and out of state birth receiving services in ND

Surveillance Methods
Case ascertainment: Passive case ascertainment
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry, FAS
Delivery hospitals: Birth certificate completion
Pediatric & tertiary care hospitals: Specialty outpatient clinics
Third party payers: Medicaid databases
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD-9-CM code 740-759, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked
Coding: ICD-9-CM, ICD 10

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, 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.)
Database storage/management: Access, Mainframe, DB2, SPSS, Excel

Data Analysis
Data analysis software: SPSS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System Integration
System links: Link case finding data to final birth file
System integration: The program/registry is integrated with birth, death, fetal death, Medicaid claims payment and Children with Special Healthcare Needs databases.

Funding
Funding Source: 100% from State System Development Initiative (SSDI) grant
Other

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Ohio
Ohio Connections for Children with Special Needs (OCCSN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 2006
Earliest year of available data: N/A
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 150,000
Statewide: Yes
Current legislation or rule: Ohio Revised Code (ORC) 3705.30 - 3705.36, signed into law in July, 2000.
"The Director of Health shall establish and, if funds for this purpose are available, implement a statewide birth defects information system for the collection of information concerning congenital anomalies, stillbirths, and abnormal conditions of newborns." Administrative rules became effective June 3, 2005.
Legislation year enacted: 2000

Case Definition
Outcomes covered: 45 major disorders recommended by NBDBN
Pregnancy outcome: Live births (all gestational ages and birth weights)
Age: Up to 5 years of age
Residence: All Ohio children 0-5 years of age seen for medical care at a hospital in Ohio

Surveillance Methods
Case ascertainment: Passive case ascertainment, Hospital based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs
Delivery hospitals: Hospital electronic data systems for medical records and billing
Pediatric & tertiary care hospitals: Hospital electronic data systems for medical records and billing
Other specialty facilities: Genetic counseling/clinical genetics facilities

Case Ascertainment
Coding: ICD-9-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.)

Data Collection Methods and Storage
Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.), Reporting hospitals upload information to ODH via secure internet transmission. Low volume reporters can manually key data into screens on secure internet site.
Database storage/management: SQL server

Data Analysis
Data analysis software: SPSS, SAS
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases
System integration: OCCSN data system shares common demographic file with vital statistics. OCCSN data system is linked with Part C early intervention program data base, Title V CSHCN program data system and Genetics Program data system.

Funding
Funding Source: 100% CDC Grant

Other
Web site:
http://www.odh.ohio.gov/odhPrograms/cmh/bdefects/birthdefects1.aspx
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Oklahoma

Oklahoma Birth Defects Registry (OBDR)

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

**Partner:** Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Cytogenetics/ Medical Genetics

**Program status:** Currently collecting data

**Start year:** 1992; statewide 1994

**Earliest year of available data:** 1992; 1994 statewide

**Organizational location:** Department of Health (Prevention and Preparedness)

**Population covered annually:** 55,000

**Statewide:** Yes

**Current legislation or rule:** 63 O.S. Section 1-550.2

**Legislation year enacted:** 1992

**Case Definition**

**Outcomes covered:** Modified 6-digit ICD-9-CM codes for birth defects and genetic diseases (CDC/BPA)

**Pregnancy outcome:** Live births (>= 20 weeks gestation), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (20 weeks gestation and greater)

**Age:** 2 years

**Residence:** In-state births to state residents

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Fetal death certificates

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics

**Midwifery facilities:** Midwifery facilities

**Third party payers:** Indian health services, military hospitals delivering babies

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** CDC coding system based on BPA

**Data Collected**

**Infant/foetus:** 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, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report filled out by staff

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SAS, Access, ArcView GIS

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Timeliness, editing of all completed abstracts

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, program quality assurance

**Funding**

**Funding Source:** 13% General state funds, 57% MCH funds, 30% CDC grant

**Other**

**Web site:**

https://www.ok.gov/health/Child_and_Family_Health/Screening_and_Special_Services/Oklahoma_Birth_Defects_Registry/index.html

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Oregon

Program status: No surveillance program

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Pennsylvania

Pennsylvania Birth Defects Surveillance Database

Program status: No surveillance program
Start year: 2003
Earliest year of available data: 2001
Organizational location: Department of Health
(Epidemiology/Environment, Vital Statistics, Maternal and Child Health)
Statewide: We do not have a birth defects surveillance program

Case Definition
Pregnancy outcome: 16 weeks gestation and greater
Age: Birth to 24 months of age
Residence: In-state births to state residents

Case Ascertainment
Coding: ICD-9-CM, limited to ICD9-CM 740-759.9 and 760.71.

