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, referral to services, referral to prevention/intervention

**Partner:** universities, hospitals, early childhood prevention programs, advocacy groups

**Program status:** currently collecting data

**Start year:** 1995

**Earliest year of available data:** 1998

**Organizational location:** University


**Case Definition**

- **Outcomes covered:** major birth defects and genetic disorders
- **Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)
- **Age:** up to one year after delivery


**Surveillance Methods**

**Case ascertainment:** active case ascertainment

**Vital Records:** birth certificates, death certificates, fetal death certificates

**Delivery hospitals:** disease index or discharge index, obesterics logs (eg., 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 Ascertained**

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

Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, development delay, CNS condition (ie seizure), GI condition (ie recurrent blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect

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

**Data Collected**

- **Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.); tests and procedures, infant complications, birth defect diagnostic information
- **Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
- **Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

**Data Collection Methods and Storage**

**Data Collection:** printed abstract/report 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, timelines

**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:** University Private foundation

**Other**

**Web site:** www.usouthal.edu/genetics/index.html

As of February 2009, the ABDSPP has suspended its birth defects activities.

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Alaska

Alaska Birth Defects Registry (ABDR)

**Purpose:** surveillance

**Partner:** local health departments, universities, hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups

**Program status:** currently collecting data

**Start year:** 1996

**Earliest year of available data:** 1996

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

**Population covered annually:** 11,000

**Statewide:** Yes

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

**Legislation year enacted:** 1996

**Case Definition**

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

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

**Age:** birth to age six

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

**Surveillance Methods**

**Case ascertainment:** passive case ascertainment, population-based

**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 and other birth defects as selected for review by the ABDR Program Manager.

**Coding:** ICD-9-CM

**Data Collected**

**Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, 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-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, timeliness

**Data use and analysis:** routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, grant proposals, education/public awareness

**System Integration**

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

**Funding**

**Funding Source:** 90% general state funds, 10% MCH funds

**Other**

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

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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 (Bureau of Public Health Statistics/Office of Health Registries)
Statewide: Yes
Current legislation: Statute-www.azleg.state.az.us/ars/36/00133.htm
Rule- www.azsos.gov/public_services/Title_09/9-04.htm
Legislation year enacted: 1988, effective in 1991

Case Definition
Outcomes covered: 32 categories (2005-Present) of major birth defects and genetic diseases, as defined by the BPA/MACDP codes
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (stillbirths with a fetal death certificate can be of any gestational age or weight). Terminations are not included in the electronic database.
Age: up to one year after delivery; if the nature of a defect diagnosed in the first year of life is diagnosed more precisely later in the child's life and this information is contained in the chart at the time of our review (which occurs 2-4 years after the child's birth or fetal death), then the more precise diagnosis is used.
Residence: cases are born in AZ and mother's residence in AZ

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
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (eg, labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, mothers' charts for stillborns
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, mothers’ charts for stillborns
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions (eg, abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal diagnostic information, maternal risk factors, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage
Data Collection: printed abstract/report filled out by staff
Database storage/management: Access, Oracle

Data Analysis
Data analysis software: SAS, Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, referral, grant proposals, education/public awareness, prevention projects

Funding
Funding Source: 42% CDC grant, 27% general state funds, 20% genetic screening revenue, 11% MCH funds

Other

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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:** 40,000
**Statewide:** Yes
**Current legislation or rule:** Senate Bill Act 214
**Legislation year enacted:** 1985

**Case Definition**
**Outcomes covered:** major structural birth defects
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)
**Age:** two years after delivery
**Residence:** in and out of state births to state residents

**Surveillance Methods**
**Case ascertainment:** active case ascertainment, population based
**Vital Records:** birth certificates
**Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (eg, labor & delivery), regular nursery logs, ICU/ICU logs or charts
**Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries, ICU/ICU logs or charts, specialty outpatient clinics
**Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetics facilities
**Other sources:** physician reports

**Case Ascertainment**
**Conditions warranting chart review in newborn period:** any chart with ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, all stillborn infants
**Conditions warranting chart review beyond the newborn period:** any infant with a codable defect
**Coding:** locally modified BPA/CDC and 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.), gravidity/parity, prenatal diagnostic information, family history
**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

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

**Data Analysis**
**Data analysis software:** SAS, Access, STATA
**Quality assurance:** validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
**Data use and analysis:** routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, education/public awareness, prevention projects

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

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

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

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State Birth Defect Surveillance Program Directory

California
California Birth Defects Monitoring Program (CBDMP)

**Purpose:** surveillance, research

**Partner:** local health departments, universities, hospitals, environmental agencies/organizations

**Program status:** currently collecting data

**Start year:** 1983

**Earliest year of available data:** 1983

**Organizational location:** California Department of Public Health in Sacramento (Maternal, Child, and Adolescent Health Division)

**Population covered annually:** 70,000

**Statewide:** No, the Program currently monitors a sampling of California births that are demographically similar to the state as a whole and whose birth defect rates and trends have been reflective of those throughout California. The Program has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.

**Current legislation or rule:** Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1986.

**Legislation year enacted:** 1982

**Case Definition**

**Outcomes covered:** serious structural birth defects, primarily encompassed within ICD codes 740-759

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)

**Age:** one year

**Residence:** in-state births to residents of 1 of 8 counties; does not include births in military hospitals

**Surveillance Methods**

**Case ascertainment:** active case ascertainment, population based

**Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (eg. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery 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

**Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clini genetics facilities, maternal serum screening facilities

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions (eg. abnormal facies, congenital heart disease), all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases, Apgar 0-0

**Conditions warranting chart review beyond the newborn period:** facial dysmorphism or abnormal facies, failure to thrive, GI condition (ie recurrent blockage), cardiovascular condition, all infant deaths (excluding prematurity), any infant with a codable defect

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

**Data Collected**

**Infant/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.), gravimetry/parity, illnesses/conditions, family history

**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Data Collection Methods and Storage**

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

**Database storage/management:** FoxPro

**Data Analysis**

**Data analysis software:** SAS

**Quality assurance:** validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, validity checks are done on all abstracts.

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, grant proposals, education/public awareness

**System Integration**

**System links:** link case finding data to final birth file, Hospital discharge

**Funding**

**Funding Source:** 50% legislative special funds, 50% other federal funding

**Other**

**Website:** www.cdph.ca.gov/programs/CBDMP

**Comments:** Please send inquiries to mchinet@cdph.ca.gov

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Colorado
Colorado Responds To Children with Special Needs: Colorado (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:** 70,028 (2008)

**Statewide:** Yes

**Current legislation or rule:** Colorado Revised Statutes (CRS) 25-1.5-101 - 25-1.5-105

**Legislation year enacted:** 1985

**Case Definition**

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

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, less than 20 weeks limited to selected post-mortem pathology sites)

**Age:** up to age 3, (up to the age 10 for fetal alcohol syndrome)

**Residence:** events occurring in-state or out-of-state to CO residents

**Surveillance Methods**

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

**Vital Records:** birth certificates, death certificates, fetal death certificates

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

**Delivery hospitals:** disease index or discharge index, postmortem/pathology logs, specialty outpatient clinics, selected postmortem pathology sites

**Pediatric & tertiary care hospitals:** disease index or discharge index, postmortem/pathology logs, specialty outpatient clinics, selected postmortem pathology sites

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

**Other sources:** physician reports, selected sites for fetal alcohol syndrome and muscular dystrophy

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** selected chart reviews for prenatal to age 3: for statistical trends monitoring (20 conditions - categories); selected death and fetal deaths; fetal alcohol syndrome (to age 10); active case ascertainment data sources (postmortem pathology and specialty clinics); quality control (selected procedures); and others as needed.

**Coding:** ICD-9-CM, extended code utilized to describe syndromes, further detail of a condition, and to specify status

**Data Collected**

**Infant/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, 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), Maptitude, SatScan

**Quality assurance:** validity checks, comparison/verification between multiple data sources, timeliness, ongoing quality control procedures for problematic conditions and situations; records linkage and de-duplication

**Data use and analysis:** routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, referral, grant proposals, education/public awareness, prevention projects, environmental studies

**System Integration**

**System links:** link to other state registries/databases, ongoing match to vital records files (birth, death, fetal death)

**Funding**

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

**Other**

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

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**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. 19a-132b). Birth defects surveillance program.; Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children.

