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 defects 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, prevention  
**Partner:** university, hospital, child program, advocacy  
**Program status:** Currently collecting data  
**Start year:** 1995  
**Earliest year of available data:** 1998  
**Population covered annually:** 8,000/year for 1998-2000  
**Organization location:** University  
**Population covered annually:** 8,000/year for 1998-2000  

**Current legislation or rule:** none

**Case Definition**  
**Outcomes covered:** major birth defects and genetic disorders  
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations  
**Age:** up to one year after delivery  

**Surveillance methods**  
**Case ascertainment:** active case ascertainment, population-based  
**Case finding/identification sources:** Vital records: birth certificates, death certificates, fetal death certificates  
**Delivery hospitals:** disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, Congenital Anomaly reporting form  
**Pediatric & tertiary care hospitals:** disease index or discharge index, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, Congenital Anomaly reporting form  
**Other specialty facilities:** cytogenetic laboratories, genetic counseling/clinical genetic facilities

**Data Collection Methods and Storage**  
**Database storage/management:** MS Access, Clipper  
**Data Analysis**  
**Data analysis software:** SPSS, MS Access, Hypercube; Excel pivot tables  
**Quality assurance:** re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness  
**Data use and analysis:** baseline rates, rates by demographic and other variables, time trends, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

**Funding**  
**Funding source:** CDC grant 80%, University 20%

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

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Alaska
Alaska Birth Defects Registry (ABDR)

**Purpose:** surveillance

**Partner:** Department of Health, hospital, nursing, environment, child program

**Program status:** Currently collecting data

**Start year:** 1996

**Earliest year of available data:** 1996

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

**Population covered annually:** 10,000

**Statewide:** yes

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

**Legislation year enacted:** 1996

**Case Definition**

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

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

**Age:** Birth to age one; Birth to age six for alcohol related birth defects (including fetal alcohol syndrome)

**Residence:** Alaska residents

**Surveillance methods**

**Case ascertainment:** passive case ascertainment, population-based; active case ascertainment for alcohol related birth defects (including fetal alcohol syndrome)

**Case finding/identification sources:**
- Vital records: birth certificates, fetal death certificates
- Other state based registries: programs for children with special needs, newborn biochemical 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 treated or diagnosed with a reportable ICD-9 code.
- Pediatric & tertiary care hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child treated or diagnosed with a reportable ICD-9 code.
- Third party payers: Medicaid databases, Indian health services
- Other specialty facilities: genetic counseling/clinical genetic 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.), birth defect diagnostic information

**Data Collection Methods and Storage**

**Database storage/management:** MS Access

**Data Analysis**

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

**Quality assurance:** validity checks, re-abstraction of cases, comparison/verification between multiple data sources, timeliness

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

**System Integration**

**System links:** final birth file

**System integration:** The ABDR is in the process of developing a system to match birth defects data to data housed in the Special Needs Services Unit (which administers programs such as Specialty Clinics, Infant Learning Programs, and Genetics Clinics) to assist with identifying gaps in services and referrals for children with birth defects.

**Funding**

**Funding source:** CDC grant 100%

**Other**

**Web site:** http://www.akepi.org/mchepi/ABDR/default.htm

**Surveillance reports on file:** Family Health Datalines, ABDR Surveillance Updates, MCH Fact Sheets (ex: Folic Acid Knowledge and Use in Alaska), Alaska Maternal and Child Health Data Book 2003

**Procedure manual available:** yes

**Additional information on file:** Results of the Alaska Folic Acid Surveys conducted in 1999 and 2000

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Arizona
Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: surveillance, service, prevention
Partner: Department of Health, university, hospital, nursing, child program, advocacy
Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1986
Organizational location: Department of Health (Epidemiology/Environment), Bureau of Public Health Statistics/Office of Health Registries
Population covered annually: 90,783 in 2003
Statewide: yes

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases
Conditions warranting a 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, 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, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage
Database storage/management: MS Access, Oracle

Data Analysis
Data analysis software: SAS, MS 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, baseline rates, rates by demographic and other variables, time trends, grant proposals, education/public awareness, prevention projects

Funding
Funding source: general state funds 25%, MCH funds 3%, genetic screening revenues 22%, CDC grant 50%

Other
Web site: www.hs.state.az.us/phs/phstats/bdr/index.htm
Procedure manual available: yes

Additional information on file: procedures manual, copy of legislation, case record form, case finding log, abstraction forms, quality assurance procedures.

Comments: Contact person 3: Bichtram Nguyen, Epidemiologist, Arizona Department of Health Services, 150 North 18th Avenue, Ste. 550, Phoenix, Arizona, 85007; Phone: 602-364-1302; FAX: 602-542-7447; E-mail: bnguyen@hs.state.az.us.

Case Definition
Outcomes covered: 44 composite categories covering the 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. (less than 20 week gestation, 20 weeks gestation and greater; All gestational ages/birth weights included starting with 2002 data.), elective terminations (20 weeks gestation and greater)
Age: up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child’s life, and this information is contained in the chart at the time of our review (which occurs 2 -4 years after the child’s birth or fetal death), then the more precise diagnosis is used.
Residence: in-state birth to state resident.

Surveillance methods
Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Other state based registries: programs for children with special needs, newborn biochemical screening program, Cases are identified through Children Rehabilitation Services Clinics and the Newborn Intensive Care Program, which are both in the Office for Children with Special Health Care Needs.
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, ultrasound reports, cytogenetic reports, stillborn logs, mother’s charts for stillborns
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, ultrasound reports, cytogenetic reports, stillborn logs, mother’s charts for still borns
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities
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Arkansas
Arkansas Reproductive Health Monitoring System (ARHMS)

**Purpose:** surveillance, research, prevention
**Partner:** Department of Health, university, hospital, advocacy, legislator
**Program status:** Currently collecting data
**Start year:** 1980
**Earliest year of available data:** 1980
**Organizational location:** University, Arkansas Children's Hospital
**Population covered annually:** 37,000
**Statewide:** yes
**Current legislation or rule:** Senate Bill Act 214
**Legislation year enacted:** 1985

**Case Definition**
**Outcomes covered:** major structural birth defects
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations
**Age:** two years after delivery
**Residence:** in and out of state births to state residents

**Surveillance methods**
**Case ascertainment:** active case ascertainment, population-based
**Case finding/identification sources:**
- **Vital records:** birth certificates
- **Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs
- **Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, specialty outpatient clinics
- **Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetic facilities, maternal serum screening facilities
- **Other sources:** physician reports

**Case Ascertainment**
**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any birth certificate with a birth defect box checked, all stillborn infants, all elective abortions
**Conditions warranting a chart review beyond the newborn period:** any infant with a codable defect
**Coding:** CDC coding system based on BPA, Modified CDC and NBDFS 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, illnesses/conditions, prenatal diagnostic information, family history
**Father:** identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

**Database storage/management:** MS Access

**Data Analysis**
**Data analysis software:** SAS, MS Access, STATA
**Quality assurance:** validity checks, re-abstraction of cases, double-checking of assigned codes, clinical review, timeliness
**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, education/public awareness, prevention projects

**System Integration**
**System links:** final birth file
**System integration:** no

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

**Other**
**Web site:** www.ARbirthdefectsresearch.uams.edu

**Surveillance reports on file:** Annual reports

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California
California Birth Defects Monitoring Program (CBDMP)

Purpose: surveillance, research
Partner: Department of Health, university
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: Occupational and Environmental Disease Control, March of Dimes under contract with the State Department of Health Services, Environmental and Occupational Disease Control.
Population covered annually: 60,000
Statewide: No: The Program currently monitors a sampling of California births that are demographically similar to the state as a whole and whose birth defects rates and trends have been reflective of those throughout California. Furthermore, the Program has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.

Current legislation or rule: Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1996.
Legislation year enacted: 1982

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

Surveillance methods
Case ascertainment: Active case ascertainment, population-based.
Case finding/identification sources:
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs
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/clinical genetic facilities, maternal serum screening facilities

Case Ascertainment
Conditions warranting chart review in newborn period:

- any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases, Apgar 0-0

Conditions warranting a chart review beyond the newborn period:
- facial dysmorphism or abnormal facies, cardiovascular condition, all infant deaths (excluding prematurity), ocular 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, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage
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 investigations, time trends, 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: final birth file

Funding
Funding source: general state funds 34%, MCH funds 20%, CDC grant 20%, other federal funding 16%, DHS/UC Pass through 10%

Other
Web site: www.cbdmp.org
Surveillance reports on file: Current data on web site.
Procedure manual available: yes
Additional information on file: Publications Index, summaries of research findings, Collaboration Protocol, Confidentiality Procedures, Cluster Investigation Protocol, statutes, video.