Data Collected
Mother: Maternal risk factors

Data Analysis
Quality assurance: Validity checks

Funding
Funding Source: 100% MCH funds

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**Puerto Rico**

**Puerto Rico Birth Defects Surveillance and Prevention System (PRBDSS)**

**State Birth Defects Surveillance Program Directory**

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

**Partner:** Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 1995

**Earliest year of available data:** 1995

**Organizational location:** Department of Health (Maternal and Child Health)

**Population covered annually:** 45,000

**Statewide:** Yes

**Current legislation or rule:** Yes, Law 351

**Legislation year enacted:** September 16th, 2004

**Case Definition**

**Outcomes covered:** Selected birth defects - neural tube defects, cleft lip and/or cleft palate, talipes equinovarus, limb defects, ventral wall defects, ambiguous genitalia, trisomy 13, 18 and 21, albinism, congenital heart defects, hipos/epipatids, laronh-Levin syndrome, anotia, microtia, anophthalmia, microphthalmia and bladder extrophy.

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)

**Age:** Up to 6 years after delivery

**Residence:** In-state birth to state residents

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Fetal death certificates

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

**Delivery hospitals:** Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs

**Third party payers:** Medicaid databases

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories

**Other sources:** Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with an ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions i.e abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

**Coding:** ICD-9-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.), Tests and procedures, Birth defect diagnostic information

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

**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.)

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SPSS, Excel

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation. Time trends, Time-space cluster analyses, Epidemiologic 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

**Funding**

**Funding Source:** 57% MCH funds, 43% CDC grant

**Web site:** http://www.salud.gov.pr

**Surveillance reports on file:** PR Birth Defects Databook 2009

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Rhode Island Birth Defects Program

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 1997
Organizational location: Department of Health (Maternal and Child Health, Center for Health Data and Analysis)
Population covered annually: 12,000
Statewide: Yes
Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws requires the development of a birth defects surveillance, reporting and information system that will: a) describe the occurrence of birth defects in children up to age five; b) detect trends of morbidity and mortality; and c) identify newborns and children with birth defects to intervene on a timely basis for treatment.
Legislation year enacted: 2003

Case Definition
Outcomes covered: Major birth defects and genetic diseases
Pregnancy outcome: Live births (all gestational ages and birth weights)
Age: Birth-4 years
Residence: RI residents

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment
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, RI has an integrated database called KIDSNET, which links data from 9 programs including: Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting and Vital Records
Delivery hospitals: Discharge summaries, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Chart reviews are conducted for infants born at the regional perinatal center and its sister hospital (represents 80% of newborns with birth defects) who were identified with an ICD-9 code 740-759 and other sentinel conditions
Coding: ICD-9-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.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, 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.)
Database storage/management: Access, Oracle

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
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link to KIDSNET (Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting; and Vital Records); hospital discharge database

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

Other
Web site: http://www.health.ri.gov/family/birthdefects/index.php
Surveillance reports on file: 2008 Rhode Island Birth Defects Data Book
Comments: Chart reviews are also conducted for ICD-9-CM codes 740-759 and other sentinel conditions after the newborn period from sources such as, genetics counseling and testing centers.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

South Carolina
South Carolina Birth Defects Program (SCBDP)

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

**Partner:** Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Greenwood Genetic Center (GGC)

**Program status:** Currently collecting data

**Start year:** GGC began monitoring in 1992; transitioned to SC DHEC and expanded in 2006

**Earliest year of available data:** via GGC, for 3 categories of defects, since 1993

**Organizational location:** SC Department of Health and Environmental Control, Maternal and Child Health

**Population covered annually:** 55,317

**Statewide:** Yes

**Current legislation or rule:** A281, R308, H4115

**Legislation year enacted:** 2004

**Case Definition**

**Outcomes covered:** Neural tube defects, cardiovascular defects, musculoskeletal defects, orofacial clefts

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective terminations (less than 20 week gestation, 20 weeks gestation and greater)