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

**Case Definition**

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

**Pregnancy outcome:** live births (all gestational ages and birth weights), PDA ≥ 2500 grams birth weight

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

**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, inpatient hospitalizations and emergency room visits

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

**Delivery hospitals:** disease index or discharge index, 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; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

**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, 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

**Other**

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

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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:** 12,000

**Statewide:** Yes

**Current legislation or rule:** House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects

**Legislation year enacted:** 1997

**Case Definition**

**Outcomes covered:** Birth Defects Registry - Selected birth defects for passive surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections, Autism

**Pregnancy outcome:** live births (all gestational ages), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

**Age:** birth to 5 years

**Residency:** in-state and out-of-state birth to state resident, and in-state birth to state non-resident.

**Surveillance Methods**

**Case ascertainment:** passive case ascertainment, population based

**Vital Records:** birth certificates, death certificates, hospital discharge records/data

**Other state based registries:** programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, development disabilities surveillance, cancer registry, AIDS/HIV registry

**Delivery hospitals:** disease index or discharge index, discharge summaries

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

**Midwifery facilities:** midwifery facilities

**Other sources:** physician reports

**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 Medical Inc.

**Data Analysis**

**Data analysis software:** Natus Medical Inc.

**System Integration**

**System links:** link to Newborn Bloodspot and Hearing Screening

**System integration:** initial check into Newborn Bloodspot

**Screening records with a link which pulls info to Birth Defects Registry from Newborn Bloodspot Screening case management system.

**Funding**

**Funding Source:** 100% genetic screening revenues

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

**Program status:** interested in developing a surveillance program

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Florida Birth Defects Registry (FBDR)

**Purpose:** surveillance, research, educate health care professionals

**Partner:** local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators, federal and state agencies

**Program status:** currently collecting data

**Start year:** 1998

**Earliest year of available data:** 1998

**Organizational location:** Department of Health

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

**Statewide:** Yes

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

**Legislation year enacted:** 1999

**Outcome Definition**

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

**Pregnancy outcome:** live births

**Age:** until age 1

**Residence:** Florida

**Surveillance Methods**

**Case ascertainment:** passive case ascertainment, population-based (FL has two CDC funded cooperative agreements which use active case ascertainment which is linked to the passive surveillance program)

**Vital Records:** birth certificates

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

**Delivery hospitals:** disease index or discharge index

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

**Case Ascertainment**

**Coding:** ICD-9-CM

**Data Collected**

**Infant/s: ** 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 submitted by other agencies

**Database storage/management:** Access

**Data Analysis**

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

**Quality assurance:** validity checks, comparison/verification between multiple data sources

**Data use and analysis:** routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, education/public awareness, prevention projects

**System Integration**

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

**Funding**

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

**Other**

**Web site:** www.rbdr.org

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

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

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Georgia
Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: surveillance, research
Partner: local health departments, universities, hospitals, laboratories, prenatal diagnostic providers, 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: 51808
Statewide: No, includes five counties in metropolitan Atlanta
Current legislation or rule: State Laws Official Georgia Code Annotated (OCCGA) 31-12-2

Case Definition
Outcomes covered: major structural or genetic birth defects
Pregnancy outcome: live births (20 weeks gestation and greater), 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
Vital Records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs, regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, induction logs, and miscarry 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 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 (eg. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, infants with low birth weight or low gestation (weight < 2500 grams and/or 20-36 weeks gestation), all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (eg. seizure), GI condition (eg. recurrent blockage), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a cardiological defect
Coding: CDC coding system based on BPA

Data Collected
Infant/ fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal diagnostic information, pregnancy/delivery complications, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

Data Collection Methods and Storage
Data Collection: 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, SQL server

Data Analysis
Data analysis software: SPSS, SAS, Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, service delivery, prevention projects, survival analysis

System Integration
System links: link case finding data to final birth file, fetal death records, laboratory records, environmental databases, and National Death Index

Funding
Funding Source: 100% federal funding

Other
Web site: http://www.cdc.gov/ncbddd/bd/macdp.htm
Surveillance reports on file: MACDP 40th Anniversary Surveillance Report; copies available at macdp@cdc.gov

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Georgia
Georgia Birth Defects Reporting and Information System (GBDRIS)

**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:** 2005

**Earliest year of available data:** 2005

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

**Population covered annually:** 150,000

**Statewide:** Yes

**Current legislation or rule:** State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2 and Chapters 290-5-3.02 and 290-5-24 of the Rules of Department of Human Resources

**Legislation year enacted:** Updated in 2003

**Case Definition**

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

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

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

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

**Surveillance Methods**

**Case ascertainment:** Passive case ascertainment

**Other state based registries:** Programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, development disabilities surveillance

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

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

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

**Other sources:** Physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease)

**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.)

**Data Collection Methods and Storage**

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

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SAS, Access

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

**Data use and analysis:** Routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, capture-recapture analyses, service delivery, grant proposals, education/public awareness, prevention projects

**Funding**

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

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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, early childhood prevention programs, advocacy groups, legislators  
**Program status:** currently collecting data  
**Start year:** 1988  
**Earliest year of available data:** 1986  
**Organizational location:** Department of Health (Children with Special Health Needs)  
**Population covered annually:** 19,198 (average over past 3 years)  
**Statewide:** Yes  
**Current legislation or rule:** HRS §321-421 to 426; §324-41 to 44  
**Legislation year enacted:** 2002  

**Case Definition**  
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths (all gestational ages), elective terminations (all gestational ages), data collected on all elective medical terminations that were carried out because a screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect, and the parents elected not to bring the baby to term.  
**Age:** up to one year after delivery, except for Fetal Alcohol Syndrome  
**Residence:** 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:** 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 during 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 during chart review.  
**Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities  

**Case Ascertainment**  
**Conditions warranting chart review in newborn period:** any chart with a ICD9 CM code 740-759, any chart with a selected list of ICD9-CM codes outside of 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions (eg. abnormal facies or congenital heart disease), all stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases, medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect and parents elected not to bring baby to term, or mother spontaneously aborted.  

**Conditions warranting chart review beyond the newborn period:** all infant deaths (excluding prematurity), childhood deaths between 1 and 6, any infant with a codable defect  
**Coding:** CDC coding system based on BPA, ICD-9-CM  

**Data Collected**  
**Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information  
**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), 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, 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 investigation, time trends, epidemiologic studies (project data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, education/public awareness, prevention projects  

**Funding**  
**Funding Source:** 100% Birth Defects Special Fund (state fund from marriage license fee)  

**Other**  
**Web site:** http://hawaii.gov/health/family-childhealth/genetics/hbdpdata.html  
**Surveillance reports on file:** Hawaii Birth Defects Program Surveillance Reports. Reports for years 1986-2005 are pending  

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Adverse Pregnancy Outcomes Reporting System (APORS)

**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, demographic information, gravidity/parity
- **Father**: identification information, demographic information

**Data Collection Methods and Storage**
- **Data Collection**: printed abstract/report filled out by staff or submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.) or submitted by other agencies (hospitals, etc.)
- **Database storage/management**: Access, Mainframe

**Data Analysis**
- **Analysis software**: SAS, Access, ArchMap, 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 (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

**Funding**
- **Funding Source**: 65% general state funds, 35% CDC grant (FY09)

**Other**
- **Web site**: www.idph.state.il.us/about/epi/apors.htm

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**Purpose**: surveillance, referral to services, referral to prevention/intervention

**Partner**: local health departments, hospitals, early childhood prevention programs, advocacy groups, state agency serving children with special healthcare needs

