Birth Defects Research (Part A) 82:906–961 (2008)

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

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Acknowledgement: State birth defect program directors provided the information for this directory. Their names can be found under the "contact" section of each state profile.

Suggested reference: National Birth Defects Prevention Network (NBDPN), 2008, State Birth Defects Surveillance Program Directory. Birth Defects Research Part A 82:906–961.

Alabama

Alabama Birth Defects Surveillance and Prevention Program (ABDSPP)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: universities, hospitals, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 1995
Earliest year of available data: 1998
Organizational location: University
Population covered annually: 8,000/year for 1998-2000 data; 18,009 for 2001 data; 19,261 for 2002 data; 19,322 for 2003 data; 19019 for 2004 data and 19739 for 2005 data.
Statewide: No; 1998-2000 data: Mobile and Baldwin counties; 2001 data: Autauga, Baldwin, Bullock, Clarke, Coffee, Crenshaw, Dale, Elmore, Escambia, Geneva, Henry, Houston, Lowndes, Macon, Mobile, Monroe, Montgomery, and Washington counties; 2002 - 2005 data: add Barbour, Butler, Pike, and Russell counties.
Current legislation or rule: none

Case Definition

Outcomes covered: major birth defects and genetic disorders
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)
Age: up to one year after delivery
Residence: 1998-2000 data: Mobile and Baldwin counties; 2001 data: Autauga, Baldwin, Bullock, Clarke, Coffee, Crenshaw, Dale, Elmore, Escambia, Geneva, Henry, Houston, Lowndes, Macon, Mobile, Monroe, Montgomery, and Washington counties; 2002 - 2005 data: add Barbour, Butler, Pike, and Russell counties.

Surveillance Methods

Case ascertainment: active case ascertainment
Vital Records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, congenital anomaly reporting form
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, congenital anomaly reporting form
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any birth certificate with a birth defect box checked, infants with low birth weight or low gestation (<2500 gms), all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, development delay, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: California's coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff
Database storage/management: Access

Data Analysis

Data analysis software: SPSS, Access, Excel pivot tables
Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, 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: 100% University

Other

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

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Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: surveillance
Partner: local health departments, hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 1996
Earliest year of available data: 1996
Organizational location: Department of Health (Maternal and Child Health), Department of Health (Womens, Childrens and Family Health)
Population covered annually: 10,000
Statewide: Yes
Current legislation or rule: 7 AAC 27.012
Legislation year enacted: 1996

Case Definition

Outcomes covered: ICD-9 Codes 237.7, 243, 255.2, 277, 279, 282, 284.0, 331, 334, 335, 343, 359, 362.74, 389,740-760, 760.71
Age: birth to age six
Residence: in and out of state births to Alaska residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population-based
Vital Records: birth certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, infant learning programs, genetics clinics, specialty clinics (heart, cleft lip/palate, neurodevelopment), MIMR (FIMR), public health nursing
Delivery hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.
Pediatric & tertiary care hospitals: disease index or discharge index. Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.
Third party payers: Medicaid databases, Indian Health Services
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS, Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, grant proposals, education/public awareness

System Integration

System links: link case finding data to final birth file
System integration: No.

Funding

Funding Source: 10% General state Funds, 90% MCH funds

Other

Web site: http://www.epi.alaska.gov/mchepi/ABDR
Surveillance reports on file: see website

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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: surveillance, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, community nursing services, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 1986
Earliest year of available data: 1986
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Bureau of Public Health Statistics/Office of Health Registries)
Population covered annually: 102,687 in 2007
Statewide: Yes
Current legislation or rule: statute: ARS sec. 36-133.
rule: Title 9, Chapter 4, Articles 1 and 5, Adopted effective 1991.
Legislation year enacted: 1988

Case Definition

Outcomes covered: 44 categories (1986-2004) and 32 categories (2005-Present) of major birth defects and genetic diseases, as defined by the BPA/MACDP codes
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (For the 2001 – 2004 data, terminations are not identified separately from stillbirths. Stillbirths can be of any gestational age or weight), elective terminations (For the 2001 – 2004 data, terminations are not identified separately from stillbirths. Stillbirths can be of any gestational age or weight.)
Age: up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review (which occurs 2 -4 years after the child's birth or fetal death), then the more precise diagnosis is used.
Residence: Cases are born in Arizona and have an Arizona abstract indicating mother's residence in AZ.