**Age:** Up to two years of age

**Residence:** Currently monitoring in-state births to persons residing in SC

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Elective termination certificates

**Other state based registries:** Programs for children with special needs, autopsy

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Postmortem/pathology logs, ICD-9 codes

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling-clinical genetics facilities

**Other sources:** Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, All prenatal diagnosed or suspected cases

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** ICD-9-CM

**Data Collected**

**Infant/foetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SAS, Access

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

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation

**Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects**

**System Integration**

**System links:** Link case finding data to final birth file, SC Vital Records

**System integration:** SC Vital Records

**Funding**

**Funding Source:** 100% General state funds

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Tennessee

**Tennessee Birth Defects Registry (TBDR)**

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

**Partner:** Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 2000

**Earliest year of available data:** 1999

**Organizational location:** Department of Health (Office of Policy, Planning & Assessment: Research Division)

**Population covered annually:** 80,000

**Statewide:** Yes

**Current legislation or rule:** TCA 68-5-506

**Legislation enacted:** 2000

**Case Definition**

**Outcomes covered:** 45 major structural birth defects

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (500 grams or more, or in the absence of weight, 22 completed weeks of gestation or more)

**Age:** Up to one year after delivery

**Residence:** In and out of state births to state residents

**Surveillance Methods**

**Case ascertainment:** Combination of active and passive case ascertainment, Population based, Hospital based

**Vital Records:** Birth certificates, Death certificates, Matched birth/hospital discharge file, Fetal death certificates

**Other state based registries:** Newborn hearing screening program, Newborn metabolic screening program, Hospital Discharge Data System

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with an ICD-9-CM code 740-759, ICD9-CM code 760.71

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** ICD-9-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.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors

**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.)

**Database storage/management:** Access, SQL Server

**Data Analysis**

**Data analysis software:** SAS, Access, SQL Server, Arc-GIS

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

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Education/public awareness, Prevention projects

**System Integration**

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

**Funding**

**Funding Source:** 100% General state funds

**Other**

**Web site:** http://dir.state.tn.us/Reports.aspx

**Surveillance reports on file:** Tennessee Birth Defects Registry 2002-2006

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State Birth Defects Surveillance Program Directory

Texas

Texas Birth Defects Epidemiology and Surveillance Branch (TBDES)

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

**Partner:** Universities, Hospitals, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 1994

**Earliest year of available data:** 1996

**Organizational location:** Department of Health (Epidemiology/Environment)

**Population covered annually:** **407,521** in 2007 provisional data

**Statewide:** Yes

**Current legislation or rule:** Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87.

**Legislation year enacted:** 1993

**Case Definition**

**Outcomes covered:** All major structural birth defects and fetal alcohol syndrome

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective terminations (all gestational ages)

**Age:** Up to one year after delivery - FAS up to 6 years

**Residence:** In and out of state births to state residents

**Surveillance Methods**

**Case ascertainment:** Active case ascertainment, Population based

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Genetics logs, stillbirth logs, radiology logs

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Genetics logs, Radiology logs

**Midwifery facilities:** Midwifery facilities

**Other sources:** Licensed birthing centers

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Infants with low birth weight or low gestation, please specify., (<34 weeks GA), All stillborn infants

**Conditions warranting chart review beyond the newborn period:** CNS condition (ie seizure), GI condition (ie recurrent blockage), GU condition (ie recurrent infections), Cardiovascular condition, Any infant with a codable defect

**Coding:** CDC coding system based on BPA

**Data Collected**

Infants/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report filled out by staff

**Database storage/management:** SQL Server

**Data Analysis**

**Data analysis software:** SAS, Access

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness, Re-case finding, Re-review of medical records

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects

**System Integration**

**System links:** Link registry to vital records for demographic data, special projects linking to other files (Texas Health Data for geocodes, Newborn Screening data)

**Funding**

**Funding Source:** 58% General state funds, 42% MCH funds

*Note: Does not include CDC-funded Texas Birth Defects Research Center funds

**Other**

**Web site:** www.dshs.state.tx.us/birthdefects/

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Utah
Utah Birth Defect Network (UBDN)