**Program status**: currently collecting data

**Start year**: 1986

**Earliest year of available data**: 1989

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

**Population covered annually**: 180,000

**Statewide**: Yes

**Current legislation or rule**: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)

**Legislation year enacted**: 1985

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

**Surveillance Methods**
- **Case ascertainment**: combination of active and passive case ascertainment
- **Vital Records**: birth certificates, fetal death certificates
- **Other state based registries**: newborn metabolic screening program
- **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 selected defects or medical conditions (eg. abnormal facies, congenital heart disease), infants with low birth weight (<1500 grams), all neonatal deaths
- **Conditions warranting chart review beyond the newborn period**: any infant with a codable defect
- **Coding**: CDC coding system based on BPA

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Indiana Birth Defects & Problems Registry (IBDPR)

Purpose: surveillance, research, referral to services
Partner: universities, hospitals, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 2002
Earliest year of available data: 2003
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health, State Health Data Center)
Population covered annually: 89,000
Statewide: Yes
Current legislation: IC 16-38-4-7, Rule 410 IAC 21-3
Legislation year enacted: 2001

Case Description
Outcomes covered: ICD-9-CM Codes 740-759.9, Fetal Alcohol Spectrum Disorder (760.71), Pervasive Developmental Disorder (299.0), fetal deaths, metabolic disorders & hearing loss from newborn screening, selected neoplasms, congenital blood disorders, and certain eye disorders.
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: 0-5 years (FAS, autism); 0-3 years (all other birth defects)
Residence: In- and out-of-state births to state residents

Surveillance Methods
Case ascertainment: combination of active and passive case ascertainment, hospital-based
Vital Records: birth certificates, death certificates, matched birth/death file
Other state based registries: newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, chart audits of 45 targeted birth defects
Pediatric & tertiary care hospitals: disease index or discharge index, chart audits of 45 targeted birth defects
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with 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 death
Coding: ICD-9-CM and BPA

Data Collected
Infant/etus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage
Data Collection: electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.), ISDH Chart Auditors submit hospital chart audit information electronically through use of a laptop and a web-based portal to the Integrated Data System, which stores and integrates the data.
Database storage/management: Oracle

Data Analysis
Data analysis software: SAS, Oracle, ArcView
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, needs assessment

System Integration
System links: link to other state registries/databases, link case finding data to final birth file
System integration: database is linked with birth, death, newborn hearing screening, and newborn metabolic screening data.

Funding
Funding Source: 40% MCH funds, 60 % birth certificate sales

Other
Web site: www.birthdefects.in.gov

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Iowa Registry for Congenital and Inherited Disorders (IRCID)

**Purpose:** surveillance, research, referral to services, referral to prevention/intervention, prevention education programs

**Partner:** local health departments, universities, hospitals, environmental agencies/organizations, advocacy groups, legislators

**Program status:** currently collecting data

**Start year:** 1983

**Earliest year of available data:** 1983

**Organizational location:** University

**Population covered annually:** 37,831 (10 year average)

**Statewide:** Yes

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


**Case Definition**

**Outcomes covered:** major birth defects, Duchenne/Becker muscular dystrophy, fetal deaths with and without birth defects, newborn screening disorders

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)

**Age:** 1 year

**Residence:** maternal residence in Iowa at time of delivery

**Surveillance Methods**

**Case ascertainment:** active case ascertainment, population based

**Vital Records:** birth certificates, death certificates, fetal death certificates, stillbirth evaluation protocol

**Other state based registries:** newborn hearing screening program, newborn metabolic screening program, state perinatal program

**Delivery hospitals:** disease index or discharge index, discharge summaries, specialty outpatient clinics

**Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries, specialty outpatient clinics

**Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities, maternal serum screening facilities

**Other sources:** physician reports, outpatient surgery facilities

**Data Collected**

**Infant/eru:*** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Data Collection Methods and Storage**

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

**Database storage/management:** Access, Oracle, PC server

**Data Analysis**

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

**Quality assurance:** validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timelines

**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, data may be linked with environmental databases or other state databases for specific studies

**Funding**

**Funding Source:** 44% general state funds, 56% CDC grant

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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, Maternal and Child Health)
Population covered annually: 41,951 (Year 2007)
Statewide: Yes
Current legislation or rule: K.S.A. 65-1,241 through 65-1,246
Legislation year enacted: 2004

Case Definition
Outcomes covered: Outcome data are available from Office of Vital Statistics. Live birth and fetal death 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: all in-state births; out of state births to state residents

Surveillance Methods
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, discharge summaries, obstetrics logs (eg. 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
Midwifery facilities: midwifery facilities
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetics facilities
Other sources: physician reports

Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: printed abstract/report 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 certificate 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, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators

**Program status:** currently collecting data

**Start year:** 1996

**Earliest year of available data:** 1998

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

**Population covered annually:** 54,500

**Statewide:** Yes

**Current legislation or rule:** KRS 211.651-211.670

**Legislation year enacted:** 1992

**Case Definition**

**Outcomes covered:** major birth defects, genetic diseases, fetal mortality

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater than 350 grams)

**Age:** up to 5 years

**Residence:** all in-state births; out of state births to state residents

**Surveillance Methods**

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

**Vital Records:** birth certificates, death certificates, matched birth/death file, fetal death certificates, medical laboratory reporting mandated; outpatient reporting voluntary

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

**Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (eg. labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics, laboratory records

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

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

**Other sources:** physician reports, local health departments

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with 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 (eg. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked

**Conditions warranting chart review beyond the newborn period:** facial dysmorphism or abnormal facies, failure to thrive, CNS condition (eg. seizure), cardiovascular condition, any infant with a codable defect

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

**Data Collected**

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

**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal 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.), 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, Link Plus

**Quality assurance:** re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness

**Data use and analysis:** routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, IRB-approved research projects

**System Integration**

**System link:** 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**

**Web site:** http://chfs.ky.gov/dph/ach/ecd/kbsr.htm

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Purpose: surveillance, referral to services
Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 2005
Earliest year of available data: 2005
Organizational location: Department of Health, Children's Special Health Services
Population covered annually: approx. 51,000 (2009)
Statewide: No, est. coverage 80% of births (2009)
Rule: LAC 48:V.Chapters 161 and 163
Legislation enacted: 2001

Case Definition
Outcomes covered: major structural birth defects and selected genetic diseases
Pregnancy outcome: live births
Age: up to third birthday
Residence: in- and out-of-state births to state residents

Surveillance Methods
Case ascertainment: active case ascertainment, limited population-based (not statewide)
Vital Records: birth certificates, matched birth/death file
Other state based registries: programs for children with special needs
Delivery hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with 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 death: 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: printed abstract/report filled out by staff
Database storage/management: Access, Excel

Data Analysis
Data analysis software: SPSS, SAS
Quality assurance: double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review
Data use and analysis: routine statistical monitoring, baseline rates, education/public awareness, prevention projects

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

Funding
Funding Source: 100% CSHCN funds

Other
Web site: http://www.dhh.louisiana.gov/offices/?ID=261
Surveillance reports on file: Louisiana Morbidity Report

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Maine

Maine Birth Defects Program (MBDP)

**Purpose**: surveillance, referral to services, referral to prevention/intervention, education

**Partner**: universities, hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups, March of Dimes

**Program status**: currently collecting data

**Start year**: 1999

**Earliest year of available data**: 2003

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

**Population covered annually**: 13,800

**Statewide**: Yes

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

**Legislation year enacted**: 1999

**Case Definition**

**Outcomes covered**: selected major birth defects: NTDs, clefts, gastroschisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias, and major heart defects

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

**Age**: through age one

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

**Surveillance Methods**

**Case ascertainment**: passive case ascertainment, population based

**Vital Records**: birth certificates, death certificates, matched birth/death file, fetal death certificates

**Other state based registries**: programs for children with special needs, newborn hearing screening programs, newborn metabolic screening programs

**Delivery hospitals**: disease index or discharge index, discharge summaries, specialty outpatient clinics

**Pediatric & tertiary care hospitals**: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, specialty outpatient clinics

**Midwifery facilities**: midwifery facilities

**Other specialty facilities**: perinatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities, maternal serum screening facilities

**Other sources**: physician reports, children with special health needs

**Case Ascertainment**

**Conditions warranting chart review in newborn period**: any chart with a ICD-9-CM code 740-759, any chart with selected defects or medical conditions (eg. 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/foetus**: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

**Mother**: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

**Father**: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

**Data Collection Methods and Storage**

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

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

**Child.INK database system electronic abstraction record/hospital case reports/electronic submission of hospital discharge data. Online hospital case report form.**

**Data Analysis**

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

**Quality assurance**: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness

**Data use and analysis**: routine statistical monitoring, baseline rates, rates by demographic and other variables, needs assessment, service delivery, referral, education/public awareness, prevention projects

**System Integration**

**System links**: Link to other state registries/databases, Link case finding 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 and abstraction

**Other**


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Purpose: surveillance, referral to services, research
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 of the upper or lower limbs, congenital hip dislocation, and Down syndrome. BDRIS strongly recommends reporting all birth defects. The term "sentinel" goes through 2008 reporting. (Statute amended to expand the number of defects.)

