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 (ABDSPP)

Purpose: Surveillance, Research, Refer 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. less than 20 week gestation, 20 weeks gestation and greater), Ectopic Terminations (all gestational ages)
Age: up to one year after delivery

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, 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 counseling/clinical genetics facilities

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 birth certificate with a birth defect box checked, Infants with low birth weight or low gestation, please specify: <2500 gm, All stillborn infants, All neonatal deaths, All elective aboritions, 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 (i.e., seizure), GI condition (i.e., recurrent blockage), GU condition (i.e., recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Occular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: California's coding system based on BPA

Data Collected
Infant/Manifestations: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apparatus, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravida/paity, 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

Funding
Funding Source: Other: 100%

Other
Web site: www.usouthal.edu/genesics/
Additional information on file: Birth Defects Syndromes fact sheets
Comments: site linked to International Birth Defect Information Systems

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Alaska
Alaska Birth Defects Registry (ABDR)

**Purpose:** Surveillance
**Partner:** Local Health Departments, 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), Department of Health (Women’s, Children’s and Family Health)
**Population covered annually:** 10,000
**Statewide:** Yes
**Current legislation or rule:** 7 AAC 27.012
**Legislation year enacted:** 1996

**Case Definition**
**Outcomes covered:** ICD-9 Codes 237.7-237.72, 243, 255.2, 270-270.9, 271.0-271.1, 277-277.9, 279.0-279.9, 282-282.9, 284.0, 331.3-331.9, 334.0-334.9, 335.0-335.9, 343.0-343.9, 359.0-359.9, 362.7, 389.0-389.9, 740-760.9, 760.71
**Age:** birth to age six
**Residence:** in and out of state births to Alaska residents

**Surveillance Methods**
**Case ascertainment:** passive case ascertainment, population based; active case ascertainment for alcohol-related birth defects (including fetal alcohol syndrome)
**Vital Records:** Birth certificates
**Other state based registries:** Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Infant learning programs, 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 other birth defects as selected for review by the ABDR Program Manager.
**Coding:** ICD-9-CM

**Data Collected**
**Infant/juvenile:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, 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-abstracting 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

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

**Funding**
**Funding Source:** 25% General state funds, 75% MCH funds

**Other**
**Web site:** http://www.epi.hss.state.ak.us/mchepi/ABDR/default.htm
**Additional information on file:** results of the Alaska Folic Acid Surveys conducted in 1999 and 2000

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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
    (Epidemiology/Environment), Department of Health (Bureau of Public Health Statistics/Office of Health Registries)

Population covered annually: 101,472 in 2006

Statewide: Yes

Current legislation or rule: statute: ARS sec. 36-133.Rule: Title 9, Chapter 4, Articles 1 and 5. Adopted effective 1991.

Legislation enacted: 1988

Case Definition

Outcomes covered: 44 composite categories covering the major birth defects & genetic diseases as defined by BPA/MACDP codes

Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths (stillbirths, spontaneous abortions, etc.), 20 weeks gestation and greater, < 20 weeks gestation included if infant > 500 gm, Elective Terminations (20 weeks gestation and greater, < 20 weeks gestation included if infant >= 500 gm)

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: In-state birth to state resident.

Surveillance Methods

Case ascertainment: Active case ascertainment, Population-based Vital Records: Birth certificates, Fetal death certificates

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

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

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

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

Conditions warranting chart review beyond the 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 prenatal diagnosed or suspected cases

Funding

Funding Source: 20% General state funds, 11% MCH funds, 15% Genetic screening revenues, 54% CDC grant

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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: 37,000
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. less than 20 week gestation, 20 weeks gestation and greater), 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 logs Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), 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. Any birth certificate with a birth defect box checked, Stillborns and elective terminations occurring in the hospital setting
Conditions warranting chart review beyond the newborn period: Any infant with a coded defect Coding: locally modified BPA/CDC and NBDDS coding system

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.), Gravity/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.), 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
System integration: no

Funding
Funding Source: 80% General state Funds, Other: 20% local pediatric hospital; Directors efforts are "in-kind"

Other
Website: www.Arbirthdefectsresearch.uams.edu
Surveillance reports on file: annual reports

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California

California Birth Defects Monitoring Program (CBDM) Program

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: March of Dimes under contract with the State Department of Health, Center for Family Health
Population covered annually: 60,000
Statewide: Yes, 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 1992, 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, stillbirth, spontaneous abortions, etc., greater than 20 weeks gestation, Elective Terminations (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, Obstetric records, labor & delivery records, Regular newborn logs, NICU logs, NICU/ICU logs, Neonatal intensive care units, NICU/ICU logs, Pediatric logs, Postmortem pathology logs, Surgery logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, NICU/ICU logs, Pediatric 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 740-759, Any chart with selected procedure, Any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, All stillborn infants, All neonatal deaths, All elective abortions, All prenatally diagnosed or suspected cases, appear 0-0
Conditions warranting chart review beyond the newborn period: Facial dysmorphology or abnormal facies, GI condition (i.e. recurrent blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a coded 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.), Gravitation/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: Printed abstract/report filled out by staff, 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: Re-abstraction of cases, Double checking of assigned codes, Linkage/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, Observed vs. expected analyses. Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Grant proposals, Education/public awareness

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

Funding
Funding Source: 38% General state Funds, 21% MCH funds, 20% CDC grant, 14% Other federal funding (non-CDC grants), 7% University of California Office of the President
Other
Web site: www.cbdmp.org
Surveillance reports on file: current data on web site
Additional information on file: Publications Index, summaries of research findings, Collaboration Protocol, Confidentiality Procedures, Cluster Investigation Protocol, statutes, video.