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Vital Records: birth certificates, fetal death certificates
Other state based registries: programs for children with special needs
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, mothers charts for stillborns
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, mother's charts for stillborns
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of icd9-cm codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

Funding

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

Other

Web site: http://www.azdhs.gov/phs/phstats/bdr/index.htm
Surveillance reports on file: Same as Above

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Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

Purpose: surveillance, research, referral to prevention/intervention
Partner: local health departments, universities, hospitals, advocacy groups, legislators
Program status: currently collecting data
Start year: 1980
Earliest year of available data: 1980
Organizational location: University, Arkansas Childrens Hospital
Population covered annually: 38,000
Statewide: Yes
Current legislation or rule: Senate Bill Act 214
Legislation year enacted: 1985

Case Definition

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

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, all stillborn infants
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: locally modified BPA/CDC and NBDPS coding system

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

System links: link case finding data to final birth file
System integration: no

Funding

Funding Source: 100% general state funds

Other

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

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California

California Birth Defects Monitoring Program (CBDMP)

Purpose: surveillance, research
Partner: local health departments, universities, hospitals
Program status: currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: Division of Maternal, Child, Adolescent Health; March of Dimes under contract with California Department of Public Health
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)
Age: one year
Residence: in-state births to residents of 1 of 8 counties; does not include births in military hospitals.

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, 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 genetics facilities, maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases, apgar 0-0
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, GI condition (i.e. recurrent blockage), cardiovascular condition, all infant deaths (excluding prematurity), any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, validity checks are done on all abstracts.
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs. expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, service delivery, grant proposals, education/public awareness

System Integration

System links: link case finding data to final birth file

Funding

Funding Source: 23% general state funds, 18% MCH funds, 59% legislative special funds

Other

Web site: www.cbdmp.org

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Colorado

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

Purpose: surveillance, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 70,804 (2007)
Statewide: Yes
Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101 - 25-1.5-105
Legislation year enacted: 1985

Case Definition
Outcomes covered: structural birth defects, fetal alcohol syndrome, selected genetic and metabolic disorders; muscular dystrophy; selected developmental disabilities; very low birth weight (less than 1500 grams); others with medical risk factors for developmental delay
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater, less than 20 week limited to selected post-mortem pathology sites)
Age: up to the 3rd birthday, (up to the 10th birthday for fetal alcohol syndrome)
Residence: events occurring in-state or out-of-state to Colorado residents

Surveillance Methods
Case ascertainment: combination of active and passive case ascertainment
Vital Records: birth certificates, death certificates, fetal death certificates
Other state based registries: newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, postmortem/pathology logs, specialty outpatient clinics, selected postmortem pathology sites
Pediatric & tertiary care hospitals: disease index or discharge index, postmortem/pathology logs, specialty outpatient clinics, selected postmortem pathology sites
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetics facilities
Other sources: physician reports, selected sites for fetal alcohol syndrome and muscular dystrophy

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

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

Data Collection Methods and Storage
Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.), 99% of data are collected in electronic format
Database storage/management: Access, Conversion to SQL Server

Data Analysis
Data analysis software: SAS, Access, ArcView (GIS software), Maptitude, SaTScan
Quality assurance: validity checks, comparison/verification between multiple data sources, timeliness, ongoing quality control procedures for problematic conditions and situations; records linkage and de-duplication.
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, capture-recapture analyses, observed vs. expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, referral, grant proposals, education/public awareness, prevention projects, environmental studies

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

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

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

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Connecticut

Connecticut Birth Defects Registry (CTBDR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention, reporting for MCH Block Grant
Partner: hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 2002
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 43,000
Statewide: Yes
Current legislation or rule: Sec. 19a-56a. (Formerly Sec. 10a-132b). Birth defects surveillance program.; Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children.
Legislation year enacted: Sec. 10a-132b: 1991; Sec. 19-21a: 1949 Sec. 19-21: 1949.