Pregnancy outcome: live births, stillbirths, fetal deaths including fetal death in utero, spontaneous abortion, and pregnancy termination; reports on all gestational ages and birth weights accepted, but gestations of <20 weeks or <500 grams not included in CDC reports because of ascertainment issues. The Maryland Vital Statistics Administration does not require a death certificate for gestations < 20 weeks unless the body is transported for private burial or cremation. BDRIS has no legal authority to collect information on terminations.

Age: reporting is at the time of birth for all pregnancy outcomes with a birth defect(s)
Residence: all in-state births

Surveillance Methods
Case ascertainment: passive case ascertainment, population based, multiple-source

Vital Records: birth certificates and infant death certificates (linked in Maryland), fetal death certificates

Other state based registries: children with special health care needs programs, newborn hearing screening, newborn metabolic screening, sickle cell disease program

Delivery hospitals: primary source: sentinel birth defects hospital report form, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts

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

Midwifery facilities: primary source: sentinel birth defects report form, midwifery facility records

Other specialty facilities: genetic counseling/clinical genetics facilities, maternal serum screening programs

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD-9-CM code 740-759, any chart with selected defects or medical conditions (eg. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, linked Infant death certificate, 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 measures (weight, gestational age, etc.), tests and procedures, birth defect diagnostic information

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage

Data Collection: printed report submitted by other agencies (hospitals, etc.), entered directly into database by staff

Database storage/management: Access, Mainframe, SQL

Data Analysis

Data analysis software: Access, SAS, GIS

Quality assurance: validity checks, double-checking of codes, comparison/verification between multiple data sources

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, GIS mapping, time trends, monitoring for clusters/cluster investigation, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, environmental public health tracking, needs assessment, service delivery, referral, public health program evaluation, grant proposals, education/public awareness, prevention projects. BDRIS data are currently available through the MD Tracking Network web site at http://eh.dhmh.md.gov/tracking

System Integration

System links: electronic data exchange with Vital Statistics, in the process of linkage with other state registries/databases

Funding

Funding Source: 100% general state funds

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Massachusetts

Birth Defects Monitoring Program, Massachusetts Center for Birth Defects Research and Prevention
Massachusetts Department of Public Health (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 Public Health (Bureau of Family Health and Nutrition)

**Population covered annually:** 77,000

**Statewide:** Yes

**Current legislation or rule:** Massachusetts General Laws, Chapter 111, Section 67E. In 2002 the Massachusetts Legislature amended this statute, expanding the birth defects monitoring program.

**Regulations:** (105 CMR 302.00) were promulgated on February 6, 2009.

**Legislation year enacted:** 1963

**Case Definition**

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

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc (≥ 20 weeks gestation or ≥ 350 grams)

**Age:** up to one year

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

**Surveillance Methods**

**Case ascertainment:** combination of active and passive case ascertainment, population-based

**Vital Records:** birth certificates, death certificates, fetal death certificates

**Delivery hospitals:** disease index or discharge index, obstetrics logs (eg. labor & delivery), regular nursery logs, ICU/NICU logs or charts, postmorlem/pathology logs

**Pediatric & tertiary care hospitals:** disease index or discharge index, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics

**Other sources:** physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD-9-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 (eg. abnormal facies, congenital heart disease), all stillborn infants, all neonatal deaths (excluding prematurity)

**Conditions warranting chart review beyond the newborn period:** facial dysmorphism or abnormal facies, failure to thrive, all infant deaths (excluding prematurity), auditory/hearing conditions, any infant with a codable defect

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

**Data Collected**

**Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Data Collection Methods and Storage**

**Data Collection:** printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.), electronic scanning of printed records, data from printed confidential reporting and abstracting form is entered into electronic surveillance database.

**Database storage/management:** Access

**Data Analysis**

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

**Quality assurance:** validity checks, re-abstraction of cases, double-checking of signed codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, education/public awareness, 1) selected cases from surveillance are eligible for CDCs National Birth Defects Prevention Study 2) Down syndrome and cardiovascular defects used for CDC grant to determine prevalence, disparities, and cost of these defects

**System Integration**

**System links:** link case finding data to final birth file, link case finding data to final fetal death file, Massachusetts Pregnancy to Early Life Longitudinal (PEL.L) Linkage Project

**Funding**

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

**Other**

**Web site:** www.mass.gov/birthdefectscenter

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Michigan
Michigan Birth Defects Registry (MBDR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention, incidence and mortality statistics
Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 126,000
Statewide: Yes
Current legislation or rule: Public Act 236 of 1988
Legislation year enacted: 1988

Case Definition
Outcomes covered: congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks or >400 grams)
Age: up to two years after delivery
Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

Surveillance Methods
Case ascertainment: combination of active and passive case ascertainment, population based
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates, fetal deaths since 2004 only
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, cancer registry, AIDS/HIV registry
Delivery hospitals: disease index or discharge index, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, specialty outpatient clinics
Third party payers: Medicaid databases, CSHCS
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions (eg. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (eg. seizure), GI condition (eg. recurrent blockage), GU condition (eg. 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/foetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors
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, CSHCS, WIC
System integration: No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures

Funding
Funding Source: 20% CDC grant, 80% vital records fees

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

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Minnesota Birth Defects Information System (BDIS)

**Purpose:** Surveillance, research, referral to services, referral to prevention/intervention

**Partner:** Local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators

**Program status:** Currently collecting data

**Start year:** 2005

**Earliest year of available data:** 2006

**Organizational location:** Department of Health

**Population covered annually:** 73,000

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

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

**Legislation year enacted:** 2004

**Case Definition**

- **Outcomes covered:** Major "reported birth defects" as defined by CDC and ICD-9 codes
- **Pregnancy outcome:** Live births (all gestational ages and birth weights)
- **Age:** Up to 1 year after delivery, up to 6 years for FAS
- **Residence:** In-state data

**Surveillance Methods**

- **Case ascertainment:** Active case ascertainment, combination of active and passive case ascertainment
- **Vital Records:** Birth certificates, death certificates, matched birth/death file
- **Other state based registries:** Programs for children with special needs, newborn hearing screening program, newborn metabolic screening program
- **Delivery hospitals:** Disease index or discharge index, discharge summaries, obstetrics logs (e.g., labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics
- **Pediatric & tertiary care hospitals:** Disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics
- **Third party payers:** Medicaid databases, Health maintenance organization (HMOs)

**Case Ascertainment**

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

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

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

**Data Collected**

- **Infant/fetus:** Identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
- **Mother:** Identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
- **Father:** Identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Data Collection Methods and Storage**

- **Data Collection:** Electronic file/report filled out by staff at facility (laptop, web-based, etc.), laptops encrypted and data 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:** 90% CDC grant, 5% general state funds, 5% March of Dimes grant

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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, Division of Genetic Services)

Population covered annually: 49,000

Statewide: Yes

Current legislation or rule: Mississippi Code: Section 41-21-205

Legislation year enacted: 1997

Case Definition

Outcomes covered: live births and reportable fetal deaths with birth defects (fetal death of 20 completed weeks of gestation or more, or a weight of 350 grams or more) shall be reported.

Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater or 350 grams and greater)

Age: 0 to 21

Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment

Vital Records: birth certificates, death certificates

Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program

Delivery hospitals: disease index or discharge index, discharge summaries

Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries

Other sources: physician reports, community health centers

Data Collected

Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), birth defect diagnostic information

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

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

Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access

Quality assurance: validity checks, double-checking of assigned codes, timeliness

Data use and analysis: routine statistical monitoring, education/public awareness

Funding

Funding Source: 100% genetic screening revenue

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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:** 78,000  
**Statewide:** Yes  

**Case Definition**  
**Outcomes covered:** ICD9 codes 740-759, plus genetic, metabolic, and other disorders  
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), fetal death certificates are only source of data, surveillance of terminations currently limited to NTDs (expansion in progress)  
**Age:** up to one year after delivery  
**Residence:** in- and out-of-state births to state residents  

**Surveillance Methods**  
**Case ascertainment:** passive case ascertainment, population-based  
**Vital Records:** birth certificates, death certificates, matched birth/death file, fetal death certificates  
**Other state based registries:** programs for children with special needs, newborn hearing screening program, newborn metabolic screening program  
**Delivery hospitals:** discharge summaries  
**Pediatric & tertiary care hospitals:** discharge summaries, specialty outpatient clinics  
**Other sources:** enrollment data, Missouri Dept. of Mental Health  

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

Data Collected  
**Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information  
**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, pregnancy/delivery complications  
**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage  
**Data Collection:** electronic file/report from staff at facility (laptop, web-based, etc.) or 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

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Montana Birth Outcomes Monitoring System (MBOMS)

**Program status:** no current surveillance program  
**Start year:** 1999  
**Earliest year of available data:** 2000  
**Organizational location:** Department of Health (Maternal and Child Health)  
**Current legislation or rule:** none

**Case Definition**  
**Outcomes covered:** major structural birth defects, chromosomal anomalies specified in the CDC 45 reportable outcomes for births occurring in calendar years 2000 through 2004. Registry suspended in 2005 due to loss of CDC funding.  
**Pregnancy outcome:** all gestational ages

Comments: We have data for 2000 through 2004; no valid data since December 31, 2004.

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Nebraska

Nebraska Birth Defects Registry

**Purpose:** surveillance, research

**Partner:** hospitals, Nebraska Department of Health and Human Services and MCH

**Program status:** currently collecting data

**Start year:** 1973

**Earliest year of available data:** 1973

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

**Population covered annually:** 27,000+ births

**Statewide:** Yes

**Current legislation or rule:** Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §71-646, §71-647, §71-648, §71-649)

**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 gestation 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 certificates, death certificates, fetal death certificates

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

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

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

**Other sources:** physician reports

**CaseAscertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions (eg. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked

**Conditions warranting chart review beyond the newborn period:** facial dysmorphism or abnormal facies, failure to thrive, CNS condition (eg. seizure), GI condition (eg. recurrent blockage), GU condition (eg. 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 information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity

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

**Data Collection Methods and Storage**

**Data Collection:** printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/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:** births, fetal deaths, deaths, and hearing screening.

**Funding**

**Funding Source:** 100% MCH funds

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Nevada

**Nevada Birth Outcomes Monitoring System**

**Purpose:** surveillance, research, referral to services, referral to prevention/intervention

**Partner:** hospitals, early childhood prevention programs, bureau of child, family, community wellness

**Program status:** currently collecting data

**Start year:** 2005

**Earliest year of available data:** 2005

**Organizational location:** State Division of Health, Bureau of Health Statistics, Planning, and Emergency Response

**Population covered annually:** 40,703 in 2007

**Statewide:** Yes

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

**Legislation year enacted:** 1999

**Case Definition**

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

**Pregnancy outcome:** live births (20 weeks of gestation and greater with all birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

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

**Residence:** in-state births

**Surveillance Methods**

**Case ascertainment:** combination of active and passive case ascertainment, population based

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

**Other state based registries:** 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 (eg. labor & delivery), pediatric logs, postmortem/pathology logs, surgery logs, cardiac catheterization laboratories, specialty outpatient clinics

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

**Third party payers:** Medicaid databases

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

**Other sources:** physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with 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 dysmorphism or abnormal facies, failure to thrive, development delay, CNS condition (eg. seizure), GI condition (eg. recurrent blockage), GU condition (eg. recurrent infections), cardiovascular condition, any infant with a codable defect

**Coding:** ICD-9-CM

**Data Collected**

**Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

**Mother:** identification information (name, address, date-of-birth, etc.), illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

**Data Collection Methods and Storage**

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

**Database storage/management:** Access

**Data Analysis**

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

**Quality assurance:** double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits

**Data use and analysis:** routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, service delivery, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

**System links:** link to other state registries/databases, birth registry data is manually linked to birth defect data, but the actual databases are not linked.

**System integration:** No

**Funding**

**Funding Source:** 100% service fees

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Data Collected
Infant/fetus: identification information except for termination cases (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 except for termination cases (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: date of birth

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

Data Analysis
Data analysis software: SPSS, Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review
Data use and analysis: public health program evaluation, baseline rates, rates by demographic and other variables, observed vs expected analyses, service delivery, grant proposals, education/public awareness, prevention projects

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

Funding
Funding Source: 100% CDC grant

Other
Web site: www.nhbcp.org

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New Jersey
Special Child Health Services Registry (SCHS REGISTRY)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health & Senior Services - Special Child, Adult, and Early Intervention Services
Population covered annually: 114,000
Statewide: Yes
Current legislation or rule: NJSA 26:8 et seq., NJAC 8:20
Legislation year enacted: 1983

Case Definition
Outcomes covered: all birth defects (structural, genetic, and biochemical), all Autism Spectrum Disorders, and severe hyperbilirubinemia are required to be reported; all special needs and any condition which places a child at risk (prematurity, asthma, cancer, developmental delay) are also reported, but not required
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: mandated reporting of birth defects diagnosed through age 5, voluntary reporting of birth defects diagnosed > age 6 and all children diagnosed with Special Needs conditions who are 22 years or younger
Residence: all NJ residents, in and out of state

Surveillance Methods
Case ascertainment: combination of active and passive case ascertainment, population based
Vital Records: birth certificates, death certificates, matched birth/death file
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (eg. 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: cytogenetic laboratories, genetic counseling/clinical genetics facilities
Other sources: physician reports, special child health services case management units, parents, medical examiners, autism diagnosticians and treatment centers

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, all neonatal deaths, all death certificates for < 3 year of age

Conditions warranting chart review beyond the newborn period: GI condition (ie recurrent blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, any infant with a codable defect
Coding: ICD-9-CM

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

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff or submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.) or submitted by other agencies (hospitals, etc.), implementation of a web-based reporting ongoing since July 1, 2009
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, 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: 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, 10% CDC grant, 5% genetic screening revenues

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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, advocacy groups, 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

**Case Definition**

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

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)

**Age:** birth through age 4 years

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

**Surveillance Methods**

**Case ascertainment:** passive case ascertainment, population based

**Vital Records:** birth certificates, death certificates, fetal death certificates

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

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

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

**Third party payers:** Medicaid databases, Health Maintenance Organization (HMOs), Indian Health Services, 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 (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, charts with a list of other ICD9-CM codes selected by CMS

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

**Data Collected**

**Infant/nerus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth defect diagnostic information

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

**Data Collection Methods and Storage**

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

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

**Data Analysis**

**Data analysis software:** Stata

**Quality assurance:** validity checks, double-checking of assigned codes, comparison/verification between multiple data sources

**data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, grant proposals, education/public awareness, prevention projects

**System Integration**

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

**Funding**

**Funding Source:** 100% other federal funding from an Environmental Public Health Tracking grant. We are actively seeking other resources to support birth defects surveillance