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COLORADO

COLORADO RESPONDS TO CHILDREN WITH SPECIAL NEEDS: COLORADO (CRCSN)

**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)

**Population covered annually:** 70,523 (2006)

**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, FAS, selected genetic and metabolic disorders; muscular dystrophy; selected developmental disabilities; very low birth weight (less than 1500 gm); others with medical risk factors for developmental delay

**Pregnancy outcome:** Live Births (all gestational ages and birth weights), Fetal deaths (stillbirths, spontaneous abortions, etc.), less than 20 weeks gestation, 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 FAS)

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

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population-based; Active for selected data sources and for special projects like fetal alcohol syndrome, 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/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, 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 Server

**Data Analysis**

**Data analysis software:** SAS, Access, ArcView (GIS software), MapEnd, 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:** Ongoing match to vital records files (birth, death, fetal death)

**Funding**

**Funding Source:** 25% General State Funds, 75% CDC grant

**Other**

**Web site:** http://www.colorado.gov/ and search on CRCSN

**Additional information on file:** CRCSN Reference Guide; CRCSN Community Notification and Referral Program Site Manual; information on the web site

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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.
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 GE to 2500 gm birth weight)
Age: Up to one year after delivery (for birth defects)
Residence: In and out of state births to state residents
Surveillance Methods
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry
Delivery hospitals: Disease index or discharge index, Reports from health care professionals in newborn nurseries and NICUs.
Pediatric & tertiary care hospitals: Disease index or discharge index, 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, CSCHN 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.), Gravity/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, Arc GIS
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

Funding
Funding Source: 100% MCH funds

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District of Columbia
District Of Columbia Birth Defects Surveillance And Prevention Program (DC BDSSPP)

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

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

**Program status:** Currently collecting data

**Start year:** 2003

**Earliest year of available data:** 2003

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

**Population covered annually:** 15000 (approximately half are District residents)

**Statewide:** Yes

**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.), 20 weeks gestation and greater, >500gm

**Age:** up to one year after birth except in the case of Fetal Alcohol Syndrome which is up to six years.

**Residence:** state resident at the time of diagnosis

**Surveillance Methods**

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

**Birth 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, ICU/NICU logs or charts, Pediatric logs

**Pediatric & territory care hospitals:** Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

**Third party papers:** Medicaid databases

**Other specialties facilities:** Prenatal diagnostic facilities (ultrasound, etc.), 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 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 infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, ICD9-CM 740-741.9, 742.3, 743.1, 744-748.5, 749-749.25,750-751.6, 758-758.2, 760.71, 389, 243, 270.1, 270.3, 271.1, 282.2, 282.4-63, 282.69, 282.27

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Auditory/hearing conditions, Any infant with a codable defect

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

**Data Collected**

**Infant/fever:** 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 info

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravida/paity, Illnesses/conditions, Pre-natal 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 to other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

**Database storage/management:** Oracle, Welligent

**Data Analysis**

**Data analysis software:** SPSS, SAS

**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, Observed vs. expected analyses, 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

**System integration:** Not currently, but in the near future

**Funding**

**Funding Source:** 100% MCH funds

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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: 2006
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: 11,046
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), 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
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
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Midwifery facilities: Midwifery facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with an ICD9-CM code 740-759
Coding: ICD-9-CM, six-digit modified BPA/ICD-9 codes

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), 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, 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, Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Natus

Data Analysis
Data analysis software: Natus
Quality assurance: Not to this point yet

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

Funding
Funding Source: 100% Genetic screening revenues

Other
Surveillance reports on file: NA

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Florida Birth Defects Registry (FBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Educate health care professionals

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Oragnizations, 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), Department of Health (Florida Department of Health, Bureau of Community Environmental Health), University

Population covered annually: 226,219 resident live births in 2005

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.

Case Definition

Outcomes covered: Major structural malformations and selected genetic disorders

Pregnancy outcome: Live Births, Fetal deaths (stillbirths, spontaneous abortions, etc.), 20 weeks gestation and greater

Age: until age 1

Residence: Florida

Surveillance Methods

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

Fetal 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

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/charts, Pediatric logs

Third party payers: Medicaid databases, HMOs

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

Other sources: Physician reports

Case 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 chart with a birth defect box checked

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), Auditory/hearing conditions, Any infant with a coodable 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 info

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, Excel

Data Analysis

Data analysis software: SPSS, 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, 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, Link to environmental databases

Funding

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

Other

Web site: www.fbd.org


Additional information on file: grants, progress reports, educational and health promotion materials, and CD/video tapes

Comments: The FBDR received funding via CDC's Environmental Public Health Tracking Program to expand active surveillance of selected malformations through 2011.

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Georgia

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups
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: 51,808
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 and greater), 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, Combination of active and passive case ascertainment for cases ascertained only at perinatal offices
Vital Records: Birth/death certificates, Fetal death certificates
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetric logs (i.e., labor & delivery), Regular nursery log, ICU/NICU logs or charts, Pediatric logs, 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, Children with low birth weight or low gestation (birth weight >2500 grams or >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 (i.e. seizure), GI condition (i.e. recurrent blockage), Cardiovascular condition, All infants deaths (excluding prematurity), Occular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collection
Data Collected
Infant/fetus: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, APGAR, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info
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: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Epi-Info, Mainframe

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 investigations, 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 to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, National Death Index

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

Other
Web site: http://www.cdc.gov/mcbddi/bd/macdp.htm
Surveillance reports on file: 2007 Surveillance Report (Data from 1968-2003), numerous reports, publications, and bibliography

Additional information on file: Rate tables by defect by year

Comments: For surveillance reports and other information regarding the MACDP, e-mail MACDP@cdc.gov

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Georgia

Georgia Birth Defects Reporting and Information System (GBDRIS)

Data Collected

- Infant/fetus: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic info
- 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, 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, Capture-recapture analyses, Epidemiologic studies (using only program data), Service delivery, 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

System integration: SENDSS Newborn is under development. Will integrate multiple children health systems including birth defects, UNHS, NBS and Children 1st.