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

**Partner:** Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Legislators

**Program status:** Currently collecting data

**Start year:** 1994

**Earliest year of available data:** 1994

**Organizational location:** Department of Health (CSHCN), University of Utah

**Population covered annually:** 50,000

**Statewide:** Yes

**Current legislation or rule:** Birth Defect Rule (R398-5)

**Legislation year enacted:** 1999

**Case Definition**

**Outcomes covered:** 742,000 - 759,000

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths – stillbirths (20 weeks gestation and greater), spontaneous abortions (less than 20 weeks gestation), Elective terminations (all gestational ages)

**Age:** 2

**Residence:** Maternal residence in Utah at time of delivery

**Surveillance Methods**

**Case ascertainment:** Combination of active and passive case ascertainment, population-based; all medical records are reviewed for all reported potential cases, Combination of active and passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Fetal death certificates

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, Champions report live births delivered at their respective hospitals

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

**Midwifery facilities:** Midwifery facilities

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

**Other sources:** Physician reports, lay midwives

All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Any infant with a codable defect

**Coding:** CDC coding system based on BPA

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

**Data Collection 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 storage/management:** Access

**Data Analysis**

**Data analysis software:** SPSS, SAS, Access, Epi2000, Stata 8

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, logical checks, duplicate check in tracking and surveillance module, case record form checked for completeness, timeliness through system, manual review of subset of surveillance module case data compared to case record form.

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention

**System Integration**

**System links:** Link to environmental databases, link to birth records

**Funding**

**Funding Source:** 100% General state funds

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Vermont
Birth Information Network (BIN)

**Purpose:** Surveillance, Referral to Services, Referral to Prevention/Intervention, Prevention education

**Partner:** Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, VT Department of Banking, Insurance, Securities & Healthcare Administration; VT Association of Hospitals and Health Systems.

**Program status:** Currently collecting data

**Start year:** 2006

**Earliest year of available data:** 2006

**Organizational location:** Department of Health (Statistics)

**Population covered annually:** 6500

**Statewide:** Yes

**Current legislation or rule:** Act 32 (TITLE 18 VSA §5087)

**Legislation year enacted:** 2003

**Case Definition**

**Outcomes covered:** Major birth defects and genetic diseases, very low birth weight (less than 1500 grams)

**Pregnancy outcome:** Live births (all gestational ages and birth weights)

**Age:** Up to one year after delivery

**Residence:** In and out of state births to state residents

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population based

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file

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

**Delivery hospitals:** Discharge summaries, Specialty outpatient clinics

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

**Third party payers:** Medicaid databases, Other sources: Physician reports from offices and clinics associated with Tertiary Care Hospital

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** ICD-9-CM

**Data Collection**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Maternal risk factors

**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 submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SPSS, Access, Excel

**Quality assurance:** Comparison/verification between multiple data sources, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Observed vs expected analyses, Referral, Grant proposals, Prevention projects

**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:** 100% CDC grant

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Virginia
Virginia Congenital Anomalies Reporting and Education System (VACARES)

Purpose: Surveillance, Research, Referral to Services
Partner: Universities, Hospitals, Children with Special Health Care Needs, Care Connection for Children Network
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1987
Organizational location: Department of Health (Division of Child and Family Health, Child and Adolescent Health Programs, Genetic and Newborn Screening)
Population covered annually: 104,990
Statewide: Yes
Current legislation or rule: Health Law 32.1-69.1, -69.1:1, -69.2

Case Definition
Outcomes covered: Major birth defects and genetic diseases
Pregnancy outcome: Live births (all gestational ages and birth weights)
Age: Below 24 months of age
Residence: In and out-of-state births to state residents

Surveillance Methods
Case ascertainment: Passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Discharge summaries, medical records abstracts codes from charts
Pediatric & tertiary care hospitals: Discharge summaries
Other specialty facilities: Genetic counseling/clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759. Any chart with a selected list of ICD9-CM codes outside 740-759. Any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All neonatal deaths, Chart review done by the coders in Health Information Management
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect Coding: ICD-9-CM, ICD-10 for death certificate

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 submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Oracle

Data Analysis
Data analysis software: SAS, Access
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, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases
System integration: Virginia birth defects registry data (VaCARES) are reported by hospitals to the state health department via the Virginia Infant Screening and Infant Tracking System (VISITS II), which is a Web-based integrated data tracking and management system. VISITS II is a component of the Virginia Vital Events and Screening Tracking System (VVESTS), which also includes the Virginia electronic birth certificate and Virginia Early Hearing Detection and Intervention Program databases.