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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)(b) 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 (eg. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catheterization laboratories, specialty outpatient clinics

**Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics

**Other specialty facilities:** cytogenetic laboratories

**Other sources:** physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** charts with major malformations - a detailed list is available upon request

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

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

**Data Collected**

**Infant/etus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic information

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

**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 by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

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

**Funding**

**Funding Source:** 25% general state funds, 10% MCH funds, 36% CDC grant, 26% other federal funding, 3% genetic screening revenues

**Other**

**Web site:**
http://www.health.state.ny.us/diseases/congenital_malformations/cmhome.htm

**Surveillance reports on file:** Reports for 1983-2006

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North Carolina

North Carolina Birth Defects Monitoring Program (NCBDMP)

**Purpose**: surveillance, research, referral to services, referral to prevention/intervention, education, advocacy

**Partner**: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators

**Program status**: currently collecting data

**Start year**: 1987

**Earliest year of available data**: 1989

**Organizational location**: Department of Health (State Center for Health Statistics)

**Population covered annually**: 130,000

**Statewide**: Yes

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

**Legislation year enacted**: 1995

**Case Definition**

**Outcomes covered**: major birth defects

**Pregnancy outcome**: live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (all gestational ages)

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

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

**Surveillance Methods**

**Case ascertainment**: active case ascertainment, population based

**Vital Records**: birth certificates, death certificates, matched birth/death file, fetal death certificates

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

**Delivery hospitals**: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), specialty outpatient clinics

**Pediatric & tertiary care hospitals**: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics

**Third party payers**: Medicaid databases

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

**Case Ascertainment**

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

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

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

**Data Collected**

**Infant/fetus**: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

**Mother**: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

**Father**: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Data Collection Methods and Storage**

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

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

**Data Analysis**

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

**Quality assurance**: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness

**Data use and analysis**: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, service delivery, referral, grant proposals, education/public awareness, prevention projects, advocacy

**System Integration**

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

**Funding**

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

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North Dakota
North Dakota Birth Defects Monitoring System (NDBGMS)

Purpose: surveillance
Partner: universities, March of Dimes
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 1994
Organizational location: Department of Health (Vital Statistics, Maternal and Child Health, Children’s Special Health Services)
Population covered annually: 8931
Statewide: Yes
Current legislation or rule: North Dakota Century code 23-41
Legislation year enacted: 1941

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

Surveillance Methods
Case ascertainment: passive case ascertainment
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, cancer registry, AIDS/HIV registry, FAS
Delivery hospitals: birth certificate completion
Pediatric & tertiary care hospitals: specialty outpatient clinics
Third party payers: Medicaid databases
Other sources: physician reports

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

Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Mainframe, DB2, SPSS, Excel

Data Analysis
Data analysis software: SPSS
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, needs assessment, service delivery, referral, grant proposals, education/public awareness

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

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

Other

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Ohio Connections for Children with Special Needs (OCSSN)

**Purpose:** Surveillance, research, referral to services, referral to prevention/intervention

**Partner:** Local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators

**Program status:** Currently collecting data

**Start year:** 2006

**Earliest year of available data:** N/A

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

**Population covered annually:** 150,000

**Statewide:** Yes


**Legislation year enacted:** 2000

**Case Definition**

**Outcomes covered:** 45 major disorders recommended by NBDPN

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

**Age:** 0-5 years of age

**Residence:** All Ohio children 0-5 years of age seen for medical care at a hospital in Ohio

**Surveillance Methods**

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

**Vital Records**

**Birth certificates**

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

**Delivery hospitals:** Hospital electronic data systems for medical records and billing

**Pediatric & tertiary care hospitals:** Hospital electronic data systems for medical records and billing

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

**Case Ascertainment**

**Coding:** ICD-9-CM

**Data Collected**

**Infant/foetus:** Identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth defect diagnostic information

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

**Data Collection Methods and Storage**

**Data Collection:** Electronic file/report submitted by other agencies (hospitals, etc.), reporting hospitals upload information to ODH via secure internet transmission, low volume reporters can manually key data into screens on secure internet site

**Database storage/management:** SQL server

**Data Analysis**

**Data analysis software:** SPSS, SAS

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

**Data use and analysis:** Routine statistical monitoring, public health program evaluation, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

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

**System integration:** OCCSN data system shares common demographic file with vital statistics. OCCSN data system is linked with Part C early intervention program data base, Title V CSHCN program data system and Genetics Program data system.

**Funding**

**Funding Source:** 100% CDC grant

**Other**

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STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Oklahoma

Oklahoma Birth Defects Registry (OBDR)

**Purpose:** surveillance, referral to services, referral to prevention/intervention

**Partner:** hospitals, early childhood prevention programs, legislators, cytogenetics and medical genetics

**Program status:** currently collecting data

**Start year:** 1992; statewide 1994

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

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

**Population covered annually:** 55,000

**Statewide:** Yes

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

**Legislation year enacted:** 1992

**Case Definition**

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

**Pregnancy outcome:** live births (≥ 20 weeks gestation), Fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (20 weeks gestation and greater)

**Age:** 2 years

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

**Surveillance Methods**

**Case ascertainment:** active case ascertainment, population-based

**Vital Records:** birth certificates, death certificates, fetal death certificates

**Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (eg. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, surgery logs, specialty outpatient clinics

**Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, surgery logs, specialty outpatient clinics

**Midwifery facilities:** midwifery facilities

**Third party payers:** Indian Health Services, military hospitals delivering babies

**Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities

**Case Ascertainment**

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

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

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

**Data Collected**

Infant/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, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Data Collection Methods and Storage**

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

**Database storage/methods:** Access

**Data Analysis**

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

**Quality assurance:** validity checks, re-abstraction of cases, double-checking of assigned codes, timeliness, editing of all completed abstracts

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, needs assessment, referral, grant proposals, education/public awareness, prevention projects, program quality assurance

**Funding**

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

**Other**

**Web site:**
http://www.ok.gov/health/Child_and_Family_Health/Screening_Special_Services_and_Sooner_Star/Oklahoma_Birth_Defects_Registry/index.html

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Oregon

**Program status:** no surveillance program

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Pennsylvania
Pennsylvania Birth Defects Surveillance Database

Program status: no surveillance program
Start year: 2003
Earliest year of available data: 2001
Organizational location: Department of Health (Epidemiology/Environment, Vital Statistics, Maternal and Child Health)
Population covered annually: 144,499 (Year 2004)

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

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

Data Collected
Mother: Maternal risk factors

Data Analysis
Quality assurance: Validity checks

Funding
Funding Source: 100% MCH funds

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Puerto Rico

Puerto Rico Birth Defects Surveillance and Prevention System (PRBDSS)

**Purpose:** surveillance, referral to services, referral to prevention/intervention

**Partner:** local health departments, universities, hospitals, community nursing services, early childhood prevention programs, advocacy groups

**Program status:** currently collecting data

**Start year:** 1995

**Earliest year of available data:** 1995

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

**Population covered annually:** 48,000

**Statewide:** Yes

**Current legislation or rule:** Law 351

**Legislation year enacted:** 2004

**Case Definition**

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

**Pregnancy outcome** live births (all gestational ages and birth weights), fetal death: stillbirths, spontaneous abortions, etc (all gestational ages), elective terminations (all gestational ages)

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

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

**Surveillance Methods**

**Case ascertainment:** active case ascertainment, population based

**Vital Records:** birth certificates, death certificates, fetal death certificates

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

**Delivery hospitals:** discharge summaries, obstetrics logs (eg. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, specialty outpatient clinics

**Pediatric & tertiary care hospitals:** discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs

**Third party payers:** Medicaid databases

**Other speciality facilities:** prenatal diagnostic facilities (ultrasound, etc.)

**Other sources:** physician reports

**Case Ascertainment**

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

**Conditions warranting chart review beyond the newborn period:** facial dysmorphism or abnormal facies, failure to thrive, cardiovascular condition, all infant deaths (excluding prematurity), any infant with a codable defect