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Colorado Responds To Children With Special Needs: Colorado (CRCSN)

**Purpose:** surveillance, service, prevention

**Partner:** Department of Health, university, environment, child program, advocacy

**Program status:** Currently collecting data

**Start year:** 1988

**Earliest year of available data:** 1989

**Organizational location:** Department of Health

**Population covered annually:** 68,420 (2002)

**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, genetic and selected metabolic conditions; selected developmental disabilities; very low birth weight (less than 1500 grams); others with medical and maternal 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, any gestational age, selected diagnoses made prenatally are ascertained)

**Age:** up to the 3rd birthday (up to the 7th birthday for fetal alcohol syndrome)

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

### Surveillance methods

**Case ascertainment:** Passive, population-based, multiple sources; active for selected data sources, and for special projects like fetal alcohol syndrome

**Case finding/identification sources:**
- Vital records: birth certificates, death certificates, fetal death certificates
- Other state based registries: newborn hearing screening program, newborn biochemical screening program
- Delivery hospitals: disease index or discharge index, postmortem/pathology logs, selected postmortem pathology sites
- Pediatric & tertiary care hospitals: disease index or discharge index, postmortem/pathology logs, specialty outpatient clinics, selected postmortem pathology sites
- Third party payers: Medicaid databases
- Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic 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.), 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

**Database storage/management:** MS Access

**Data Analysis software:** SAS, ArcView (GIS software), Maptitude

**Quality assurance:** validity checks, comparison/verification between multiple data sources, timeliness, data audits performed for problematic conditions; clinical review performed when necessary

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, 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:** final birth file, Newborn Hearing Screening and Newborn Genetic Screening

### Funding

**Funding source:** general state funds 15%, MCH funds 15%, CDC grant 60%, other federal funding 10%

### Other

**Web site:** http://www.cdphe.state.co.us/dc/crcsn/
crcsnhome.asp

**Procedure manual available:** yes

**Additional information on file:** CRCSN Reference Guide; CRCSN Community Notification and Referral Program Site Manual; Fact sheets (available on web site)

### Contact(s)

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Purpose: surveillance, service, prevention, Reporting for MCH Block Grant
Partner: hospital, child program, advocacy
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: to be determined
Organizational location: Department of Public Health (Maternal and Child Health)
Population covered annually: 45,000
Statewide: yes
Current legislation or rule: Sec. 19a-56a. (Formerly Sec. 10a-132b). Birth defects surveillance program.; Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children.

Case Definition
Outcomes covered: All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71
Pregnancy outcome: live births (all gestational ages and birth weights, PDA GE to 2500 gms 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, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, inpatient hospitalizations, ambulatory surgery and emergency room visits
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical 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: Yes
Other sources: physician reports, mandatory reporting by health care providers and facilities; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, cases from birth admissions where the reporting form is the sole source of case ascertainment; cases of multiple anomalies without a specified syndrome; cases where diagnoses are qualified as ‘preliminary’ or ‘rule-out’; all cases of chromosomal anomalies lacking confirmation by karyotype, and a 10% random sample, stratified on birth hospital, of all obvious birth defects that were not reported from birth admission but documented from pediatric reports or in the CHIME database.
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.), gravidity/parity, 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
Database storage/management: MS Access, Oracle

Data Analysis
Data analysis software: SAS, MS Access
Quality assurance: validity checks, 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 investigations, time trends, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, provider education

System Integration
System links: final birth file

Funding
Funding source: MCH funds 100%

Other
Web site: none
Surveillance reports on file: none
Procedure manual available: yes
Additional information on file: none

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Delaware

Delaware Birth Defects Surveillance Project

Purpose: surveillance, prevention  
Partner: hospital, child program  
Program status: Currently collecting data  
Organizational location: Department of Health and Social Services, Division of Public Health, Community Health Care Access  
Population covered annually: 11,046  
Statewide: yes  
Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects  
Legislation year enacted: 1997  

Case Definition
Outcomes covered: Birth Defects Registry - All birth defects for passive surveillance, selected birth defects for active surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections  
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (greater than 20 weeks)  
Age: Birth to 5 years  
Residence: In-state and out-of-state birth to state resident, and in-state birth to state non-resident.

Surveillance methods
Case ascertainment: Active and passive surveillance, population-based, Hospital discharge records/data  
Case finding/identification sources: 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 biochemical screening program, cancer registry, AIDS/HIV registry  
Delivery hospitals: disease index or discharge index  
Pediatric & tertiary care hospitals: disease index or discharge index  

Case Ascertainment  
Coding: ICD-9-CM, six-digit modified BPA/ICD-9 codes

Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), infant complications  
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, 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
Database storage/management: electronic birth certificate

Data Analysis
Data use and analysis: baseline rates, time trends, time-space cluster analyses, observed vs expected analyses, needs assessment

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

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**District of Columbia**

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

**Purpose:** surveillance, research, service, prevention

**Partner:** Department of Health, university, hospital, child program, advocacy

**Program status:** Currently collecting data

**Start year:** 603

**Earliest year of available data:** 2003

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

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

**Statewide:** yes

**Case Definition**

**Outcomes covered:** major birth defects and genetic disorders.

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, >500gm)

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

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

**Surveillance methods**

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

**Case finding/identification sources:**

- **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 biochemical screening program
- **Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs
- **Pediatric & tertiary care hospitals:** 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 genetic facilities, maternal serum screening facilities
- **Other sources:** physician reports

**Conditions warranting chart review beyond the newborn period:**

- facial dysmorphism or abnormal facies,
- congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, ICD9-CM 740-741.9, 742.3, 743.1, 744-748.5, 749-749.25,750-751.6, 758-758.2, 760.71, 389, 243, 270.1, 270.3, 271.1, 282.2, 282.4-63, 282.69, 282.7

**Conditions warranting a chart review beyond the newborn period:**

- facial dysmorphism or abnormal facies,
- developmental delay, all infant deaths (excluding prematurity), auditory/hearing conditions, any infant with a codable defect

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

**Data Collected**

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

**Database storage/management:** Oracle

**Data Analysis**

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

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

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

**System links:** state registry, final birth file

**Funding**

**Funding source:** MCH funds 15%, CDC grant 80%

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Purpose: surveillance, research, service, prevention, Educate health care professionals
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator, federal and state agencies
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment), Florida Department of Health, Bureau of Community Environmental Health, University
Population covered annually: 205,580 in 2002
Statewide: yes
Current legislation or rule: Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added to the list in July 1999.

Case Definition
Outcomes covered: Major structural malformations and selected genetic disorders
Pregnancy outcome: live births, fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: until age 1
Residence: Florida

Surveillance methods
Case ascertainment: Population-based, passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs
Third party payers: Medicaid databases, health maintenance organizations (HMOs)
Other sources: physicians reports

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, CNS condition (ie seizure), GI condition (ie intestinal blockage), auditory/hearing conditions
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, 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
Database storage/management: MS Access, Excel

Data Analysis
Data analysis software: SPSS, SAS, MS Access, Excel
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, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, education/public awareness, prevention projects

System Integration
System links: state registry

Funding
Funding source: general state funds 70%, CDC grant 30%

Other
Web site: http://flbdr.hsc.usf.edu
Procedure manual available: yes
Additional information on file: Grants, progress reports, educational and health promotion materials, and video tapes

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Purpose: surveillance, research, service
Partner: university, hospital
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: 50746
Statewide: No: Births to mothers residing within one of five counties in the metropolitan Atlanta area of the state of Georgia
Current legislation or rule: State Laws Official Georgia Code Annotated (OCGA) 31-12-2

Case Definition
Outcomes covered: Major structural or genetic birth defects
Pregnancy outcome: live births (≥20 weeks), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (less than 20 weeks gestation, 20 weeks gestation and greater)
Age: Before 6 years of age
Residence: Births to mothers residing in one of five metropolitan Atlanta counties

Surveillance methods
Case ascertainment: Active case ascertainment; population-based; Combination of active and passive case ascertainment for cases ascertained only at perinatal offices.
Case finding/identification sources:
- Vital records: birth certificates, fetal death certificates
- Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/ pathology logs, Induction logs and miscarriage logs
- Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
- Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories

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
Database storage/management: Epi-Info, Mainframe

Data Analysis
Data analysis software: SPSS, SAS, MS Access
Quality assurance: validity checks, double-checking of assigned codes, 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 investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, service delivery, prevention projects

System Integration
System links: state registry, final birth file

Funding
Funding source: other federal funding 100%

Other
Web site: www.cdc.gov/ncbddd/bd
Surveillance reports on file: numerous reports and bibliography
Procedure manual available: yes
Additional information on file: rate tables by defect by year
Comments: For surveillance reports and other information regarding the MACDP, e-mail MACDP@cdc.gov.