Case Definition

Outcomes covered: all major structural birth defects; biochemical, genetic and hearing impairment through linkage with newborn screening system; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71
Pregnancy outcome: live births (all gestational ages and birth weights, PDA 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 case ascertainment, population based
Vital Records: birth certificates, death certificates, matched birth/death file, inpatient hospitalizations and emergency room visits
Other state based registries: newborn hearing screening program, newborn metabolic screening program, cancer registry, AIDS/HIV registry
Delivery hospitals: disease index or discharge index, reports from health care professionals in newborn nurseries and NICUs.
Pediatric & tertiary care hospitals: disease index or discharge index, reports from health care professionals in pediatric inpatient and outpatient services planned for future.
Midwifery facilities: midwifery facilities
Other sources: physician reports, mandatory reporting by health care providers and facilities; CSHCN programs; newborn screening system (for genetic disorders and hearing impairment).

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, Access, STATA, Arc GIS
Quality assurance: validity checks, comparison/verification between multiple data sources, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, capture-recapture analyses, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, provider education

System Integration

System links: link case finding data to final birth file

Funding

Funding Source: 100% MCH funds

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District of Columbia

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

Program status: Interested in developing a surveillance program

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Delaware

Delaware Birth Defects Surveillance Project

Purpose: surveillance, referral to prevention/intervention
Partner: hospitals, early childhood prevention programs
Program status: currently collecting data
Start year: 2006
Earliest year of available data: none yet
Organizational location: Department of Health and Social Services, Division of Public Health, Family Health Services
Population covered annually: 11,046
Statewide: Yes
Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects
Legislation year enacted: 1997

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment, population based
vital records: birth certificates, death certificates, hospital discharge records/data
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, development disabilities surveillance, cancer registry, AIDS/HIV registry
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Midwifery facilities: midwifery facilities
Other sources: physician reports

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: Natus
Quality assurance: not to this point yet

System Integration

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

Funding

Funding Source: 100% genetic screening revenues

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Florida

Florida Birth Defects Registry (FBDR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention, educate health care professionals
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators, federal and state agencies
Program status: currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: Department of Health (Epidemiology/Environment), University
Population covered annually: 237,166 resident live births in 2006
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: passive case ascertainment, population based, FL has two CDC funded cooperative agreements which use active case ascertainment which is linked to the passive surveillance program.
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, cancer registry
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs
Third party payers: Medicaid databases, health maintenance organization (HMOs)
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetics facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), 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, maternal risk factors, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

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

Funding

Funding Source: 70% General state Funds, 20% CDC grant, 10% state CMS program contribution

Other

Web site: www.fbdr.org
Surveillance reports on file: publications, procedure manuals, electronic case ascertainment database and educational materials

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Georgia

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: surveillance, research
Partner: local health departments, universities, hospitals, environmental agencies/organizations, advocacy groups
Program status: currently collecting data
Start year: 1967
Earliest year of available data: 1968
Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities
Population covered annually: 51808
Statewide: No, births to mothers residing within one of five central counties in the metropolitan Atlanta area of the state of Georgia
Current legislation or rule: State Laws Official Georgia Code Annotated (OCGA) 31-12-2

Case Definition

Outcomes covered: major structural or genetic birth defects
Pregnancy outcome: live births, other gestational age and/or birth weight criterion (>=20 weeks), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (all gestational ages)
Age: Before 6 years of age
Residence: births to mothers residing in one of five central metropolitan Atlanta counties

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Vital Records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, Postmortem/pathology logs, induction logs and miscarriage logs
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, infants with low birth weight or low gestation (birth weight < 2500 grams and/or 20-36 weeks gestation), all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff, electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Epi-Info, Mainframe

Data Analysis

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

System Integration

System links: link case finding data to final birth file, link to environmental databases, national death index

Funding

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

Other

Web site: http://www.cdc.gov/ncbddd/bd/macdp.htm
Surveillance reports on file: MACDP 40th Anniversary Surveillance Report
Comments: The 40th Anniversary Surveillance Report was published:
Correa A, Cragan JD, Kucik JE, et al. Reporting birth defects surveillance data 1968-2003. Birth Defects Research Part A. 2007;79(2):65-186.