**Coding:** ICD-9-CM

**Data Collected**

**Infant/feet:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic information

**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, prenatal diagnostic information

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

**Data Collection Methods and Storage**

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

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SPSS, Excel

**Quality assurance:** validity checks, re-abstracting 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, trend analysis, time-space cluster analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

**Funding**

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

**Other**

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

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

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Rhode Island
Rhode Island Birth Defects Program

Purpose: surveillance, referral to services, referral to prevention/intervention
Partner: hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 2000
Earliest year of available data: 1997
Organizational location: Department of Health (Maternal and Child Health, Center for Health Data and Analysis)
Population covered annually: 12,000
Statewide: Yes
Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws
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: 0-4 years
Residence: RI residents

Surveillance Methods
Case ascertainment: combination of active and passive case ascertainment
Vital Records: birth certificates, death certificates, matched birth/death file
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, RI has an integrated database called KIDSNET, which links data from 9 programs including: Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting and Vital Records
Delivery hospitals: discharge summaries, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: discharge summaries, specialty outpatient clinics
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities, maternal serum screening facilities
Other sources: physicians reports

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, chart reviews are conducted for infants born at the regional perinatal center and its sister hospital (represents 30% of newborns with birth defects) who were identified with an ICD-9 code 740-759 and other sentinel conditions
Coding: ICD-9-CM

Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Oracle

Data Analysis
Data analysis software: SAS, Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness

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: 75% CDC grant, 25% MCH funds

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

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South Carolina
South Carolina Birth Defects Program (SCBDP)

**Purpose:** surveillance, research, referral to services, referral to prevention/intervention

**Partner:** local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators, Greenwood Genetic Center (GGC)

**Program status:** currently collecting data

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

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

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

**Population covered annually:** 55,317

**Statewide:** Yes

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

**Legislation year enacted:** 2004

**Case Definition**

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

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)

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

**Residence:** in-state births to South Carolina residents

**Surveillance Methods**

**Case ascertainment:** active case ascertainment

**Vital Records:** birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates

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

**Delivery hospitals:** disease index or discharge index, discharge summaries, postmortem/pathology logs, ICD-9 codes

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

**Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities

**Other sources:** physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with 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 (eg. 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, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

**Mother:** identification information (name, address, date of birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

**Father:** identification information (name, address, date of birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

**Data Collection Methods and Storage**

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

**Database storage/management:** Access

**Data Analysis**

**Data analysis software:** SAS, Access

**Quality assurance:** validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review

**Data use and analysis:** routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

**System links:** link case finding data to 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

Tennessee

Tennessee Birth Defects Registry (TBDR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention

Partner: local health departments, universities, hospitals, community nursing services, early childhood prevention programs, advocacy groups, legislators

Program status: currently collecting data

Start year: 2000

Earliest year of available data: 1999

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

Population covered annually: 80,000

Statewide: Yes

Current legislation or rule: TCA 68-5-506

Legislation year enacted: 2000

Case Definition

Outcomes covered: 44 major structural birth defects

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

Age: up to one year after delivery

Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population based, hospital based

Vital Records: birth certificates, death certificates, matched birth/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 (eg, 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 ICD9-CM code 740-759, ICD9-CM code 760.71

Conditions warranting chart review beyond the newborn period: any infant with a codeable defect

Coding: ICD-9-CM

Data Collected

Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), 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, clinical review

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, education/public awareness, prevention projects

System Integration

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

Funding

Funding Source: 100% general state funds

Other

Web site: http://hit.state.tn.us/Reports.aspx


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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:** 385,537 (Year 2005)
**Statewide:** Yes
**Current legislation or rule:** Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87.
**Legislation year enacted:** 1993

**Case Definition**
**Outcomes covered:** all major structural birth defects and fetal alcohol syndrome
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)
**Age:** up to one year after delivery - FAS up to 6 years
**Residence:** in and out of state births to state residents

**Surveillance Methods**
**Case ascertainment:** active case ascertainment, population based
**Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs, regular nursery logs, NICU/ICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catheterization laboratories, specialty outpatient clinics, genetics logs, stillbirth logs, radiology logs
**Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries, NICU/ICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics, genetics logs, radiology logs
**Midwifery facilities:** midwifery facilities
**Other sources:** licensed birthing centers

**CaseAscertainment**
**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 (e.g. abnormal facies, congenital heart disease), infants with low gestation (<34 weeks GA), all stillborn infants
**Conditions warranting chart review beyond the newborn period:** CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections), cardiovascular condition, any infant with a codable defect
**Coding:** CDC coding system based on BPA

**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 information

**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Data Collection Methods and Storage**
**Data Collection:** printed abstract/report filled out by staff
**Database storage/management:** SQL Server

**Data Analysis**
**Data analysis software:** SAS, Access
**Quality assurance:** validity checks, re-abstraction of cases, double-checking of assigned codes, clinical review, timeliness, re-casefinding, re-review of medical records

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, referral, grant proposals, education/public awareness, prevention projects

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

**Funding**
**Funding Source:** 58% general state funds, 42% MCH funds,
*Note: does not include CDC-funded Texas Birth Defects Research Center funds*

**Other**
**Web site:** [www.dshs.state.tx.us/birthdefects/](http://www.dshs.state.tx.us/birthdefects/)

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Utah
Utah Birth Defect Network (UBDN)

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
information
Mother: identification information (name, address, date-of-birth,
etc.), demographic information (race/ethnicity, sex, etc.),
gravidity/parity, illnesses/conditions, prenatals, 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.),
illegacies/conditions, family history

Data Collection Methods and Storage
Data Collection: electronic abstract/report filled out by program
staff
Database storage/management: Access

Data Analysis
Data analysis software: SPSS, SAS, Access, State 8
Quality assurance: validity checks, re-abstraction of cases, double-
checking of assigned codes, comparison/verification between
multiple data sources, clinical review, timeliness, logical checks,
duplicate check in tracking and surveillance module, case record
form checked for completeness, timeliness through system, manual
review of subset of surveillance module case data compared to case
record form.

Data use and analysis: routine statistical monitoring, public health
program evaluation, baseline rates, rates by demographic and other
variables, time trends, epidemiologic studies (using only program
data), identification of potential cases for other epidemiologic
studies, referral, grant proposals, education/public awareness,
prevention projects, Oral Facial Cleft Case-Control Study, UT
Center for Birth Defects Research and Prevention

System Integration
System links: link to environmental databases, link to birth records

Funding
Funding Source: 100% general state funds

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Purpose: surveillance, research, referral to services, referral to
prevention/intervention, education
Partner: universities, hospitals, environmental
agencies/organizations, advocacy groups, legislators
Program status: currently collecting data
Start year: 1994
Earliest year of available data: 1994
Organizational location: Department of Health (CSHCN)
University of Utah
Population covered annually: 53,000
Statewide: Yes
Current legislation or rule: Birth Defect Rule (R398-5)
Legislation year enacted: 1999

Case Definition
Outcomes covered: 742,000 – 759,000
Pregnancy outcome: live births (all gestational ages and birth
weights), stillbirths (20 weeks gestation or greater), spontaneous
abortions (less than 20 weeks gestation), and elective terminations
(any gestational week)
Age: 2
Residence: maternal residence in Utah at time of delivery

Surveillance Methods
Case ascertainment: combination of active and passive case
ascertainment, population-based
Vital Records: birth certificates, death certificates, fetal death
certificates
Delivery hospitals: disease index or discharge index, discharge
summaries, obstetrics logs (eg. labor & delivery), regular nursery
logs, ICU/NICU logs or charts, postmortem/pathology logs,
specialty outpatient clinics, neonatal intensive care units
Pediatric care: disease index or discharge index, discharge
summaries, ICU/NICU logs or charts, postmortem/pathology logs,
surgery logs, specialty outpatient clinics
Midwifery: midwifery facilities
Other specialty facilities: prenatal diagnostic facilities (ultrasound,
etc.), cytogenetic laboratories, genetic counseling
Other sources: physician reports, lay midwives