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Georgia
Georgia Birth Defects Reporting And Information System (GBDRIS)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, advocacy
Program status: Currently collecting data
Start year: 2003
Earliest year of available data: 2003
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 133,000
Statewide: yes
Current legislation or rule: Birth defects are reportable under State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2 which mandate the reporting of notifiable diseases and newborn hearing screening, and Chapters 290-5-3-02 and 290-5-24 of the Rules of Department
Legislation year enacted: Updated in 2003

Case Definition
Outcomes covered: Major birth defects, genetic diseases, FAS and CP
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations
Age: Up to 6 years of age
Residence: In and out of state births to state residents

Surveillance methods
Case ascertainment: passive
Case finding/identification sources:
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 biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Third party payers: Medicaid databases
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie 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
Database storage/management: MS Access

Data Analysis
Data analysis software: SAS, MS Access
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, epidemiologic studies (using only program data), service delivery, grant proposals, education/public awareness

System Integration
System links: state registry, final birth file
System integration: Newborn Surveillance and Tracking System (NSTS) is under development. Will integrate multiple children health systems including birth defects, UNHS, NBS and Children 1st.

Funding
Funding source: general state funds 60%, other federal funding 40%

Other
Web site: http://health.state.ga.us/epi/mch/publications.shtml
Procedure manual available: yes

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Hawaii
Hawaii Birth Defects Program (HBDP)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, nursing, environment, child program, advocacy, legislator
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: DOH/Children With Special Health Needs Branch, Research Corporation of the University of Hawaii
Population covered annually: ~19,906 average over 16 years
Statewide: yes

Case Definition
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (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
Residence: All in-state Hawaii births (resident and non-resident)

Surveillance methods
Case ascertainment: Active case ascertainment, population-based.
Case finding/identification sources:
Vital records: Vital records are used to supplement information collected from other data sources but are not used to primarily identify potential cases. Vital records data are also used as denominators for determining birth defects rates per 10,000 births.
Other state based registries: The HBDP supplies aggregate, de-identified data to the entities listed; they do not supply data to the HBDP.
Delivery hospitals: disease index or discharge index, discharge summaries, postmortem/pathology logs. Note: Information from specific logs, laboratories, clinics, etc. are usually found in the medical record when doing chart review.
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries. Information from

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

Data Collection Methods and Storage
Database storage/management: MS Access

Data Analysis
Data analysis software: MS 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 investigations, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, education/public awareness, prevention projects, publication of articles in peer reviewed professional journals.

System Integration

System links: Although not initiated yet, the HBDP is in the planing stages of embarking on a GIS statistical mapping project.

Funding
Funding source: general state funds 63%, CDC grant 28%,
other federal funding 5%, private foundations 4%

Other
Web site: http://members.aol.com/entropynot/
hbdp.html
Procedure manual available: yes
Additional information on file: HBDP informational brochure; copies of legislation; original and revised abstraction forms; abstraction manual; annual reports; HBDP data; quality assurance reports (completeness, accuracy, timeliness); special study reports (6).

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Program status: No surveillance program

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Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

**Purpose:** surveillance, service, prevention

**Partner:** Department of Health, university, hospital, environment, advocacy, legislator

**Program status:** Currently collecting data

**Start year:** 1988

**Earliest year of available data:** 1989

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

**Population covered annually:** 184,000

**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, fetal alcohol

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

**Age:** End of newborn hospitalization

**Residence:** In-state births mandatory

**Surveillance methods**

**Case ascertainment:** Population based, passive ascertainment of newborn cases. Active ascertainment of major birth defects diagnosed up to 2 years of age began 7/01.

**Case finding/identification sources:**

- Vital records: birth certificates, fetal death certificates
- Delivery hospitals: disease index or discharge index, discharge summaries, Hospitals are mandated to identify newborn cases and report to IDPH.
- Pediatric & tertiary care hospitals: disease index or discharge index, Hospitals are mandated to report newborns discharged from any to the NICU or speciality units.

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, <1500 grams, all neonatal deaths

**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.)

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

**Data Collection Methods and Storage**

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

**Data Analysis**

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

**Quality assurance:** 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, 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 integration:** No

**Funding**

**Funding source:** general state funds 69%, CDC grant 31%

**Other**

- Web site: idph.state.il.us/about/epi/aporsrpt.htm
- Surveillance reports on file: See Web Site
- Comments: APORS is transition to more active case ascertainment and expand case age to 2 years.

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**Indiana**

**Indiana Birth Defects and Problems Registry (IBDPR)**

**Purpose:** surveillance, research, service

**Partner:** university, hospital, child programs, advocacy groups, legislators

**Program status:** Currently collecting data

**Start year:** 2002

**Earliest year of available data:** 2005 (for births occurring in 2003)

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

**Population covered annually:** 85,000

**Statewide:** yes

**Current legislation or rule:** IC 16-38-4-7

**Rule 410 IAC 21-3**

**Legislation year enacted:** 2001

**Case Definition**

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

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

**Age:** Less than 3 years of age; age up to 5 years for Fetal Alcohol Spectrum Disorder and Pervasive Developmental Disorder

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

**Surveillance methods**

**Case ascertainment:** Passive, population-based, hospital

**Case finding/identification sources:** Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates

**Other state based registries:** newborn hearing screening program, cancer registry, newborn screening lab data

**Delivery hospitals:** disease index or discharge index, chart audits of 45 targeted birth defects

**Pediatric & tertiary care hospitals:** discharge summaries, chart audits of 45 targeted birth defects

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

**Other sources:** physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** charts of 45 targeted medical 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.), family history

**Data Collection Methods and Storage**

**Database storage/management:** Oracle

**Data Analysis**

**Data analysis software:** SAS

**Quality assurance:** validity checks, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness, physician reports

**System Integration**

**System links:** state registry, final birth file

**System integration:** The database is linked with births, deaths, fetal deaths, and newborn screening data.

**Funding**

**Funding source:** general state funds 3%, MCH funds 25%, CDC grant 72%

**Other**

**Web site:** www.in.gov/isdh/programs/idbpr

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*Birth Defects Research (Part A) 70:609–676 (2004)*
**Iowa Birth Defects Registry (IBDR)**

**Purpose:** surveillance, research, service, prevention, Prevention Education Programs

**Partner:** Department of Health, university, hospital, environment, legislator

**Program status:** Currently collecting data

**Start year:** 1983

**Earliest year of available data:** 1983

**Organizational location:** University

**Population covered annually:** 37,831 avg 10 yr

**Surveillance methods**

**Case ascertainment:** Population-based (state-wide), active case ascertainment

**Case finding/identification sources:**
- **Vital records:** birth certificates, death certificates, fetal death certificates
- **Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, specialty outpatient clinics
- **Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, specialty outpatient clinics
- **Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
- **Other sources:** physician reports, Outpatient Surgery Facilities

**Data Analysis**

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

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

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, 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:** state registry, final birth file, environmental

**System integration:** No

**Funding**

**Funding source:** general state funds 10%, CDC grant 90%

Other

- **Web site:** http://www.public-health.uiowa.edu/birthdefects
- **Surveillance reports on file:** Iowa Birth Defects Registry Annual Report 2000, 2002
- **Procedure manual available:** yes

**Contact(s)**

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Kansas Birth Defects Reporting System

Purpose: Registry
Partner: Hospital
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 39,338 (Year 2002)
Statewide: Yes
Current legislation or rule: KSA 65-102
Legislation year enacted: 1979

Case Definition
Outcomes covered: The outcome data below are available from Office of Vital Statistics, but are not used as part of a birth defects surveillance system. Twenty-four anomalies are listed on the birth certificate and are reported, however, these are not linked to ICD 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
Age: Passive reporting on congenital malformation reports continues through the first year of life.
Residence: In and out of state births to Kansas residents and in-state births to out of state residents.

Surveillance methods
Case ascertainment: Passive, population-based, passive, hospital
Case finding/identification sources:
Vital records: Birth certificates
Pediatric & tertiary care hospitals: Congenital Malformations reporting form - sent by hospitals for infants up to one year of age.

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

Data Collection Methods and Storage
Database storage/management: Mainframe

Data Analysis
Data analysis software: SAS, Ad-hoc summary reports developed as needed from Crystal Reports.
Quality assurance: Office of Vital Statistics conducts verification on birth certificate data.
Data use and analysis: routine statistical monitoring, rates by demographic and other variables, monitoring outbreaks and cluster investigations, Ad-hoc upon request.

System Integration
System links: State registry
System integration: Our program has a link with vital statistics records.

Funding
Funding source: MCH funds 100%

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Kentucky

Kentucky Birth Surveillance Registry (KBSR)

**Purpose:** surveillance, service, prevention of birth defects

**Partner:** Department of Health, university, hospital, environment, child program, advocacy, legislator

**Program status:** Currently collecting data

**Start year:** 1996

**Earliest year of available data:** 1998

**Organizational location:** Department for Public Health, Division of Adult and Child Health Improvement, Maternal and Child Health 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), 20 weeks or 350 gms., elective terminations (20 weeks gestation and greater). Elective terminations prior to 20 weeks are identified in pilot active surveillance project at eight hospitals in Kentucky which represent 36% of births.