Copies are available upon request from: macdp@cdc.gov

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Georgia

Georgia Birth Defects Reporting And Information System (GBDRIS)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 2003
Earliest year of available data: 2005
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 150,000
Statewide: Yes
Current legislation or rule: Birth defects are reportable under State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2 which mandate the reporting of notifiable diseases and newborn hearing screening, and Chapters 290-5-3-.02 and 290-5-24 of the Rules of Department of Human Resources, which regulate the reporting of notifiable diseases and metabolic disorders.
Legislation year enacted: updated in 2003

Case Definition

Outcomes covered: major birth defects, genetic diseases, FAS and CP
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater)
Age: up to 6 years of age
Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, development disabilities surveillance
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Third party payers: Medicaid databases
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetics facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, capture-recapture analyses, epidemiologic studies (using only program data), service delivery, grant proposals, education/public awareness, prevention projects

System Integration

System links: link to other state registries/databases, link case finding data to final birth file
System integration: SENDSS Newborn integrates multiple children health systems including birth defects, UNHS, NBS and Children 1st.

Funding

Funding Source: 100% general state funds

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Hawaii

Hawaii Birth Defects Program (HBDP)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: combination of DOH/Children With Special Health Needs Branch, and the Research Corporation of the University of Hawaii.
Population covered annually: ~19,803 average over the last 20 years.
Statewide: Yes
Current legislation or rule: 8/15/1988 to 6/30/2002 - Hawaii Revised Statutes (HRS), Sections 321-31 and 338-2 in conjunction, per Executive Chamber ruling by Governor on 6/16/1989. HRS Sections 324-1 and 324-2, for additional legislative authority (1990 Amendments). 7/1/02 to Present - Act 252 (2002) - Relating to Birth Defects (SB 2763, SD 2, HD 2, CD 1).
Legislation year enacted: 1989, 1990 and 2002

Case Definition

Outcomes covered: All ~1,154+ outcomes recommended by CDC in their May 1987 Birth Defects Branch Six Digit Code for Reportable Congenital Anomalies, based on B.P.A. Classification of Diseases (1979) and W.H.O. ICD-9 CM (1977).
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages), data collected on all elective medical terminations that were carried out because a screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect, and the parents elected not to bring the baby to term.
Age: up to one year after delivery, except for Fetal Alcohol Syndrome which can be diagnosed at any age.
Residence: all in-state Hawaii births (resident and non-resident).

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based
Vital Records: Vital records are used to supplement information collected from other data sources, but are not used to primarily identify potential cases. Vital records data are also used as denominators for determining birth defects rates per 10,000 births.
Other state based registries: The HBDP supplies aggregate, de-identified data to the entities listed; they do not supply data to the HBDP.
Delivery hospitals: disease index or discharge index, discharge summaries, information from specific logs, laboratories, clinics, etc. are usually found in the medical record when doing chart review.
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, information from specific logs, laboratories, clinics, etc. are usually found in the medical record when doing chart review.
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, all stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases, medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect, and parents elected not to bring baby to term, or mother spontaneously aborted.
Conditions warranting chart review beyond the newborn period: all infant deaths (excluding prematurity), childhood deaths between 1 and 6, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff, electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Access, SQL Server 2000

Data Analysis

Data analysis software: Access, SQL Server 2000
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, education/public awareness, prevention projects, publication of 71 articles (as of 9/9/08) in professional peer-review journals.

System Integration

System links: The Program is in the process of working on a GIS statistical mapping project for the HBDP.
System integration: No

Funding

Funding Source: 43% general state funds, 25% CDC grants, 4% other federal funding (non-CDC grants), 3% private foundation, 25% Birth Defects Special Fund (state non-general fund funding). Please note that all the figures above represent average funding amounts for 20 years from 1988 to 2008.