Funding
Funding Source: 100% MCH funds

Other
Web site: http://www.vahealth.org/gns/vaCares.htm
Additional information on file: Family Brochure and Parent Fact Sheets (English and Spanish) available on Web site.

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Washington

Washington State Birth Defects Surveillance System (BDSS)

**Purpose:** Surveillance

**Partner:** Universities, Hospitals, Environmental Agencies/Organizations

**Program status:** Currently collecting data

**Start year:** 1986- Active and 1991- Passive

**Earliest year of available data:** 1987

**Organizational location:** Department of Health (Maternal and Child Health)

**Population covered annually:** 90,000

**Statewide:** Yes

**Current legislation or rule:** Notifiable Conditions: WAC 246-101

**Legislation year enacted:** 2000

**Case Definition**

**Outcomes covered:** From 1987 to 1991 (active surveillance), and from 1991 to the 2000 (passive surveillance), the cases reportable to the Birth Defects Registry included those with ICD-9-CM codes 740-759, selected primary cancers, selected metabolic conditions, and FAS/FAE. Since the adoption of the Notifiable Conditions law in 2000, conditions subject to mandatory reporting are neural tube defects, orofacial clefts, limb deficiencies, abdominal wall defects, hypospadias/epispadias and Down Syndrome. FAS/FAE, Cerebral Palsy and Autism are designated as reportable with systems being established to ascertain cases outside the hospital setting.

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

**Age:** We ascertain cases through 1 year of age for structural defects and to age ten for FAS/FAE, Cerebral Palsy and Autism.

**Residence:** Resident births; children born, diagnosed or treated in-state

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment

**Vital Records:** Birth certificates, Fetal death certificates

**Other state based registries:** Programs for children with special needs

**Delivery hospitals:** Disease index or discharge index

**Pediatric & tertiary care hospitals:** Disease index or discharge index

**Other sources:** University-based FAS/FAE and Autism specialty centers

**Case Ascertainment**

**Coding:** ICD-9-CM, ICD-9-CM, FAS/FAE coding scheme will be utilized in data collection and case description for FAS/FAE cases

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Tests and procedures, Birth defect diagnostic information

**Mother:** Identification information (name, address, date-of-birth, etc.)

**Father:** Identification information (name, address, date-of-birth, etc.)

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Casefinding Log listing of all data elements required for each case are completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff. Several facilities submit print-outs from data query of internal system of discharge data. Minimal use of diskette or other forms of electronic data transfer. A web-based reporting system is currently in development.

**Database storage/management:** Web-based SQL server

**Data Analysis**

**Data analysis software:** SAS, Stata

**Quality assurance:** Validity checks, Comparison/verification between multiple data sources

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Education/public awareness

**System Integration**

**System links:** Link case finding data to final birth file, CSHCN program participant file

**Funding**

**Funding Source:** 40% General state funds, 60% MCH funds

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

West Virginia

West Virginia Birth Defects Surveillance System Congenital Abnormalities Registry, Education And Surveillance System (CARESS)

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

**Partner:** Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 1989

**Earliest year of available data:** 1989

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

**Population covered annually:** 21,000

**Statewide:** Yes

**Current legislation or rule:** State Statute Section 16-5-12a

**Legislation year enacted:** 1991 Legislation updated: 2002

**Case Definition**

**Outcomes covered:** Congenital anomalies of ICD-9 codes 740-759, 760, 764, 765, 766

**Pregnancy outcome:** Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (20 weeks gestation and greater)

**Age:** 0-6 years

**Residence:** In and out of state births to state residents

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, monthly reports sent from birthing facilities across the state and reproductive outcome forms submitted by facilities and individual physicians

**Vital Records:** Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Elective termination certificates

**Other state based registries:** Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry, SIDS/SUID

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics, physicians complete reproductive outcomes forms for those diagnosed after delivery

**Other specialty facilities:** Genetic counseling/clinical genetics facilities

**Other sources:** Physician reports, pediatric referrals of children diagnosed after delivery and discharge

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** Access

**Quality assurance:** Validity checks, Comparison/verification between multiple data sources, Timeliness

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), 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, Plans continue to link several programs housed in the Office of Maternal, Child and Family Health.