**Age:** up to fifth birthday

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

**Surveillance methods**

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

**Case finding/identification sources:** Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, Medical laboratory reporting is mandated, voluntary outpatient reporting

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

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

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

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

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

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

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

**Data Collected**

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

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

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

**Data Collection Methods and Storage**

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

**Data Analysis**

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

**Quality assurance:** 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 investigations, time trends, identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

**System links:** final birth file, KBSR will be incorporated into the early childhood data repository in Kentucky

**Funding**

**Funding source:** general state funds 25%, CDC grant 75%

**Other**

**Web site:** http://publichealth.state.ky.us/kbsr.htm

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

**Procedure manual available:** yes

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Purpose: surveillance, service
Partner: university, hospital, child program, advocacy
Program status: Program has not started collecting data yet
Start year: 2004
Earliest year of available data: 2005
Organizational location: Children’s Special Health Services
Population covered annually: 65,000 +
Statewide: yes
Current legislation or rule: R.S. 40:31.41 - 40:31.48, Act No. 194
Legislation year enacted: 2001

Case Definition
Outcomes covered: major structural, functional, or genetic birth defect
Age: up to third birthday
Residence: in- and out-of-state births to state residents (tentative criteria)

Surveillance methods
Case ascertainment: active
Case finding/identification sources:
Vital records: in progress
Other state based registries: in progress
Delivery hospitals: in progress
Pediatric & tertiary care hospitals: in progress
Third party payers: in progress

Case Ascertainment
Conditions warranting chart review in newborn period: in progress
Coding: in progress

Data Collection Methods and Storage
Database storage/management: MS Access, in progress

Data Analysis
Data analysis software: in progress
Quality assurance: in progress
Data use and analysis: in progress

System Integration
System links: in progress

Other
Web site: http://oph.dhh.state.la.us/childrensspecial/birthdefect/index.html

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Maine Birth Defects Program (MBDP)

**Purpose:** surveillance, service, prevention  
**Partner:** university, hospital, nursing, child program, advocacy  
**Program status:** Currently collecting data  
**Start year:** 1999  
**Earliest year of available data:** Reporting began May 1, 2003  
**Organizational location:** Department of Health and Human Services, Bureau of Health  
**Population covered annually:** 13,500  
**Statewide:** yes  
**Current legislation or rule:** 22 MRSA c. 1687  
**Legislation year enacted:** 1999  

**Case Definition**

**Outcomes covered:** Selected major birth defects: NTD, Clefts, Gastrochisis and Omphalocele, Trisomy 21 and Major heart defects,  
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), prenatally diagnosed at any gestation, elective terminations  
**Age:** Through age one  
**Residence:** All in-state births to Maine residents

**Surveillance methods**

**Case ascertainment:** Combination of active and passive case ascertainment, population-based  
**Case finding/identification sources:** 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 biochemical screening program  
Delivery hospitals: disease index or discharge index, specialty outpatient clinics  
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts, pediatric logs, specialty outpatient clinics  
Other specialty facilities: genetic counseling/clinical genetic facilities, maternal serum screening facilities  
Other sources: physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD-9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases

**Conditions warranting a chart review beyond the newborn period:** facial dysmorphism or abnormal facies, 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.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, 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**

**Database storage/management:** MS Access, Citrix

**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, observed vs expected analyses, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

**System links:** state registry, final birth file

**Funding**

**Funding source:** MCH funds 5%, genetic screening revenues 25%, CDC grant 70%

**Other**

**Web site:** pending

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

**Contact(s)**

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**Purpose:** surveillance, research, service  
**Partner:** Department of Health, university, hospital, environment, child program, advocacy, legislator  
**Program status:** Currently collecting data  
**Start year:** 1983  
**Earliest year of available data:** 1984  
**Organizational location:** Family Health Administration, Office for Genetics & Children with Special Health Care Needs  
**Population covered annually:** 68,000  
**Statewide:** yes  
**Current legislation or rule:** Health-General Article, Section 18-206; Annotated Code of Maryland  
**Legislation year enacted:** 1982  

**Case Definition**  
**Outcomes covered:** Selected Birth Defects - Anencephaly, Spina Bifida, Hydrocephaly, Cleft Lip, Cleft Palate, Esophageal Atresia/Stenosis, Rectal/Anal Atresia, Hypospadias, Reduction Deformity - Upper or Lower Limb, Congenital Hip Dislocation, and Down Syndrome  
**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater or \( \geq 500 \) grams weight; We do accept reports on fetal deaths <500 grams or <20 weeks if sent to us.), elective terminations (20 weeks gestation and greater or \( \geq 500 \) grams weight; We do accept reports on terminations <500 grams or <20 weeks if sent to us.)  
**Age:** Newborn  
**Residence:** All in-state births  

**Surveillance methods**  
**Case ascertainment:** Passive surveillance, multiple source, population based  
**Case finding/identification sources:** Vital records: birth certificates, fetal death certificates  
**Other state based registries:** programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, Sickle Cell Disease  
**Delivery hospitals:** obstetric logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, Sentinel Birth Defects hospital report form is our primary source.  
**Pediatric & tertiary care hospitals:** discharge summaries, ICU/NICU logs or charts, Sentinel Birth Defects hospital report form is our primary source.  
**Midwifery facilities:** Yes  
**Other specialty facilities:** genetic counseling/clinical genetic facilities, maternal serum screening facilities  

**Case Ascertainment**  
**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, All fetal death certificates  
**Coding:** ICD-9-CM  

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

**Data Collection Methods and Storage**  
**Database storage/management:** MS Access, Mainframe, Visual dBASE, SAS, ASCII files  
**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 investigations, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects  

**System Integration**  
**System links:** In the process of linkage with other state registries/databases  
**System integration:** No  
**Funding**  
**Funding source:** general state funds 100%  

**Other**  
**Web site:** http://fha.state.md.us/genetics (then select Birth Defects Reporting and Information System)  
**Surveillance reports on file:** Provisional surveillance reports 1984-1992; 1995-2000, 2001  
**Procedure manual available:** yes  
**Additional information on file:** Copies of publications, legislation, miscellaneous booklets and other information related to birth defects surveillance in Maryland.  

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Massachusetts Center For Birth Defects Research And Prevention, Birth Defect Monitoring Program, Massachusetts Department Of Public Health (MCBDRP)

**Purpose:** surveillance, research, service, prevention

**Partner:** university, hospital, environment, advocacy

**Program status:** Currently collecting data

**Start year:** 1997

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

**Organizational location:** Bureau of Family and Community Health

**Population covered annually:** 81,000

**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. The new law: 1) increases mandated reporting up to age three; 2) requires physicians to report to MDPH within 30 days of diagnosis; 3) sets out requirements for the use of this data; 4) requires MDPH to promulgate regulations governing the operation of the Birth Defects Monitoring Program.

**Legislation year enacted:** 1963

**Case Definition**

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

**Pregnancy outcome:** live births, reportable fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater or \( \geq 350 \text{ grams} \))

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

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

**Surveillance methods**

**Case ascertainment:** population based, state-wide, combination of active case ascertainment and administrative review

**Case finding/identification sources:**

- **Vital records:** birth certificates, death certificates, fetal death certificates
- **Delivery hospitals:** disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, postmortem/pathology logs
- **Pediatric & tertiary care hospitals:** disease index or discharge index, ICU/NICU logs or charts, postmortem/pathology logs

**Other sources:** physician reports

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, all stillborn infants

**Conditions warranting a chart review beyond the newborn period:** facial dysmorphism or abnormal facies, 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, family history

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

**Data Collection Methods and Storage**

**Database storage/management:** Microsoft Access

**Data Analysis**

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

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

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, Selected cases from surveillance are eligible for CDC’s National Birth Defects Prevention Study

**System Integration**

**System links:** final birth file, fetal death file, Massachusetts Pregnancy to Early Life Longitudinal (PELL) Linkage Project

**Funding**

**Funding source:** general state funds 10%, CDC grant 90%

**Other**

**Web site:** website in development

**Surveillance reports on file:** First surveillance report published in November 2001; available online at http://www.state.ma.us/dph/hsre/birthdefects/bdefects.htm or by calling contacts; MCBDRP Prevention and Resource Booklet at http://www.state.ma.us/dph/hsre/birthdefects/bdefects.htm

**Procedure manual available:** yes

**Comments:** Statewide coverage started October 1998

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Michigan

Michigan Birth Defects Registry (MBDR)

Purpose: surveillance, research, service, prevention, incidence and mortality statistics
Partner: Department of Health, university, hospital, environment, legislator
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics)
Population covered annually: 135,400
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)
Age: up to two years after delivery
Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

Surveillance methods
Case ascertainment: passive, population-based, combination
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death reporting, matched birth/death file, cytogenic laboratories, genetics clinics, hospital discharge data
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer 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
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: ICD-9-CM

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

Data Collection Methods and Storage
Database storage/management: FoxPro

Data Analysis
Data analysis software: SPSS, MS Access, Fox-pro
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, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, 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: final birth file
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: general state funds 50%, CDC grant 25%, other federal funding 12%, EHDI 12.5%

Other
Web site: http://www.michigan.gov/mdch/0,1607,7-132-2944_4670--00.html
Surveillance reports on file: birth defects incidence and mortality annual reports
Procedure manual available: yes

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**Purpose:** surveillance, research, service, prevention

**Partner:** Department of Health, university, hospital, early childhood prevention programs, advocacy, legislator

**Program status:** Currently collecting data

**Start year:** 2005

**Earliest year of available data:** 2005

**Organizational location:** Department of Health, Environmental Health

**Population covered annually:** 68,000

**Statewide:** yes

**Current legislation or rule:** MS 144.2215

**Legislation year enacted:** 2004

**Case Definition**

**Outcomes covered:** major “reported birth defects” as defined by CDC and ICD-9 codes.

**Pregnancy outcome:** live births, fetal deaths—stillbirths, spontaneous abortions, etc.

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

**Residence:** only will abstract in-state data

**Surveillance methods**

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

**Case finding/identification sources:**

- Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, infant death records
- Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
- Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics
- Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics
- Third party payers: Medicaid databases, HMOs

**Case Ascertainment**

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

**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

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

**Data Analysis**

**Data analysis software:** SAS

**Quality assurance:** validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, physician review as needed, additional quality control checks may be added after start-up

**Data use and analysis:** epidemiologic studies (using only program data), referral, grant proposals, education/public awareness, prevention projects; Note: full system implementation in 2005 and many of these listed above will be used.