Funding

Funding Source: 30% General state Funds, 70% Other federal funding (non-CDC grants)

Website:

http://health.state.ga.us/epi/mch/birthdefects/gbdris/index.asp

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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
(Epidemiology/Environment)

Population covered annually: 140,000

Statewide: Yes

Current legislation or rules: 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.), less than 20 week gestation, 20 weeks gestation and greater

Age: up to 6 years 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, Fetal death certificates

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

Third party payers: Medicaid databases

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

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

Coding: ICD-9-CM
Hawaii
Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance, Research, 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, Legislators
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: Combination of DOH/Children with Special Health Needs Branch, and the Research Corporation of the University of Hawaii.
Population covered annually: ~19,724 average over the last 19 yrs Statewide: Yes

Case Definition
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 (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 Vital Records: Vital records are used to supplement information collected from other data sources, but are not used to primarily identify potential cases. Vital records data are also used as denominators for determining birth defects rates per 10,000 births.
Other state based registries: The HBDP supplies aggregate, de-identified data to the entities listed; they do not supply data to the HBDP.
Delivery hospitals: Disease index or discharge index, Discharge summaries, Information from specific logs, laboratories, clinics, etc. are usually found in the medical record when doing chart review.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Information from specific logs, laboratories, clinics, etc. are usually found in the medical record when doing chart review.
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.); Cytogenetic labs, 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 i.e. 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 cohabable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected
Infant/infantus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar's, 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/purity, 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, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Access, SQL Server 2000

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 investigations, Time trends. Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Education/public awareness, Prevention projects, Publication of 61 articles (as of 4/30/07) in peer-review professional journals, with 3 more accepted, but not yet published.

System Integration
System links: The Program is in the process of working on a GIS statistical mapping project for the HBDP.

Funding
Funding Source: 45% General state funds, 26% CDC grant, 4% Other federal funding (non-CDC grants), 4% Private foundation, Other: 21% Birth Defects Special Fund (state non-general fund funding). Please note that all the figures above represent average funding amounts for years 1988 to 2007.
Other
Web site: HBDP web site taken down by the DOH/CSHB
Surveillance reports on file: Thirteen (13) 135+ page Hawaii Birth Defects Program Statewide Surveillance Data Reports Published -

Additional information on file: HBDP informational brochure; copies of legislation; original and revised abstraction forms; abstraction manual; annual reports; HBDP data; quality assurance reports (completeness, accuracy, timeliness); presentation slides; special study reports; and HBDP articles published in peer-review Journals.

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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, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups

**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, intracranial 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:** end of newborn hospitalization

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

**Surveillance Methods**

**Case ascertainment:** Combination of active and passive case ascertainment, Population-based; birth defect diagnoses are confirmed in a review of medical records by APORS staff.

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

**Other state based registries:** Newborn metabolic screening

**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 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, Infants with low birth weight or low gestation, please specify, <1500 grams, All neonatal deaths

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

**Data Collected**

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

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

**Data Analysis**

**Data analysis software:** SAS, Access, Arch 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 Set

**System Integration**

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

**System integration:** No

**Funding**

**Funding Source:** 65% General state Funds, 35% CDC grant

**Other**

**Web site:** idph.state.il.us/about/epi/aporsrpt.htm

**Surveillance reports on file:** available on website

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Indiana

Indiana Birth Defects and Birth 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), Department of Health (Maternal and Child Health), State Health Data Center

**Population covered annually:** 88,000

**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 and hearing disorders from Newborn Screening, selected neoplasms, and congenital blood disorders, and certain eye disorders

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

**Age:** up to 5 years

**Residence:** in and out of state births to state residents (out-of-state births are not included in final numbers)

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment, Population-based, combined with selected active confirmation

**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 an 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:** 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 info
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

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

Other state based registries: State perinatal program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obsteries 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: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, 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 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 prenatally diagnosed/suspected cases, muscular dystrophy

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

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 info (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: Validation 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, 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.

System integration: no

Funding

Funding source: 44% General state Funds, 56% CDC grant

Other

Web site: http://www.public-health.uiowa.edu/ircid


Comments: former name: Iowa Birth Defects Registry

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Kansas

Birth Defects Reporting System

**Purpose:** Registry

**Partner:** Hospitals

**Program status:** Currently collecting data

**Start year:** 1985

**Earliest year of available data:** 1985

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

**Population covered annually:** 39,701 (Year 2005)

**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.

**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, (all gestational ages)

**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, Hospital-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

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

**Midwifery facilities:** Midwifery facilities

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

**Other sources:** Physician reports

**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 info

**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 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.

**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, 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 Adult and Child Health Improvement, 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, (II gestational ages and birth weights), Fetal deaths (stillbirths, spontaneous abortions, etc.), 20 weeks gestation and greater, 20 weeks or 250 gm., Elective Terminations, (20 weeks gestation and greater). Elective terminations prior to 20 weeks are identified in pilot active surveillance project at eight hospitals in Kentucky which represent 36% of births

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, Population-based

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, lab records

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic labs, 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 i.e. abnormal facies, congenital heart disease, Any birth certificate with a birth defect box checked, All prenatal diagnosed or suspected cases

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

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

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 diagnostic info

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

Father: Identification info (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.)