**Funding**

**Funding Source:** Title V Block grant funds

**Other**

**Web site:** http://www.wvdhhr.org/caress/

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Wisconsin

Wisconsin Birth Defects Registry (WBDR)

**Purpose**: Surveillance, Research, Referral to Services
**Partner**: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups
**Program status**: Currently collecting data
**Start year**: 2004
**Earliest year of available data**: 2004
**Organizational location**: Department of Health Services (Maternal and Child Health)
**Population covered annually**: ~72,000
**Statewide**: Yes
**Current legislation or rule**: Wisconsin Statutes 253.12
**Rules**: HFS 116 - Took effect April 1, 2003
**Legislation year enacted**: 2000

**Case Definition**
**Outcomes covered**: Structural malformations, deformations, disruptions, or dysplasias; genetic, inherited, or biochemical diseases.
**Pregnancy outcome**: Live births (20 weeks gestational age or greater), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
**Age**: Birth to 2 years
**Residence**: Statute mandates reporting of birth defects diagnosed or treated in Wisconsin regardless of residence status

**Surveillance Methods**
**Case ascertainment**: Passive case ascertainment, Population based
**Delivery hospitals**: Case reports from nursery managers
**Pediatric & tertiary care hospitals**: Case reports from pediatric specialty clinics
**Midwifery facilities**: Midwifery facilities
**Third party payers**: Health maintenance organization (HMOs)
**Other specialty facilities**: Genetic counseling/clinical genetics facilities
**Other sources**: Physician reports

**Data Collection Methods and Storage**
**Data Collection**: 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.), Organizations can report by uploading multiple records from their electronic patient records system to the WBDR secure website.
**Database storage/management**: Oracle

**Data Analysis**
**Data analysis software**: SAS
**Quality assurance**: Validity checks, Comparison/verification between multiple data sources
**Data use and analysis**: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic 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**: Legislation currently prohibits data linkage.

**Funding**
**Funding Source**: MCH Block grant - staffing and Birth Record/Certificate fees - Registry/Program

**Other**
**Web site**: [https://wbdr.han.wisc.edu/index.html](https://wbdr.han.wisc.edu/index.html)
**Surveillance reports**
[http://dhs.wisconsin.gov/DPH1_BFCH/cshcn/bdpsdesc/bdpsystem.htm](http://dhs.wisconsin.gov/DPH1_BFCH/cshcn/bdpsdesc/bdpsystem.htm)
**Comments**: We have stopped printing reports as of 2008 and instead post them to our website.

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Wyoming

**Program status**: Interested in developing a surveillance program
**Start year**: 2010
**Organizational location**: Department of Health (Epidemiology/Environment, Maternal and Child Health)

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

US Department of Defense
United States Department of Defense (DoD) Birth and Infant Health Registry

Purpose: Surveillance, Research
Partner: Universities, Hospitals, DoD Programs
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: DoD Center for Deployment Health Research, Naval Health Research Center, San Diego, CA
Population covered annually: approximately 100,000 per year
Statewide: No, National/Worldwide; includes all DoD beneficiaries
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum
Legislation year enacted: 1998

Case Definition
Outcomes covered: Outcomes include those birth defects listed in the case definition of the National Birth Defects Prevention Network. For a birth defect to be represented, the diagnosis must appear at least once in an inpatient record, or at least twice on two separate dates for outpatient encounters. Same sex multiples are excluded from analysis.

Pregnancy outcome: Live births (all gestational ages and birth weights)
Age: Birth to 1 year
Residence: Worldwide; any birth to a US military beneficiary

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment, Population based electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries
Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Third party payers: All inpatient and outpatient encounters are captured in standardized DoD data

Other sources: Validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military healthcare facilities

Conditions warranting chart review beyond the newborn period: Any infant with a codeable defect

Coding: ICD-9-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.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications

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

Data Collection Methods and Storage
Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, SAS

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Prevention projects

System Integration
System links: DoD databases
System integration: DoD databases

Funding
Funding Source: 100% Other federal funding (non-CDC grants)

Other
Surveillance reports on file: DoD/Health Affairs policy memorandum; annual reports

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