**System Integration**

**System links:** final birth file

**Funding**

**Funding source:** general state funds 5%, CDC grant 90%, March of Dimes in-kind match to CDC grant 5%

**Other**

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

**Surveillance reports on file:** data summaries and services/prevention updates are available on website

**Comments:** System will use an opt-out format that will be monitored regularly to ensure that data trends remain valid.

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Purpose: surveillance
Partner: Department of Health, hospital
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, Mississippi State Department of Health
Population covered annually: 42,000
Statewide: yes
Current legislation or rule: Section 41-21-205 of the Mississippi Code
Legislation year enacted: 1997

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

Surveillance methods
Case ascertainment: combination of active and passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Other state based registries: newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
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 a chart review beyond the newborn period: CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: ICD-9-CM

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

Data Collection Methods and Storage
Database storage/management: MS Access

Data Analysis
Data analysis software: MS Access
Quality assurance: validity checks
Data use and analysis: routine statistical monitoring, education/public awareness

Funding
Funding source: MCH funds 10%, genetic screening revenues 90%

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**Missouri Birth Defects Registry**

**Purpose:** surveillance, research, service, prevention

**Partner:** Department of Health, university, hospital, environment, child program, advocacy, legislator

**Program status:** Currently collecting data

**Start year:** 1985

**Earliest year of available data:** 1980

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

**Population covered annually:** 75,000

**Statewide:** yes

**Case Definition**

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

**Pregnancy outcome:** live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, fetal death certificates are only source of data). 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, multi-source

**Case finding/identification sources:**
- **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 biochemical screening program
- **Delivery hospitals:** discharge summaries
- **Pediatric & tertiary care hospitals:** discharge summaries, specialty outpatient clinics
- **Other sources:** enrollment data, Missouri Dept. of Mental Health

**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**

**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 investigations, time trends, time-space cluster analyses, observed vs expected analyses, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

**System Integration**

**System links:** final birth file

**Funding**

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

**Other**

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

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

Purpose: surveillance, service, prevention
Partner: Department of Health, hospital, advocacy, private practice physicians
Program status: Currently collecting data
Start year: 1999
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 11,000
Statewide: yes
Current legislation or rule: none

Case Definition
Outcomes covered: Major structural birth defects, chromosomal anomalies
Pregnancy outcome: live births (>20 weeks gestation & 500 grams), fetal deaths—stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations
Age: Birth through age 3
Residence: in-state births and out of state births to MT residents

Surveillance methods
Case ascertainment: combination of active and passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index
Third party payers: Medicaid databases, SSDI referrals
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports, fetal pathology

Data Collection Methods and Storage
Database storage/management: Oracle

Data Analysis
Data analysis software: SAS, Cluster Seer 2
Quality assurance: double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, 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: state registry
System integration: Integrated with Children with Special Health Care Needs database

Funding
Funding source: CDC grant 100%

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Nebraska
Nebraska Birth Defects Registry

**Purpose:** surveillance, research; we are in the process of developing a program of referral to services and prevention programs.

**Partner:** DHHS, MCH, and hospital

**Program status:** Currently collecting data

**Start year:** 1973

**Earliest year of available data:** 1973

**Organizational location:** Nebraska Health and Human Services Regulation & Licensure Data Management Section

**Population covered annually:** Statewide, 24,000+ births annually

**Statewide:** yes

**Current legislation or rule:** Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare Codes §71-643, §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 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

**Case finding/identification sources:**

- **Vital records:** birth certificates, death certificates, fetal death certificates
- **Delivery hospitals:** disease index or discharge index, discharge summaries, ICU/NICU lists 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 genetic facilities
- **Other sources:** physician reports

**Case Ascertainment**

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

**Conditions warranting a chart review beyond the newborn period:** facial dysmorphism or abnormal facies, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie 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**

**Database storage/management:** Key-entry 3

**Data Analysis**

**Data analysis software:** SAS

**Quality assurance:** re-abstracting 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 investigations, 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

**Funding**

**Funding source:** MCH funds 100%

**Other**


**Procedure manual available:** Yes

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

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

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Nevada Birth Defects Registry

**Purpose:** surveillance, service, prevention

**Partner:** university

**Program status:** Currently collecting data

**Start year:** 2000

**Earliest year of available data:** 2000

**Organizational location:** Division of Health, Bureau of Family Health Services (MCH)

**Population covered annually:** 33,000

**Statewide:** No: Year 2000 data is for Las Vegas only. Year 2001 - Statewide data complete.

**Current legislation or rule:** NRS 442.300 - 442.330 - Birth Defects Registry Legislation *** Regulation /H11005 NAC 442

**Legislation year enacted:** 1999

### Case Definition

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

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

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

**Residence:** In-state births

### Surveillance methods

**Case ascertainment:** Combination of active and passive ascertainment initially. Currently - system is a “passive” system., active ascertainment to re-commence 7/1/04

**Case finding/identification sources:**

- **Vital records:** birth certificates, matched birth/death file, Hospital medical records - for year 2000
- **Other state based registries:** programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry
- **Delivery hospitals:** disease index or discharge index
- **Pediatric & tertiary care hospitals:** disease index or discharge index
- **Third party payers:** Medicaid databases
- **Other specialty facilities:** genetic counseling/clinical genetic facilities
- **Other sources:** physician reports

### Case Ascertainment

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

**Conditions warranting a chart review beyond the newborn period:** facial dysmorphism or abnormal facies, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, any infant with a codable defect

**Coding:** ICD-9-CM

### Data Collected

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

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

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

### Data Analysis

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

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

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, education/public awareness

### System Integration

**System links:** state registry

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

### Funding

**Funding source:** service fees 100%

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*Birth Defects Research (Part A) 70:609–676 (2004)*
New Hampshire Birth Conditions Program (NHBCP)

**Purpose:** surveillance, research, service, prevention

**Partner:** university, hospital, child program, advocacy, legislator

**Program status:** Currently collecting data

**Start year:** 2003

**Earliest year of available data:** 2003

**Organizational location:** Department of Health (Maternal and Child Health), Bureau of Vital Records: Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, University

**Population covered annually:** 13,560

**Statewide:** No: Currently collecting data at Dartmouth Hitchcock Medical Center, New Hampshire’s primary tertiary center for obstetrical and neonatal care. Work is underway to begin data collection in all birth hospitals.

**Current legislation or rule:** Currently working toward a legislative rules revision that would include birth defects.

**Case Definition**

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

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

**Age:** Fetuses >20 weeks gestation and newborns/infants up to 1 year of age.

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

**Surveillance methods**

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

**Case finding/identification sources:**
- Delivery hospitals: discharge summaries, Medical records abstraction of charts of selected ICD 9 Codes
- Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics, cytogenetics laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files
- Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, all stillborn infants, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases

**Conditions warranting a chart review beyond the newborn period:** facial dysmorphism or abnormal facies, cardiovascular condition, any infant with a codable defect

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

**Data Collected**

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

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

**Data Collection Methods and Storage**

**Database storage/management:** Oracle, The AURIS web-based reporting system, currently utilized by NH newborn hearing screening program, is being expanded to meet the birth defects tracking requirements.

**Data Analysis**

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

**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:** Data collection began at one hospital in 2003 and so no data use or analysis occurred in the past 12 months.

**Funding**

**Funding source:** CDC grant 100%

**Other**

**Web site:** Not as of 1/2004

**Surveillance reports on file:** Not at this time

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Purpose: surveillance, research, service, prevention

Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator

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: 114,500

Statewide: yes


Legislation year enacted: 1983

Case Definition

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

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

Age: mandated reporting of birth defects diagnosed <= age 1, voluntary reporting of birth defects diagnosed > age 1 and all children diagnosed with Special Needs conditions who are <= 21 yrs. of age

Residence: in/out NJ births to NJ res; Because of link with SCHS Case Management system, also enroll anyone becoming NJ res.