Database storage/management: Access, Mainframe

Data Analysis

Data analysis software: SPSS, SAS, Access

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: 100% General state Funds

Other


Surveillance reports on file: legislation and regulation; Hospital Reporting Administrative Manual; draft confidentiality guidelines; conditions definitions, KBSR fact sheet, KBSR brochure

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Purpose: Surveillance, Referral to Services
Partner: 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. 30,000 for 2007 (based on projected coverage of 50% of births)
Statewide: No, for 2007, covering the following parishes:
Rule: LAC 48:V.Chapters 161 and 163
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
Vital Records: Birth certificates
Other state based registries: Programs for children with special health care needs
Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

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
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.), Tests and procedures, Infant complications, Birth defect diagnostic info
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnosis 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: Printed abstract/report filled out by staff
Database storage/management: Access

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, Public health program evaluation

Funding
Funding Source: Other: 100% CSHCN finds

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Maine
Maine Birth Defects Program (MBDP)

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

**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:** Reporting began May 1, 2003

**Organizational location:** Department of Health (Children with Special Health Needs, Department of Health & Human Services)

**Population covered annually:** 14,000

**Statewide:** Yes

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

**Legislation year enacted:** 1999

**Case Definition**

**Outcomes covered:** Selected major birth defects: NTD, clefts, gastrointestinal, ophthalmologic, trisomy 21 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, postnatally diagnosed at any gestation, Elective Terminations (postnatally diagnosed at any gestation)

**Age:** Through age one

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

**Surveillance Methods**

**Case ascertainment:** Combination of active and 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, Specialty outpatient clinics

**Pediatric & tertiary care hospitals:** Disease index or discharge index, ICU/ICU 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, CSHN

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with an ICD9-CM code 740-759, 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 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 focus:** 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 info

**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 ChildLINK database system electronic abstraction record/hospital case reports/electronic submission of hospital discharge data. On-line 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, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Capture-recapture analyses, Observed vs. expected analyses, 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

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

**Funding**

**Funding Source:** 80% MCH funds, 20% Maine Environmental Public Health Tracking Unit epidemiological support & abstraction

**Other**

**Web site:** http://www.maine.gov/dhhs/bob/chs infant_defects/index.html

**Additional information on file:** Program manual in draft form

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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: 70,000
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
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 20 weeks gestation and greater, or >500 grams weight; 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, multiple sources, 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, Sickle Cell Disease
Delivery hospitals: Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICUs/NICUs, logs or charts, primary source: sentinel birth defects hospital report form
Pediatric & tertiary care hospitals: Discharge summaries, ICUs/NICUs, 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 ICD-9-CM code 740-759. Any chart with selected defects or medical conditions i.e. abdominal 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.), Maternal risk factors, Family history
Infant: Identification info (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

Funding
Funding Source: 100% General state Funds

Other
Web site: http://www.fha.state.md.us/genetics (select Birth Defects Reporting Information)
Additional information on file: Copies of publications, legislation, miscellaneous booklets and other information related to birth defects surveillance in Maryland
Comments: Manual update in process

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Massachusetts
Birth Defects Monitoring Program, Massachusetts Center for Birth Defects Research and Prevention (MBDMP)

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 Health (Bureau of Family and Community Health)

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.

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.), reportable fetal deaths (~20 weeks gestation or ~500 grams)

Age: Up to one year, up to three years when new legislation implemented (regulations pending)

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

Surveillance Methods
Case ascertainment: Population-based, state-wide, combination of active case ascertainment and administrative review

Vital Records: Birth/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

CaseAscertainment
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 defects or medical conditions i.e. abnormal facies, congenital heart disease, All stillborn infants, All neonatal deaths

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, All infant deaths (excluding prematurity), Auditory/hearing conditions, Any infant with a cleft palate 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 info

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 info (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 Case Reporting and Tracking 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, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, 1) selected cases from surveillance are eligible for CDC’s National Birth Defects Prevention Study 2) craniofacial defects used for grant to determine cost of these defects

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

Funding
Funding Source: 20% General state Funds, 80% CDC grant

Other
Web site: http://www.mass.gov/birthdefectscenter


Comments: statewide coverage started October 1998

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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 (Epidemiology/Environment), 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:** Combination of active and passive case ascertainment, Population-based

**Vital Records:** Birth/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, CSCHS

**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 ICD-9-CM codes outside 740-759. Any chart with selected defects/medical conditions i.e. 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, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, 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, Infant complications, Birth defect diagnostic info

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

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

**Data Collection Methods and Storage**

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

**Database 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, 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, 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, CSCHS, 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:** 80% Vital Records Fees, 20% CDC grant

**Other**

**Web site:** http://www.michigan.gov/mdch/0,1607,7-132-2944_4670--,00.html

**Surveillance reports on file:** birth defects incidence and mortality annual reports

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Minnesota

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 data available in 2008
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 71,000
Statewide: Yes. 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% 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
Vital Records: Birth certificates, Death certificates, Matched birth/death files
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 an ICD9-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 i.e. 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
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.), Tests and procedures, Infant complications, Birth defect diagnostic info
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravida/purity, Prenatal care, Prenatal diagnostic info, Pregnancy delivery complications, Maternal risk factors, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic info (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 downloaded regularly
Database storage/management: Access, final production format/platform to be determined based on collaborative partners

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, Timeliness, physician review as needed
Data use and analysis: Public health program evaluation, Baseline rates, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Full system implementation in 2005; many of these listed above will be used when full data sets are available

System Integration
System links: 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: 2.5% General state Funds, 90% CDC grant, 5% Other federal funding (non-CDC grants), Other: 2.5% - March of Dimes in-kind match to CDC grant

Other
Web site: www.health.state.mn.us/divs/eh/birthdefects
Surveillance reports on file: Data summaries and services/prevention updates are available on website.
Comments: System will use an opt-out format that will be monitored regularly to ensure that data trends remain valid.