Other

Web site: HBDP web site taken down by the DOH/Children With Special Health Needs Branch

Surveillance reports on file: Twelve (12) 135+ page Hawaii Birth Defects Program Statewide Surveillance Data Reports have been published by the HBDP - 1) = 1989-1991, 2) = 1988-1993, 3) = 1988-1994, 4) = 1988-1995, 5) = 1987-1996, 6) = 1986-1997, 7) = 1986-1998, 8) = 1996-1999, 9) = 1986-2000, 10) = 1986-2001, 11) = 1986-2002, and 12) = 1986-2003. Data for years 1986-2004, and years 1986-2005 are complete but since the state has taken over publication of the HBDP Data Book, no Reports have been published by the DOH to date.
Additional information on file: HBDP informational brochure; copies of legislation; original and revised abstracting form; abstraction manual; annual reports; HBDP data; quality assurance reports (completeness, accuracy, timeliness)

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Idaho

Program status: No surveillance program

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Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: surveillance, referral to services, referral to prevention/intervention
Partner: local health departments, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 1986
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 180,000
Statewide: Yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)
Legislation year enacted: 1985

<u>Case Definition</u>

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

<u>Surveillance Methods</u>

Case ascertainment: combination of active and passive case ascertainment
Vital Records: birth certificates, fetal death certificates
Other state based registries: newborn metabolic screening program
Delivery hospitals: disease index or discharge index, discharge summaries, hospitals mandated to identify newborn cases and report to IDPH
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, hospitals mandated to report newborns discharged from any to the NICU or specialty units

<u>Case Ascertainment</u>

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, infants with low birth weight or low gestation (<1500 grams, All neonatal deaths)
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA

<u>Data Collected</u>

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.)

<u>Data Collection Methods and Storage</u>

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

<u>Data Analysis</u>

Data analysis software: SAS, Access, Arch Map, JoinPoint & SaTScan
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, public use data set

<u>System Integration</u>

System links: link case finding data to final birth file
System integration: No

<u>Funding</u>

Funding Source: 65% general state funds, 35% CDC grant

<u>Other</u>

Web site: www.idph.state.il.us/about/epi/apors.htm
Surveillance reports on file: Surveillance reports are available on-line -- visit website listed above, as are public use data sets.

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Indiana

Indiana Birth Defects And Birth Problems Registry (IBDPR)

Purpose: surveillance, research, referral to services
Partner: universities, hospitals, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 2002
Earliest year of available data: 2003 birth data is available in 2006
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Maternal and Child Health), State Health Data Center
Population covered annually: 88,000
Statewide: Yes
Current legislation or rule: IC 16-38-4-7
Rule 410 IAC 21-3
Legislation year enacted: 2001

Case Definition

Outcomes covered: ICD-9-CM Codes 740-759.9, Fetal Alcohol Spectrum Disorder (760.71), Pervasive Developmental Disorder (299.0), fetal deaths, metabolic and hearing disorders from Newborn Screening, selected neoplasms and congenital blood disorders, and certain eye disorders.
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: up to 5 years
Residence: in and out of state births to state residents

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM, and BPA

Data Collected

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

Data Collection Methods and Storage

Data Collection: electronic file/report submitted by other agencies (hospitals, etc.), ISDH chart auditors submit hospital chart audit information electronically through use of a laptop and a web-based portal to the Operational Data Store which store and integrates the data.
Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, Oracle and ArcView GIS
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, We are just now getting enough data to begin analyzing.