Surveillance methods

Case ascertainment: Passive, population-based reporting system with annual quality assurance visits by BDR staff to birthing hospitals, birthing centers and, pediatric care facilities. Medical chart review is conducted on all children registered with any of the defects eligible for participation in the NBDBP.

Case finding/identification sources:

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 biochemical screening program, AIDS/HIV registry

Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catheterization laboratories, specialty outpatient clinics, quality Assurance visit consisting of chart review of 3 month period

Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics, quality Assurance visit consisting of chart review of 3 m period

Midwifery facilities: Yes

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

Other sources: M.D. reports, Special Child Health Services city based Case Management units, parents, schools, medical examiners

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, all neonatal deaths, all death certificates for < 1 year of age

Conditions warranting a chart review beyond the newborn period: GI condition (ie intestinal 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, etc.)

Father: identification information (name, address, etc.)

Data Collection Methods and Storage

Data analysis software: SAS, MS 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, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time-space cluster analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: state registry, final birth file

System integration: hearing screening registry provides direct feed into SCHS Registry.

Funding

Funding source: MCH funds 85%, genetic screening revenues 5%, CDC grant 10%

Other

Web site: http://www.state.nj.us/health/fhs/scregis.htm

Surveillance reports on file: Special Child Health Services Registry 1983-1989; Special Child Health Services Registry 1985-1991; Special Child Health Services Registry
Registry 1985-1994; Special Child Health Services
Procedure manual available: yes
Additional information on file: Information sheet, case
record form, copy of legislation, quality assurance audit
information

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New Mexico

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

**Purpose:** surveillance, research, service, prevention

**Partner:** university, hospital, child program, legislature

**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:** 27,000

**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

**Pregnancy outcome:** live births (all gestational ages and birth weights); fetal deaths and terminations included in NTD counts

**Age:** birth through age 14 years

**Residence:** In state births to New Mexico residents (2001 definition: previous years included out-of-state births to NM residents)

**Surveillance methods**

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

**Case finding/identification sources:**
- Vital records: birth certificates
- Other state based registries: Children and Youth with Special Health Care Needs, Children’s Chronic Conditions Registry
- Delivery hospitals: medical record chart review
- Pediatric & tertiary care hospitals: specialty outpatient clinics, including neurosurgery and plastic surgery
- Midwifery facilities: Yes
- Third party payers: Medicaid databases, health maintenance organizations (HMOs), Indian Health Services, Children’s Medical Services (CMS)
- Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetic facilities
- Other sources: physician reports

**Data Collection Methods and Storage**

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759 and 760.71, any birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases, any chart with a list of other ICD9-CM codes selected by CMS

**Conditions warranting a chart review beyond the newborn period:** same as above

**Coding:** ICD-9-CM

**Data Collected**

**Infant/fetus:** 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.)

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

**Data Analysis**

**Data analysis software:** SAS

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

**Data use and analysis:** routine statistical monitoring, baseline rates, rates by demographic and other variables, grant proposals, education/public awareness, prevention projects; Mar03-Mar04 NM BDPASS did not have epidemiology staff; prevention teams developed teaching modules.

**System Integration**

**System links:** state registry, final birth file

**System integration:** Currently, BDPASS is integrated with the Children’s Chronic Conditions Register.

**Funding**

**Funding source:** general state funds 16%, MCH funds 25%, CDC grant 59%

**Other**

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

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

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New York

New York State Congenital Malformations Registry (CMR)

**Purpose:** surveillance, research, service, prevention

**Partner:** university, hospital, child program, 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:** 260,000

**Statewide:** yes

**Current legislation or rule:** Public Health Law Art. 2, Title II, Sect 225(5)(t) and Art. 2 Title I, sect 206(1)(j): Codes, Rules and Regulations, Chap 1, State Sanitary Code, part 22.3

**Legislation year enacted:** 1982

**Case Definition**

**Outcomes covered:** Major malformations, detailed list 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

**Case finding/identification sources:**

- **Delivery hospitals:** disease index or discharge index, ICU/NICU logs or charts
- **Pediatric & tertiary care hospitals:** disease index or discharge index, ICU/NICU logs or charts
- **Other sources:** physician reports, hospital discharge 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, 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**

**Database storage/management:** MS Access, FoxPro, Sybase

**Data Analysis**

**Data analysis software:** SAS, MS Access, Visual FoxPro

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

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

**System Integration**

**System links:** state registry, final birth file, Statewide Hospital Discharge Database (SPARCS)

**Funding**

**Funding source:** general state funds 12%, MCH funds 27%, CDC grant 37%, other federal funding 24%

**Other**

**Web site:** [http://www.health.state.ny.us/nysdoh/cmr/cmrglobal.htm](http://www.health.state.ny.us/nysdoh/cmr/cmrglobal.htm)

**Surveillance reports on file:** Reports for 1983-1997.

**Procedure manual available:** yes

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**Purpose:** surveillance, research, service, prevention, education, advocacy

**Partner:** Department of Health, university, hospital, child program, advocacy, legislator

**Program status:** Currently collecting data

**Start year:** 1987

**Earliest year of available data:** 1989

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

**Population covered annually:** 118,000

**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

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

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

**Surveillance methods**

**Case ascertainment:** Population-based, active ascertainment

**Case finding/identification sources:**

- **Vital records:** birth certificates, death certificates, matched birth/death file, fetal death certificates
- **Other state based registries:** programs for children with special needs
- **Delivery hospitals:** disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery)
- **Pediatric & tertiary care hospitals:** disease index or discharge index, discharge summaries
- **Third party payers:** Medicaid databases
- **Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetic facilities

**Case Ascertainment**

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

**Conditions warranting a 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.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications

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

**Data Collection Methods and Storage**

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

**Data Analysis**

**Data analysis software:** SAS, MS 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, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, 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, advocacy

**System Integration**

**System links:** state registry, final birth file, Vital Statistics, Medicaid Paid Claims, MCH Program Data

**Funding**

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

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*Birth Defects Research (Part A) 70:609–676 (2004)*
North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

**Purpose:** surveillance

**Partner:** university, March of Dimes

**Program status:** Currently collecting data

**Start year:** 2002

**Earliest year of available data:** 1994

**Organizational location:** Department of Health (Vital Statistics), Department of Health (Maternal and Child Health), ND Department of Human Services (Children’s Special Health Services)

**Population covered annually:** 7676

**Statewide:** yes

**Current legislation or rule:** North Dakota Centry code 50-10

**Legislation year enacted:** N/A

**Case Definition**

**Outcomes covered:** Selected birth defects (NTDs, congenital heart defects, cleft lip and palate, chromosomal anomalies) and other risk factors that may lead to health and developmental problems.

**Pregnancy outcome:** live births (all gestational ages and birth weights, numbers collected and reported via Vital Records), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, numbers collected and reported via Vital Records), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)

**Age:** Newborn period

**Residence:** In-state resident births and out of state birth receiving services in ND

**Surveillance methods**

**Case ascertainment:** passive

**Case finding/identification sources:**

- 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 biochemical screening program, cancer registry, AIDS/HIV registry, FAS
- Delivery hospitals: Birth certificate completion
- Pediatric & tertiary care hospitals: specialty outpatient clinics
- Third party payers: Medicaid databases, health maintenance organizations (HMOs), private insurers
- Other specialty facilities: genetic counseling/clinical genetic facilities
- Other sources: physician reports

**Case Ascertainment**

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

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

**Data Collected**

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

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

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

**Data Collection Methods and Storage**

**Database storage/management:** MS Access, Mainframe, Db2, SPSS, Excel

**Data Analysis**

**Data analysis software:** SPSS

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

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

**Funding**

**Funding source:** SSDI Grant

**Other**

**Web site:** www.health.state.nd.us/ndhd/admin/vital/

**Procedure manual available:** yes

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Ohio Connections For Children With Special Needs (OCCSN)

**Purpose:** surveillance, research, service, prevention

**Partner:** Department of Health, university, hospital, child program, advocacy, legislator

**Program status:** Program has not started collecting data yet

**Start year:** 2004

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

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

**Population covered annually:** System in development

**Statewide:** No: System in development

**Current legislation or rule:** Ohio House Bill 534 signed into law in July, 2000. “The Director of Health shall establish and, if funds for this purpose are available, implement a statewide birth defects information system for the collection of information concerning congenital anomaly

**Legislation year enacted:** 2000

**Case Definition**

**Outcomes covered:** System in development

**Surveillance methods**

**Case ascertainment:** System in development

**Funding**

**Funding source:** CDC grant 100%

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Oklahoma
Oklahoma Birth Defects Registry (OBDR)

Purpose: surveillance, prevention
Partner: hospital, Cytogenetics & Medical Genetics
Program status: Currently collecting data
Start year: 1992; statewide 1994
Earliest year of available data: 1992
Organizational location: Department of Health (Family Health Services)
Population covered annually: 50,000
Statewide: yes
Current legislation or rule: 63 O.S. Section 1-550.2
Legislation year enacted: 1992