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Mississippi
Mississippi Birth Defects Registry (MBDR)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health), Department of Health (Division of Genetic Services)
Population covered annually: 42,000
Statewide: Yes
Current legislation or rule: Section 41-21-205 of Mississippi Code
Legislation year enacted: 1997

Case Definition
Outcomes covered: A birth defect is an abnormality of structure, function or metabolism, whether genetically determined or as a result of environmental influences during embryonic or fetal life. A birth defect may present from the time of conception through one year after birth, or later in life.
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, 350 grams or more
Age: 0 to 21
Residence: In and out-of-state births to state residents

Surveillance Methods
Case ascertainment: 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, Discharge summaries
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other sources: Physician reports, Community Health Centers

Data Collected
Infant/jetus: 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: Access
Quality assurance: Validity checks
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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Missouri
Missouri Birth Defects 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
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1980
Organizational Location: Department of Health (Vital Statistics)
Population covered annually: 75,000
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, Elective Terminations (all gestational ages), 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, multi-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
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 info
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

Funding
Funding Source: 40% MCH funds, 60% Service fees

Other
Surveillance reports on file: Missouri Birth Defects 1995-99

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

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

**Partner:** Hospitals, private practice physicians

**Program status:** Currently collecting data

**Start year:** 1999

**Earliest year of available data:** 2000

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

**Population covered annually:** 11,500

**Statewide:** Yes

**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:** Other gestational age and/or birth weight criterion, all gestational ages

**Age:** Birth through age 3

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

**Surveillance Methods**

**Case ascertainment:** Combination of active and passive case ascertainment

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

**Case Ascertainment**

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

**Coding:** ICD-9-CM

**Data Collection Methods and Storage**

**Database storage/management:** Oracle

**Data Analysis**

**Data analysis software:** ClusterSeer 2

**System Integration**

**System links:** Link to other state registries/databases

**System integration:** Integrated with Children with Special Health Care Needs database

**Funding**

**Funding Source:** Other: No funding available since 8/26/2005

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Nebraska

Nebraska Birth Defects Registry

**Purpose**: Surveillance, Research. We are in the process of developing 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**: Department of Health (Nebraska Department of Health and Human Services Public Health Data Management Section)

**Population covered annually**: Statewide, 24,000+ 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**: Combination of active and passive case ascertainment.

**Vital Records**: Birth/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

**Case Ascertainment**

**Conditions warranting chart review in newborn period**: Any chart with an ICD9-CM code 740-759. Any chart with selected defects or medical conditions i.e. 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, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), Cardiovascular condition, Ocular conditions, 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.), Birth defect diagnostic information

**Mother**: Identification info (name, address, date-of-birth, etc.), Demographic info (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 (hospitals, etc.). Defects taken from paper copies of birth certificates submitted to the Vital Statistics Office.

**Database storage/management**: Netsmart

**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 links**: Netsmart.

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

**Funding**

**Funding Source**: 100% MCH funds

**Other**


**Additional information on file**: Copy of legislation, congenital defects case record form

**Comments**: State legislation introduced to allow release of patient-identifying information to approved researcher for the purpose of research; development of a system so that hospitals may use the electronic birth certificate to initially alert the surveillance program of the birth of a child with an anomaly.

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Nevada
Nevada Birth Defects Registry

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Hospitals, Early Childhood Prevention Programs, Bureau of Health Planning and Statistics
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2005
Organizational location: State Division of Health, Bureau of Family Health Services (MCH)
Population covered annually: 37,318 in 2005
Statewide: Year 2000 data is for Las Vegas only. Year 2001 - statewide data completed, but not in the system. Statewide active case review and abstraction from hospitals and birthing centers started from 2005. Collection of data for the year 2005 is complete and the process of analysis is in progress. Currently, we are collecting data for 2006.
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)
Age: cover from 0-7 years of age
Residence: in-state births

Surveillance Methods
Case ascertainment: Combination of active and passive ascertainment initially; Restarted combination case ascertainment in July 2005. Population-based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, hospital medical records, diagnostic/lab reports
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry
Delivery hospitals: Disease index or discharge index, Maternal records, 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, Maternal records
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 an 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 dysmorphology or abnormal facies, Development delay, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), Cardiovascular condition, Any infant with a coded 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, Apgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info
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, 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, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System integration: Nevada has a data warehouse which is currently able to link approximately 30 databases. Plans for this system indicate eventual capacity to link up to 45 databases.

Funding
Funding Source: 100% Service fees

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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 Env. Health), University

**Population covered annually:** 14,500

**Statewide:** Yes, Currently collecting 2006 data for all birth hospitals in the state.

**Current legislation or rule:** Currently working with the NH Chapter of the March of Dimes and the NH Department of Health and Human Services to begin the process of proposed legislation for birth conditions reporting in New Hampshire.

**Legislation year enacted:** N/A

**Case Definition**

**Outcomes covered:** All major birth defects and genetic diseases recommended by the CDC/NBDPNI

**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:** Fetuses >20 weeks gestation and newborns/infants up to 1 year

**Residence:** All New Hampshire residents, those born in-state as well as out-of-state

**Surveillance Methods**

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

**Vital Records:** Birth certificates, Fetal death 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, NICU/ICU logs or charts, Specialty outpatient clinics, medical records abstraction of charts of selected ICD 9 Codes

**Pediatric & tertiary care hospitals:** Discharge summaries, ICU/NCIU 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 lab, Genetic counseling/clinical genetics facilities

**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. abnormalities, 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

**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, Appgar, 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 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.