System Integration

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

Funding

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

Other

Web site: www.birthdefects.in.gov

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Iowa

Iowa Registry For Congenital And Inherited Disorders (IRCID)

Purpose: surveillance, research, referral to services, referral to prevention/intervention, prevention education programs
Partner: local health departments, universities, hospitals, environmental agencies/organizations, advocacy groups, legislators
Program status: currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: University
Population covered annually: 37,831 avg 10 yr
Statewide: Yes
Current legislation or rule: Iowa Code 136A, Iowa Administrative Code 641-4.7
Legislation year enacted: 1986; Revised 2001, 2003, 2004

Case Definition

Outcomes covered: major birth defects, Duchenne/Becker muscular dystrophy, fetal deaths with and without birth defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (all gestational ages)
Age: 1 year
Residence: maternal residence in Iowa at time of delivery

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Vital Records: birth certificates, death certificates, fetal death certificates
Other state based registries: state perinatal program
Delivery hospitals: disease index or discharge index, discharge summaries, 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 genetics facilities, maternal serum screening facilities
Other sources: physician reports, outpatient surgery facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases, muscular dystrophy
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, development delay, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data Collection: electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Access, Oracle, PC server

Data Analysis

Data analysis software: SPSS, SAS, Access, Oracle
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, capture-recapture analyses, observed vs. expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: link case finding data to final birth file, link to environmental databases, For specific studies, data may be linked with environmental databases or other state databases.
System integration: no

Funding

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

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Kansas

Birth Defects Reporting System

Purpose: registry
Partner: hospitals
Program status: currently collecting data
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 40,896 (Year 2006)
Statewide: Yes
Current legislation or rule: K.S.A. 65-1,241 through 65-1,246
Legislation year enacted: 2004

Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics. Live births and fetal deaths information are used as part of the birth defects reporting system. Thirteen anomalies (and "other" congenital anomalies) are listed on the birth certificate and are reported, however, these are not linked to ICD-9 codes.
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (all gestational ages)
Age: under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition
Residence: in state and out of state births to Kansas residents and in-state births to out of state residents

Surveillance Methods

Vital Records: birth certificates, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, development disabilities surveillance
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catherization laboratories, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catherization laboratories, specialty outpatient clinics
Midwifery facilities: midwifery facilities
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetics facilities
Other sources: physician reports

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.), In Kansas, birth defects (congenital anomalies) are collected through two data sources: birth certificates and the birth defects prevention program reporting form. The birth certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to the birth defects reporting system. Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into the birth defects reporting system.
Database storage/management: Mainframe

Data Analysis

Data analysis software: SAS
Quality assurance: comparison/verification between multiple data sources, Office of Vital Statistics conducts verification on birth certificate data.
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, grant proposals, ad-hoc upon request

System Integration

System links: link to other state registries/databases
System integration: Our program has a link with vital statistics records.

Funding

Funding Source: 100% MCH funds

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Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: surveillance, referral to services, referral to prevention/intervention, prevention of birth defects
partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1996
Earliest year of available data: 1998
Organizational location: Department of Health (Maternal and Child Health), Department for Public Health, Division of Maternal and Child Health, Early Childhood Development Branch
Population covered annually: 54,500
Statewide: Yes
Current legislation or rule: KRS 211.651-211.670
Legislation year enacted: 1992

<u>Case Definition</u>
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.)
Age: up to fifth birthday
Residence: all in-state births; out of state births to state residents

<u>Surveillance Methods</u>
Case ascertainment: combination of active and passive case ascertainment
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates, medical laboratory reporting mandated; outpatient reporting voluntary
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics, laboratory records
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, laboratory records
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities
Other sources: physician reports, local health departments

<u>Case Ascertainment</u>
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (i.e. seizure), cardiovascular condition, any infant with a codable defect
Coding: ICD-9-CM, ICD-10 for Vital Statistics death data

<u>Data Collected</u>
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

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

<u>Data Analysis</u>
Data analysis software: SPSS, SAS, Access
Quality assurance: re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, IRB-approved research projects

<u>System Integration</u>
System links: link case finding data to final birth file
System integration: True positives identified by newborn screening are integrated into the KBSR database.