Case Definition
Outcomes covered: modified 6-digit ICD-9-CM codes for birth defects and genetic diseases
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: population based, active case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, surgery logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, pediatric logs, surgery logs, specialty outpatient clinics
Third party payers: Indian health services, Military hospitals delivering babies
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA

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

Funding
Funding source: general state funds 10%, MCH funds 50%, CDC grant 40%

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Program status: No surveillance program

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Pennsylvania

Pennsylvania Follow-Up, Outreach, Referral And Education For Families (PA FORE FAMILIES)

Purpose: surveillance, service
Partner: university, hospital, nursing, advocacy
Program status: Program has not started collecting data yet
Start year: 2003
Earliest year of available data: 2003, statewide matched data file being collected
Organizational location: Department of Health (Maternal and Child Health)
Statewide: yes
Current legislation or rule: Not applicable

Case Definition
Outcomes covered: 740-759.9 and 760.71 ICD-9
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: birth to 24 months of age
Residence: in-state births to state residents

Surveillance methods
Case ascertainment: population-based, passive
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, Hospital discharge data collected by the Pennsylvania Health Care Cost Containment Council—(PHC4—a state agency).
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, Those checked above will eventually be linked.
Delivery hospitals: discharge summaries, PHC4 data is based on hospital discharge summaries
Pediatric & tertiary care hospitals: discharge summaries, PHC4 data is based on hospital discharge summaries
Other specialty facilities: genetic counseling/clinical genetic facilities

Case Ascertainment

Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, 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
Database storage/management: MS Access, Mainframe

Data Analysis
Data analysis software: SAS, MS Access
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, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

Funding
Funding source: MCH funds 100%

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

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Puerto Rico
Puerto Rico Folic Acid Campaign And Birth Defects Surveillance System (PRFAC/BDSS)

**Purpose:** surveillance, research, service, prevention

**Partner:** Department of Health, university, nursing, child program, advocacy

**Program status:** Currently collecting data

**Start year:** 1995

**Earliest year of available data:** 1995

**Organizational location:** Division of Children with Special Health Care Needs

**Population covered annually:** 56,000

**Statewide:** yes

**Current legislation or rule:** No

**Case Definition**

**Outcomes covered:** Neural Tube Defects (Anencephaly, Encephalocele, Myelomeningocele and Meningocele), Cleft Lip and/or Cleft Palate, Gastrochisis, Club Foot, Limb reduction defects, Down Syndrome, Omphalocele, Ambiguous Genitalia, Trisomy 13, Trisomy 18, Conjoint Twins, Albinism and Congenital Heart Defects.

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

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

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

**Surveillance methods**

**Case ascertainment:** Active case ascertainment and population-based

**Case finding/identification sources:**

- **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, cancer registry, AIDS/HIV registry
- **Delivery hospitals:** disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, specialty outpatient clinics
- **Pediatric & tertiary care hospitals:** ICU/NICU logs or charts, pediatric logs, surgery logs, laboratory logs
- **Third party payers:** Medicaid databases, health maintenance organizations (HMOs)
- **Other specialty facilities:** prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetic facilities
- **Other sources:** physician reports

**Data Collection**

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

**Data Collection Methods and Storage**

**Database storage/management:** MS Access

**Data Analysis**

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

**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, baseline rates, rates by demographic and other variables, time trends, needs assessment, referral, grant proposals, education/public awareness, prevention projects

**Funding**

**Funding source:** general state funds 3%, MCH funds 38%, CDC grant 52%, other federal funding 10%, CDC Visiting Fellowship Program

**Other**

**Web site:** http://www.salud.gov.pr/AF/AFindex.htm

**Surveillance reports on file:** Description of Registry Development, Case Report Form, manual for case report form,

**Procedure manual available:** yes

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Rhode Island Birth Defects Surveillance Program

Purpose: surveillance, service, prevention
Partner: hospital, child program, advocacy
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 1997
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 12,500
Statewide: yes
Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws requires the development of a birth defects surveillance, reporting and information system that will: a) describe the occurrence of birth defects in children up to age five; b) detect trends of morbidity and mortality; and c) identify newborns and children with birth defects to intervene on a timely basis for treatment.
Legislation year enacted: 2003

Case Definition
Outcomes covered: major birth defects and genetic diseases
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: Currently at birth
Residence: RI residents

Surveillance methods
Case ascertainment: Currently, passive case ascertainment
Case finding/identification sources:
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 biochemical screening program, RI has an integrated database called KIDS NET, which links data from 9 programs including: Universal Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting and Vital Records
Delivery hospitals: discharge summaries, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: specialty outpatient clinics
Other specialty facilities: genetic counseling/clinical genetic facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Chart reviews are conducted for every newborn identified with a birth 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 diagnosis 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, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Database storage/management: MS Access, Oracle
Data analysis software: SAS, MS Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, needs assessment, service delivery, referral, grant proposals, education/public awareness

System Integration
System links: state registry, KIDSNET (Universal 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: MCH funds 60%, CDC grant 40%, Note: CDC Grant = no cost extension $ from birth defects surveillance grant

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South Carolina
South Carolina Birth Defects Surveillance And Prevention Program

Purpose: surveillance, research, service
Partner: Department of Health, university, hospital
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1993
Organizational location: Greenwood Genetic Center
Population covered annually: 55,873
Statewide: yes

Case Definition
Outcomes covered: Neural Tube Defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)
Age: Up to one year after delivery
Residence: In and out of state births to residents of South Carolina

Surveillance methods
Case ascertainment: Combination of active and passive case ascertainment
Case finding/identification sources:
- 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, specialty outpatient clinics, ICD-9 Codes
- Pediatric & tertiary care hospitals: discharge summaries, specialty outpatient clinics
- Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
- Other sources: physician reports

Case Ascertainment
Conditions warranting chart review in newborn period:
- any chart with a ICD9-CM code 655.00-755.9
- any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, limb reduction defects, all prenatal diagnosed or suspected cases
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, 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
Database storage/management: MS Access

Data Analysis
Data analysis software: SAS, MS 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, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, education/public awareness, prevention projects

Funding
Funding source: general state funds 35%, CDC grant 20%, other federal funding 35%, March of Dimes 10%

Other
Web site: http://www.ggc.org
Procedure manual available: yes

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Program status: No surveillance program

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Tennessee

Tennessee Birth Defects Registry (TBDR)

**Purpose:** surveillance, research, service, prevention

**Partner:** hospital, child program, advocacy, legislator

**Program status:** Currently collecting data

**Start year:** 2000

**Earliest year of available data:** 2000

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

**Population covered annually:** 80,000

**Statewide:** yes

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

**Legislation year enacted:** 2000

**Case Definition**

**Outcomes covered:** Major Birth Defects

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

**Residence:** in and out state births to state resident

**Surveillance methods**

**Case ascertainment:** hospital records matched to vital records, population based

**Case finding/identification sources:**

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

**Case Ascertainment**

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

**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

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

**Data Collection Methods and Storage**

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

**Data Analysis**

**Data analysis software:** SAS, MS 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 investigations, observed vs expected analyses, needs assessment, service delivery, grant proposals, education/public awareness, prevention projects

**Funding**

**Funding source:** general state funds 94%, private foundations 6%

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Texas Birth Defects Monitoring Division (TBDMD)

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. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations
Age: Up to one year after delivery - FAS up to 6 years
Residence: In-state births to state residents.

Surveillance methods
Case ascertainment: Active, population-based

Data Collection Methods and Storage
Database storage/management: SQL Server

Data Analysis
Data analysis software: SPSS, SAS, MS 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: baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, referral, grant proposals, education/public awareness

System Integration
System links: Link registry to vital records for demographic data

Funding
Funding source: general state funds 51%, MCH funds 33%, Preventive Health block grant 16%. Note: does not include CDC-funded Texas Birth Defects Research Center funds

Additional information on file: copy of legislation; Texas Birth Defects Monitoring Division fact sheet; Fetal Alcohol Syndrome brochure (English and Spanish); Pregnancy Outcome Patterns for Various Defects; Impact of Including Induced Pregnancy Terminations Before 20 Weeks Gestation on Birth Defect Rates; Birth Defects Glossary; Recent Trends in Neural Tube Defects in Texas.

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

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Residence: Maternal residence in Utah at time of delivery

Pediatric & tertiary care hospitals: respective hospitals clinics, Champions report live births delivered at their charts, postmortem/pathology logs, specialty outpatient delivery), newborn nursery logs, ICU/NICU logs or discharge summaries, obstetrics logs (i.e., labor & Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), newborn nursery logs, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics, Champions report live births delivered at their respective hospitals

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

Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling, clinical genetic facilities, physician reports, lay midwives

Case Ascertainment
Conditions warranting chart review in newborn period: any fetus or infant with a ICD9-CM code 740-759 suggesting an eligible birth defect, any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants with suggested minor or major malformations), 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 a chart review beyond the newborn period: any infant with a codable defect as listed above.