**Funding**

**Funding Source:** 100% CDC grant

**Other**

**Website:** www.nhbcp.org

**Surveillance reports on file:** See program website for state-wide and county level data reports

**Additional information on file:** Abstract for a pilot study on the comparison between birth certificate data and ICD-9 code data alone and with the use of medical chart abstraction for NH birth defects surveillance.
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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

**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:** 115,000

**Statewide:** Yes


**Legislation year enacted:** 1983

**Case Definition**

**Outcomes covered:** All birth defects, including structural, genetic, and biochemical are required to be reported. While not mandated, all special needs and any condition which places a child at risk (e.g. prematurity, asthma, cancer, developmental delay) are also reported.

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

**Age:** Mandated reporting of birth defects diagnosed through age 5, voluntary reporting of birth defects diagnosed > age 6 and all children diagnosed with Special Needs conditions who are <= 22 yrs. of age

**Residence:** In/Out-of-state NJ births to NJ residents; because of our link to the SCHS Case Management system, we also enroll anyone becoming NJ resident.

**Surveillance Methods**

**Case ascertainment:** Passive, population-based reporting system with annual quality assurance visits by BDR staff to birthing hospitals, birthing centers and, pediatric care facilities; medical providers are contacted to confirm questionable diagnoses.

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

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

**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, 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 laboratories, Specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period

**Midwifery facilities:** Midwifery facilities

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

**Other sources:** Physician reports, Special Child Health Services, county-based Case Management units, parents, medical examiners

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 (i.e. recurrent blockage), GU condition (i.e. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, 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.), Birth defect diagnostic information

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

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

**Data Collection Methods and Storage**

**Data Collection:** Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), plan to implement web-based reporting within next year

**Database storage/management:** 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, Monitoring outbreaks and cluster investigation, 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

**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:** hearing screening registry provides direct feed into SCHS Registry.

**Funding**

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

**Other**

**Web site:** http://www.state.nj.us/health/fhs/index.shtml

**Report forms are at:** http://web.doh.state.nj.us/forms/

**Surveillance reports on file:** Special Child Health Services Registry 1985-1989; Special Child Health Services Registry 1995-1999; Special Child Health Services Registry 1987-1994; Special Child Health Services Registry 1990-1999 (in press).

**Additional information on file:** Information sheet, case record form, copy of legislation, quality assurance audit information
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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, Legislators, Private providers

**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:** 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

**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., less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (all gestational ages)

**Age:** birth through age 4 years—This was just changed April 2006.

**Residence:** Births to New Mexico residents. Due to a change in Vital Records procedures, we only receive birth records for NM residents with births occurring in-state.

**Surveillance Methods**

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

**Vital Records:** Birth/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, Children’s 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

**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 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

**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

**System integration:** BDPass is integrated with the Children’s Chronic Conditions Registry

**Funding**

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

**Other:** 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.

**Web site:** www.health.state.nm.us

**Surveillance reports on file:** Birth Defects in New Mexico 1997-1998; Birth Defects in New Mexico 1995-1999

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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(5)(i) 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, hospital discharge data

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), 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

Funding

Funding Source: 18.8% General state Funds, 14.9% MCH funds, 11.5% Genetic screening revenues, 54.8% CDC grant

Other

Web site: http://www.health.state.ny.us/nysdoh/cmrm/home.htm


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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:** 120,000

**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:** Population based, Active 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

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

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/ICU logs or charts, Speciality 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 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 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 codable defect

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

**Data Collected**

**Infant/ Fetuses:** 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/purity, 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:** 70% General state Funds, 30% CDC grant

**Other**

**Web site:** www.sches.state.ncc.us/SCHS

**Surveillance reports on file:** Annual reports, special studies

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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),
Department of Health (Maternal and Child Health), ND
Department of Health (Children’s Special Health Services)
Population covered annually: 7719
Statewide: Yes
Current legislation or rule: North Dakota Century code 50-10
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 births 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, Health maintenance
organization (HMOs), private insurers
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 ICD9-CM code 740-759, Any chart with selected defects or
medical conditions i.e. abnormal faces, 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 info
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.), Electronic scanning of printed records
Database storage/management: Access, Mainframe, Db2, SPSS,
Excel

Data Analysis
Data analysis software: SPSS
Quality assurance: Validity checks, 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,
Needs assessment, Service delivery, Referral, Grant proposals,
Education/public awareness, Prevention projects

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

Other
Web site: www.health.nd.gov/vital/

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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: Currently collecting data from pilot sites. Statewide reporting to begin Sept. 2007 covering 150,000 births.

Statewide: No, Statewide reporting to begin Sept. 2007

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 disorders recommended by NBDPN

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 (to begin Sept. 2007)

Surveillance Methods

Case ascertainment: Passive case ascertainment, Hospital-based

Vital Records: Birth certificates

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

Conditions warranting chart review in newborn period: Any birth certificate with a birth defect box checked. Children from birth to 5 years with at least one of reportable ICD-9 codes

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.), Illnesses/conditions, Maternal risk factors

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: SAS

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

Data use and analyses: Routine statistical monitoring, Public health program evaluation

System Integration

System links: Link to other state registries/databases

Funding

Funding Source: 100% CDC grant

Other

Web site: N/A at this time

Comments: Contact person 3: Norma J. Ryan, PhD, RN, CHES

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Oklahoma

Oklahoma Birth Defects Registry (OBDR)