Case Ascertainment
Conditions warranting chart review in new born: any chart
with 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 (eg. 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 death certificates, NICU reports, infant
deaths are reviewed

Conditions warranting chart review beyond the newborn period:
facial dysmorphism or abnormal facies, failure to thrive,
cardiovascular condition, all infant deaths (excluding prematurity),
childhood deaths between 1 and 6, any infant with a coded defect
Coding: CDC coding system based on BPA
Vermont
Birth Information Network (BIN)

**Purpose:** surveillance, referral to services, referral to prevention/intervention, prevention education

**Partner:** local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, VT Department of Banking, Insurance, Securities & Healthcare Administration; VT Association of Hospitals and Health Systems

**Program status:** currently collecting data

**Start year:** 2006

**Earliest year of available data:** 2006

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

**Population covered annually:** 6500

**Statewide:** Yes

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

**Legislation year enacted:** 2003

**Case Definition**

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

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

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

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

**Surveillance Methods**

**Case ascertainment:** passive case ascertainment, population based

**Vital Records:** birth certificates, death certificates, matched birth/death file

**Other state based registries:** programs for children with special needs, newborn hearing screening program

**Delivery hospitals:** discharge summaries, specialty outpatient clinics

**Pediatric & tertiary care hospitals:** discharge summaries, specialty outpatient clinics

**Third party payers:** Medicaid databases

**Other sources:** physician reports from offices and clinics associated with tertiary care hospital

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with selected defects or medical conditions (eg. abnormal facies, congenital heart disease)

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

**Coding:** ICD-9-CM

**Data Collected**

**Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, maternal risk factors

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

**Data Collection Methods and Storage**

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

**Database storage/management:** Access

**Data Analysis**

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

**Quality assurance:** comparison/verification between multiple data sources, clinical review, timeliness

**Data use and analysis:** routine statistical monitoring, baseline rates, referral, grant proposals, prevention projects

**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)

**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

**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 Early Hearing Detection and Intervention Program. VISITS II, due for implementation later this year, will be integrated with the birth certificate registry making birth data available to enhance the equality of birth defect data.

**Funding**
- Funding Source: 60% MCH funds, 40% CDC grant

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**Surveillance Methods**
- Case ascertainment: passive case ascertainment, population based, active component includes periodic on site 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 bloodspot 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 Ascertained**
- 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 (eg. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all neonatal deaths, chart review done by the coders in Health Information Management
- Conditions warranting chart review beyond the newborn period: any infant with a codable defect
- Coding: ICD-9-CM, ICD-10 for death certificate

**Purpose**
- surveillance, research, referral to services Part C-E

**Partner**
- universities, hospitals, children with special healthcare needs care coordination services

**Program status**
- currently collecting data

**Start year**
- 1985

**Earliest year of available data**
- 1987

**Organizational location**
- Department of Health (Genetic and Newborn Screening), Child and Adolescent Health

**Population covered annually**
- 107,261

**Statewide**
- Yes

**Current legislation or rule**
- Health Law 32.1-69.1, -69.1:1, -69.2

**Legislation year enacted**
Purpose: Surveillance
Partner: Universities, Hospitals, Environmental Agencies/Organizations
Program status: Currently collecting data
Start year: 1986- Active and 1991- Passive
Earliest year of available data: 1987
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 86,000
Statewide: Yes
Current legislation or rule: 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 information (name, address, date-of-birth, etc.)
Father: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), 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, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Baseline rates, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Education/public awareness

System Integration
System links: Link case finding data to final birth file, CSHCN program participant file
System integration: Member of the Environmental Health Tracking Grant project.

Funding
Funding Source: 60% MCH funds, 40% general state funds

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

**Purpose:** surveillance, research, referral to services, referral to prevention/intervention

**Partner:** universities, hospitals, early childhood prevention programs, advocacy groups

**Program status:** currently collecting data

**Start year:** 1989

**Earliest year of available data:** 1989

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

**Population covered annually:** 21,000

**Statewide:** Yes

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

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

**Case Definition**

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

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (20 weeks gestation and greater)

**Age:** 0-6 years

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

**Surveillance Methods**

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

**Vital Records:** birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates

**Other state based registries:** programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, development disabilities surveillance, cancer registry, AIDS/HIV registry, SIDS

**Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs, regular nursery logs, ICU/NICU logs or charts, pediatric logs

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

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

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

**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 (eg. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, infants with low birth weight or low gestation (< 2500 grams or < 37 weeks), all stillborn infants, all neonatal deaths, all elective abortions, all infants with low Apgar scores, all infants in NICU

**Conditions warranting chart review beyond the newborn period:** facial dysmorphism or abnormal facies, failure to thrive, development delay, CNS condition (eg. seizure), GI condition (eg. recurrent blockage), GU condition (eg. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 6, ocular conditions, auditory/hearing conditions, any infant with a coded defect

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

**Data Collected**

**Infant/fetus:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), infant complications, birth defect diagnostic information

**Mother:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history

**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

**Data Collection Methods and Storage**

**Data Collection:** printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report 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 final birth file, plans to link to several programs in the Office of Maternal, Child and Family Health.

**Funding**

**Funding Source:** 100% Title V Block Grant funds

**Other**

**Web site:** http://www.wvdhhr.org/caress/

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Wisconsin
Wisconsin Birth Defects Registry (WBDR)

Purpose: surveillance, research, referral to services
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 2004
Earliest year of available data: 2004
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: ~70,000
Statewide: Yes
Current legislation or rule: Wisconsin Statutes 253.12
Rules: HFS 116--took effect April 1, 2003
Legislation year enacted: 2000

Case Definition
Outcomes covered: structural malformations, deformations, disruptions, or dysplasias; genetic, inherited, or biochemical diseases.
Pregnancy outcome: live births (20 weeks gestational age or greater), fetal deaths: stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: birth to 2 years
Residence: statute mandates reporting of birth defects diagnosed or treated in Wisconsin regardless of residence status

Surveillance Methods
Case ascertainment: passive case ascertainment, population based
Delivery hospitals: case reports from nursery managers
Pediatric & tertiary care hospitals: case reports from pediatric specialty clinics
Midwifery facilities: midwifery facilities
Third party payers: Health maintenance organization (HMOs)
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports

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

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.)
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 from their electronic patient records system to the WBDR secure website.
Database storage/management: Oracle

Data Analysis
Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration
System links: Legislation currently prohibits data linkage

Funding
Funding Source: 50% general state funds, 50% MCH funds

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

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E-mail: Peggy.HelmQuest@dhs.wisconsin.gov

Wyoming

Program status: Interested in developing a surveillance program
Start year: 2010
Organizational location: Department of Health
(Epidemiology/Environment, Maternal and Child Health)

Contacts
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6101 Yellowstone Rd, Ste 420
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E-mail: angela.crotzenberg@health.wyo.gov
Purpose: surveillance, research
Partner: universities, hospitals, other DoD programs
Program status: currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: DoD Center for Deployment Health Research, Naval Health Research Center, San Diego, CA
Population covered annually: approximately 100,000 per year
Statewide: No, National/Worldwide; includes all DoD beneficiaries
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum
Legislation year enacted: 1998

Case Definition
Outcomes covered: Outcomes include those birth defects listed in the case definition of the National Birth Defects Prevention Network. For a birth defect to be represented, the diagnosis must appear at least once in an inpatient record, or at least twice on two separate dates for outpatient encounters. Same sex multiples are excluded from analysis.

Pregnancy outcome: live births (all gestational ages and birth weights); elective terminations (less than 20 weeks gestation)
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
Other state based registries: cancer registry
Delivery hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Third party payers: all inpatient and outpatient encounters are captured in standardized DoD data
Other sources: validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military facilities

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military healthcare facilities
Conditions warranting chart review beyond the newborn period: failure to thrive, any infant with a codable defect
Coding: ICD-9-CM

Data Collected
Infants/fees: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestations, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information

Purpose: surveillance, research
Partner: universities, hospitals, other DoD programs
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