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

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, 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
Database storage/management: Microsoft Access 2000

Data Analysis
Data analysis software: Epi2000, SAS, Microsoft Access, Statview

Quality assurance: logical checks, duplicate check in tracking and surveillance module, case record form checked for completeness, comparison/verification between multiple data sources, clinical review, timeliness through system, manual review of subset of surveillance module case data compared to case record form.

Data use and analysis: routine statistical monitoring, 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, and Utah Center for Birth Defects Research and Prevention

Funding
Funding source: MCH funds 50%, CDC grant 50%

Other
Web site: health.utah.gov/birthdefect


Procedure manual available: yes

Additional information on file: Data Sharing Protocol

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Vermont
Birth Information Network

Purpose: surveillance, service, prevention
Partner: Department of Health, university, hospital, advocacy
Program status: Program has not started collecting data yet
Organizational location: Department of Health (Statistics)
Population covered annually: 6500
Statewide: yes
Current legislation or rule: Act 32
Legislation year enacted: 2003

Case Definition
Outcomes covered: major birth defects and genetic diseases, very low birthweight (less than 1500 grams)
Age: up to one year after delivery
Residence: in and out of state births to state residents

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Virginia Congenital Anomalies Reporting And Education System (VACARES)

**Purpose:** surveillance

**Partner:** university, hospital, child program

**Program status:** Currently collecting data

**Start year:** 1985

**Earliest year of available data:** 1987

**Organizational location:** Pediatric Screenings and Genetic Services, Div. of Child and Adolescent Health

**Population covered annually:** Calendar Year 2002-98,864

**Statewide:** yes

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

**Legislation year enacted:** 1985, amended 1986, 1988

**Case Definition**

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

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

**Age:** below 24 months of age

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

**Surveillance methods**

**Case ascertainment:** Passive, population-based

**Case finding/identification sources:**
- Vital records: birth certificates, death certificates, matched birth/death file
- Other state based registries: newborn hearing screening program, newborn biochemical screening program
- Delivery hospitals: discharge summaries, Medical records abstracts codes from charts
- Pediatric & tertiary care hospitals: discharge summaries, Medical Records abstracts codes from charts

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all neonatal deaths, Chart review is done by the coders in Health Information Management

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

**Coding:** ICD-9-CM, ICD-10 for death certificate

**Data Collected**

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

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

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

**Data Collection Methods and Storage**

**Database storage/management:** Oracle

**Data Analysis**

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

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

**Data use and analysis:** routine statistical monitoring, 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:** state registry

**System integration:** The current system, Virginia Infant Screening and Infant Tracking System (VISITS), is an integrated database that tracks screening results for VaCARES and the following programs and services: Virginia Newborn Hearing Screening Program, Virginia Newborn Screening Services (future) and At Risk Referral Service (pilot).

**Funding**

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

**Other**

**Web site:** www.vahealth.org/genetics

**Surveillance reports on file:** A 10-Year report (1989-1998) was published in 2002.

**Procedure manual available:** yes

**Additional information on file:** Oracle database

**Comments:** As of March 2004, most hospitals are entering data directly into database from the hospital contacts via Virginia Infant Screening and Infant Tracking Program (VISITS), a web-based tracking and data management system.

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Washington State Birth Defects Surveillance System (BDSS)

**Purpose:** surveillance, service

**Partner:** university, hospital

**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:** 80,000

**Statewide:** yes

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

**Legislation year enacted:** 2000

**Case Definition**

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

**Residence:** resident births; children born or diagnosed in-state

**Surveillance methods**

**Case ascertainment:** passive

**Case finding/identification sources:**

- **Vital records:** birth certificates, death certificates, fetal death certificates, elective termination certificates
- **Delivery hospitals:** disease index or discharge index
- **Pediatric & tertiary care hospitals:** disease index or discharge index

**Other sources:** Currently developing data sharing with University-based FAS/FAE clinic.

**Case Ascertainment**

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

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

**Data Collection Methods and Storage**

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

**Data Analysis**

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

**Quality assurance:** validity checks, re-abstraction of cases, comparison/verification between multiple data sources, data/hospital audits, timeliness

**Data use and analysis:** routine statistical monitoring, baseline rates, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, service delivery, grant proposals, education/public awareness, prevention projects

**Funding**

**Funding source:** general state funds 40%, MCH funds 60%

**Other**

**Surveillance reports on file:** Brighter Futures report available for 1987-1988 data; Available by June 2004


**Procedure manual available:** yes

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West Virginia
West Virginia Congenital Abnormalities Registry, Education And Surveillance System (WVCARESS)

Purpose: surveillance, service, prevention
Partner: university, hospital, child program, advocacy
Program status: currently collecting data
Start year: 1989
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 21,000
Statewide: yes
Current legislation or rule: State Statute Section 16-5-12a
Legislation year enacted: 1991
State Statute Section 16-40-1
Legislation updated: 2002

Case Definition
Outcomes covered: Congenital anomalies of ICD-9 codes 740-759, 760, 764, 765, 766
Pregnancy outcome: (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), (all gestational ages and birth weights), elective terminations (20 weeks gestation and greater)
Age: 0-6
Residence: In and out of state births to state residents

Surveillance methods
Case ascertainment: active, population-based
Case finding/identification sources:
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 biochemical screening program, cancer registry, AIDS/HIV registry, SIDS
Delivery hospitals: Hospital personnel complete Birth Defect Reporting forms, reports also sent from Genetics Program.
Pediatric & tertiary care hospitals: Hospital personnel complete Birth Defect Reporting forms, reports also sent from Genetics Program.
Other specialty facilities: genetic counseling/clinical genetic 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 selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, less than 2500 grams or less than 37 weeks, all stillborn infants, all neonatal deaths, all elective abortions, all infants with low Apgar scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 6, ocular conditions, auditory/hearing conditions, any infant with a codable 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.), 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, 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
Database storage/management: MS Access, Mainframe, Visual D-Base
Data Analysis
Data analysis software: custom
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, time trends, observed vs expected analyses, epidemiologic studies (using only program data), needs assessment, referral, grant proposals, education/public awareness, prevention projects

System Integration
System links: Plans are underway to link several programs housed in the office of Maternal, Child and Family Health

Funding
Funding source: CDC grant 100%

Other
Web site: www.wvdhhr.org
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Wisconsin
Wisconsin Birth Defects Registry (WBDR)

Purpose: surveillance, research, service
Partner: Department of Health, university, hospital, child program, advocacy
Program status: Currently collecting data
Start year: 2004
Earliest year of available data: 2004
Organizational location: Department of Health and Family Services (CSHCN)
Population covered annually: ~67,000
Statewide: yes
Current legislation or rule: Statute 253.12 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 (all gestational ages and birth weights), 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, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: newborn hearing screening program, newborn biochemical screening program
Pediatric & tertiary care hospitals: Case reports from pediatric specialty clinics
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports, hospital discharge data through 2 yrs of age

Case Ascertainment
Coding: ICD-9-CM

Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), 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
Database storage/management: Oracle

Data Analysis
Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, 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, Items checked above are the ones likely to be used.

System Integration
System links: Would like to link to birth records, the Newborn Screening Program and the Newborn Hearing Screening Program in the future.

Funding
Funding source: general state funds 35%, MCH funds 23%, CDC grant 42%

Other
Web site: http://www.dhfs.state.wi.us/dph_bfch/cshcn

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Wyoming

Program status: Interested in developing a surveillance program

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Purpose: surveillance, research  
Partner: university, hospital, CDC  
Program status: Currently collecting data  
Start year: 1998  
Earliest year of available data: 1998  
Organizational location: Department of Defense Center for Deployment Health Research, Naval Health Research Center, San Diego, CA  
Population covered annually: approx 90,000 per year  
Statewide: No: Nation/World; Department of Defense (DoD) beneficiaries, includes all uniformed services personnel who are eligible for health care benefits  
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum  
Legislation year enacted: 1998

Case Definition
Outcomes covered: CDC-recommended major birth defects  
Pregnancy outcome: live births (all gestational ages and birth weights)  
Age: Birth to 1 year  
Residence: Worldwide; any birth to a US military beneficiary

Surveillance methods
Case ascertainment: Electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries, combination, population-based  
Case finding/identification sources:  
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 is performed by active case ascertainment and chart review of a random sample of births from both military and civilian facilities.

Case Ascertnment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a CDC/BPA code, Validation of standardized electronic data is performed by active case ascertainment and chart review of a random sample of births from both military and civilian facilities.

Conditions warranting a 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.), illnesses/conditions, prenatal diagnostic information, pregnancy/delivery complications  
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions

Data Collection Methods and Storage
Database storage/management: MS Access, SAS  
Data Analysis
Data analysis software: SAS  
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review  
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, prevention projects

System Integration
System links: DoD databases  
System integration: DoD databases

Funding
Funding source: other federal funding 100%

Other
Surveillance reports on file: DoD/HA policy memorandum; Technical Reports

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