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

**Partner**: Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Cytogenetics/ & Medical Genetics

**Program status**: Currently collecting data

**Start year**: 1992; statewide 1994

**Earliest year of available data**: 1992

**Organizational location**: Department of Health (Family Health Services)

**Population covered annually**: 50,000

**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, Obstetric 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, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics

**Midwifery facilities**: Midwifery deliveries

**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 an 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 coded 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, Illnesses/conditions, Prenatal care, 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

**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

**System Integration**

**System links**: Link to environmental databases, 9/2003 awarded Environmental Public Health Tracking Grant to link health outcomes & environmental contamination data

**Funding**

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

**Other**


**Additional information on file**: PRAMS Gram Vol 8 No 3: Folic Acid Knowledge and Multivitamin Use Among Oklahoma Women Provisional rate tables for 1994-2002

**Comments**: Statewide data collection began in 1994. Additional information for case definitions; residence; 1995 began abstraction of Oklahoma residents born in Fort Smith, Arkansas

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Oregon

**Program status:** No surveillance program

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Pennsylvania

Pennsylvania Birth Defects Surveillance Database

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

**Partner:** Universities, Hospitals, Community Nursing Services, Advocacy Groups

**Program status:** Currently collecting data

**Start year:** 2003

**Earliest year of available data:** 2001

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

**Population covered annually:** 143,404 total live births in 2001; 142,388 total live births in 2002; 145,952 total live births in 2003; 144,499 total live births in 2004.

**Statewide:** Yes

**Current legislation or rule:** Not applicable

**Case Definition**

**Outcomes covered:** 740-759.9 and 760.71 ICD-9

**Pregnancy outcome:** Live Births (all gestational ages and birth weights), Fetal deaths (stillbirths, spontaneous abortions, etc. 16 weeks gestation and greater)

**Age:** Birth to 24 months of age

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

**Surveillance Methods**

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

**Vital Records:** Birth certificates, Matched birth/death file, Fetal death certificates, Hospital discharge data collected by the Pennsylvania Health Care Cost Containment Council (PHC4—a separate independent state agency).

**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:** Discharge summaries, PHC4 data is based on hospital discharge summaries

**Pediatric & tertiary care hospitals:** Discharge summaries, PHC4 data is based on hospital discharge summaries

**Case Ascertainment**

**Coding:** ICD-9-CM, limited to ICD9-CM 740-759.9 and 760.71

**Data Collected**

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

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidaity/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.), Electronic file/report submitted by other agencies (hospitals, etc.), Hospitals submit patient discharge data to the Pennsylvania Health Care Cost Containment Council (PHC4—a state agency). PA Department of Health receives data from PHC4.

**Database storage/management:** Access

**Data Analysis**

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

**Quality assurance:** Validity checks, 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, Epidemiologic studies

**Comments:** Pennsylvania has developed a handbook that contains general information about how parents and caregivers of children with special needs can access free or low cost insurance coverage and specialized support services.

**Funding**

**Funding Source:** 100% MCH funds

**Other**

**Web site:**
http://www.dsh.state.pa.us/health/cwp/view.asp?a=179&q=242196&PM=1

**Additional information on file:** see website URL for written explanation of birth defects monitoring system data matching and file building process

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Puerto Rico Birth Defects Surveillance System and Folic Acid Campaign (PRBDSS/FAC)

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, Infant complications, Birth defect diagnostic info
- Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravida/parity, 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.)

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, 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

Funding
- Funding Source: 59% MCH funds, 41% CDC grant

Other
- Website: http://www.salud.gov.pr/AF/AFindex.htm
- Surveillance reports on file: Description of registry development, case report form, manual for case report form

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Rhode Island
Rhode Island Birth Defects Surveillance Program

**Purpose:** Surveillance, Referral to Services, Referral to Prevention/Intervention  
**Partner:** Hospitals, Community Nursing Services, 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)  
**Population covered annually:** 12,500  
**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:** Currently at birth  
**Residence:** RI residents  

**Surveillance Methods**  
**Case ascertainment:** 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:** 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  

**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.)  

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

**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:** 30% MCH funds, 70% CDC grant  

**Other**  
**Web site:** http://www.health.ri.gov/family/birthdefects/index.php  
**Surveillance reports on file:** Birth Defects Data Book  

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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
Program status: Currently collecting data
Start year: 2006
Earliest year of available data: 1993
Organizational location: Department of Health (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 South Carolina

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.), Genetic counseling/clinical genetics facilities,
Other sources: Physician reports

Case Ascertained
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 defects or medical conditions i.e. 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/ fetus: 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.), Illness/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: Microsoft SQL

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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South Dakota

Program status: No surveillance program

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY 863

Tennessee
Tennessee Birth Defects Registry (TBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Universities, Hospitals, 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 (Research)
Population covered annually: 80,000
Statewide: Yes
Current legislation or rule: TCA 68-5-506
Legislation year enacted: 2000

Case Definition
Outcomes covered: 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, of 22 completed weeks of gestation or more).
Age: Diagnosed up to one year after delivery
Residence: In and out-of-state births to state resident

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment, Population-based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates
Other state based registries: 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 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
Third party payers: Medicaid databases

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with an ICD9-CM code 740-759, Infants with low birth weight or low gestation (review sample infants with no known diagnosis and over sample for low birth weight), 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
Infants/ Fetuses: 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, Observed vs. expected analyses, Epidemiologic studies (using only program data), Needs assessment, 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

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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:** 381,441 in 2004 finalized 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 FAS

**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 (All gestational ages)

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

**Residence:** In-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, genecis 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, genecis 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 (i.e. abnormal facies, congenital heart disease, Infants with low birth weight or low gestation (<34 weeks GA)), All stillborn infants

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

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

**Data Collected**

**Infants/Feet:** 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, 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:** Printed abstract/report filled out by staff

**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, 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

**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

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

**Other**

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


Queriable web based data base URL:

http://smapril.tdh.state.tx.us/obtdoc.htm

**Additional Information on file:** Copy of legislation; Texas Birth Defects Monitoring Division fact sheet; Texas Center for Birth Defects Research and Prevention fact sheet; Fetal Alcohol Syndrome brochure (English and Spanish); Pregnancy Outcome Patterns for Various Defects; Impact of Including Induced Abortion Terminations Before 20 Weeks Gestation on Birth Defect Rates; Cluster Investigation Reports; Birth Defects Glossary; Recent Trends in Neural Tube Defects in Texas Birth Defects Risk Factor Series

**Comments:** Statewide as of 1999 deliveries. Until 2000, the Texas Department of Health also had the Texas Neural Tube Defect Surveillance and Intervention Project along the Texas border with Mexico, which conducted active surveillance and research on neural tube defects for 14 counties.
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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 (Maternal and Child Health), CSHCN, University

Population covered annually: 50,000

Statewide: Yes

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

Legislation year enacted: 1999

Case Definition

Outcomes covered: All major structural birth defects

Pregnancy outcome: Live Births (all gestational ages & birth weights), Fetal deaths (stillbirths, spontaneous abortions, 20 weeks gestation and greater), stillbirths (20 weeks gestation or greater), Elective Terminations (all gestational ages)

Age: 2

Residence: Maternal residence in Utah at time of delivery

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, 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 (i.e. ultrasound), Cytogenetic labs, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, lay midwives

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (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, All fetal deaths certificates, NICU reports, infant deaths are reviewed

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, 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, Appgar, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

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, 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, Epil2000, 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, 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 (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

Other

Web site: www.health.utah.gov/birthdefect
Scientific Collaboration Protocol - Data Sharing Agreement
Additional Information on file: Newsletters, brochure

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Vermont

Birth Information Network (BIN)

**Purpose:** Surveillance, Referral to Services

**Partner:** Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, VT Association of Hospitals and Health Systems

**Program status:** Currently collecting data

**Start year:** 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

**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

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

**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

**Coding:** ICD-9-CM

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**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 diagnosis information

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Prenatal diagnostic information, 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, Data/hospital audits, Clinical review, Timeliness

**System Integration**

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

**Funding**

**Funding Source:** 100% CDC grant

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Virginia

Virginia Congenital Anomalies Reporting and Education System (VACARES)

Purpose: Surveillance, Research
Partner: Universities, Hospitals
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1987
Organizational location: Department of Health (Pediatric Screenings and Genetic Services, Div. of Child and Adolescent Health)
Population covered annually: 103,830
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 or out-of-state births to state residents

Surveillance Methods
Active component includes periodic on site QA monitoring of eligible cases by VACARES staff.
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, medical records abstracts codes from charts
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 i.e. 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 coded 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, Data/hospital audits, 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, Prevention projects

System Integration
System links: Link to other state registries/databases
System integration: The current system, Virginia Infant Screening and Infant Tracking System (VISITS), is an integrated database for VACARES and the Virginia Newborn Hearing Screening Program.

Funding
Funding Source: 70% MCH funds, 30% CDC grant

Other
Web site: www.vahealth.org/genetics
Additional Information on file: Oracle database
Comments: 99% of birth and pediatric care hospitals are entering data directly into the Virginia Infant Screening and Infant Tracking Program (VISITS), a web-based tracking and data management system. Additional case ascertainment is currently underway in the three contracted genetic centers.

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Washington

Washington State Birth Defects Surveillance System (BDSS)

**Purpose:** Surveillance, Referral to Services

**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:** 82,000

**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:** To age 4 years historically. We are transitioning to ascertainment 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.), Birth defect diagnostic information

**Mother:** Identification info (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.), Case finding 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, Access, Stata

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

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

**System Integration**

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

**System integration:** Member of the Environmental Health Tracking Grant project.

**Funding**

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

**Other**


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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), Department of Health (Vital Statistics), Department of Health (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 all state birthing facilities

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

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

**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:** Discharge summaries, Specialty outpatient clinics, physicians complete birth defect reporting 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

**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, Infants with low birth weight or low gestation, please specify; less than 2500 grams or less than 37 weeks, All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Occular conditions, Auditory/visual conditions, Any infant with a coded defect

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

**Data Collected**

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

**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravida/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 and electronic file/report submitted by other agencies (hospitals, etc.)

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

**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 birth certificate, Plans to link several programs housed in the Office of Maternal, Child, and Family Health.

**Funding**

**Funding Source:** Other: Title V Block Grant funds

**Other**

**Web site:** 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 (Maternal and Child Health)
Population covered annually: ~70,000
Statewide: Yes
Current legislation or rule: Statute 253.12
Rules: IFS 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, hospital discharge data through 2 yrs of age

Case Ascertainment
Coding: Wisconsin codes assigned to a specific list of birth defects cross walked to ICD-9-CM where possible

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report 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 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: 50% General state Funds, 50% MCH funds

Other
Web site: https://wbdr.han.wisc.edu

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Wyoming

Program status: Interested in developing a surveillance program

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Purpose: Surveillance, Research
Partner: Universities, Hospitals, CDC
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: approx. 100,000 per year
Statewide: No; National/Worldwide, DoD beneficiaries (includes all uniformed services personnel who are eligible for health care benefits)
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum
Legislation year enacted: 1998

Case Definition
Outcomes covered: Birth defects included in the case definition of the National Birth Defects Prevention Network
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 both military and civilian facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-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 both military and civilian healthcare facilities
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.), 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 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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