<u>Funding</u>
Funding Source: 100% general state funds

<u>Other</u>
Web site: http://chfs.ky.gov/dph/ach/ecd/kbsr.htm

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Louisiana

Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: surveillance, referral to services
Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 2005
Earliest year of available data: 2006
Organizational location: Department of Health (Children's Special Health Services)
Population covered annually: approx. 42,000 in 2008
Statewide: No, for 2008, projected coverage of 70% of births
Current legislation or rule: Law: LA R.S. 40:31.41 - 40:31.48. Rule: LAC 48:V.Chapters 161 and 163
Legislation year enacted: 2001

Case Definition

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

Surveillance Methods

Case ascertainment: active case ascertainment, limited population-based
Vital Records: birth certificates, matched birth/death file
Other state based registries: programs for children with special needs
Delivery hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff
Database storage/management: Access

Data Analysis

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

System Integration

System links: link birth defects case data to final birth file and infant death file

Funding

Funding Source: 100% CSHCN funds

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Maine

Maine Birth Defects Program (MBDP)

Purpose: surveillance, referral to services, referral to prevention/intervention, education
Partner: universities, hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups, March of Dimes
Program status: currently collecting data
Start year: 1999
Earliest year of available data: 2003
Organizational location: Department of Health, (Children with Special Health Needs, Department of Health and Human Services)
Population covered annually: 14,000
Statewide: Yes
Current legislation or rule: 22 MRSA c. 1687
Legislation year enacted: 1999

Case Definition

Outcomes covered: Selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias and major heart defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater , prenatally diagnosed at any gestation), elective terminations (prenatally diagnosed at any gestation)
Age: through age one
Residence: all in-state births to Maine residents

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population based
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, specialty outpatient clinics
Midwifery facilities: midwifery facilities
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities, maternal serum screening facilities
Other sources: physician reports, children with special health needs

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: cardiovascular condition, all infant deaths (excluding prematurity), any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Citrix, University of Maine/Center for Excellence in Developmental Disabilities ChildLINK database system electronic abstraction record/hospital case reports/electronic submission of hospital discharge data. On-line hospital case report form.

Data Analysis

Data analysis software: SAS, Stat-exact
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, needs assessment, service delivery, referral, education/public awareness, prevention projects

System Integration

System links: link to other state registries/databases, link case finding data to final birth file
System integration: newborn hearing/ newborn bloodspot screening programs

Funding

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

Other

Web site:
http://www.maine.gov/dhhs/boh/cshn/birth_defects/index.html

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Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

Purpose: surveillance, research, referral to services
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1983
Earliest year of available data: 1984
Organizational location: Department of Health (Family Health Administration, Office for Genetics & Children with Special Health Care Needs)
Population covered annually: 70,000
Statewide: Yes
Current legislation or rule: Health-General Article, Section 18-206; Annotated Code of Maryland
Legislation year enacted: 1982

Case Definition

Outcomes covered: Selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater or >=500 grams weight), reports accepted on fetal deaths (<500 grams or <20 weeks gestation if sent to us., 20 weeks gestation and greater, or >=500 grams weight) reports accepted on terminations <500 grams or <20 weeks gestation if sent to us, BDRIS has no specific legal authority to collect information on terminations. Maryland does not require that any certificate be filed with vital records for a termination unless the body is transported for burial.
Age: newborn
Residence: all in-state births

Surveillance Methods

Case ascertainment: passive case ascertainment, multiple sources, population based
Vital Records: birth certificates, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, sickle cell disease
Delivery hospitals: obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form
Pediatric & tertiary care hospitals: ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form
Midwifery facilities: midwifery facilities
Other specialty facilities: genetic counseling/clinical genetics facilities, maternal serum screening facilities

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Mainframe, Visual dBASE, SAS, ASCII files

Data Analysis

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

System Integration

System links: in the process of linkage with other state registries/databases
System integration: No

Funding

Funding Source: 100% general state funds

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Massachusetts

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

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: universities, hospitals, environmental agencies/organizations, advocacy groups
Program status: currently collecting data
Start year: 1997
Earliest year of available data: 1999 for statewide data
Organizational location: Department of Health (Bureau of Family Health and Nutrition)
Population covered annually: 77,000
Statewide: Yes
Current legislation or rule: Massachusetts General Laws, Chapter 111, Section 67E. In 2002 the Massachusetts Legislature amended this statute, expanding the birth defects monitoring program.
Legislation year enacted: 1963

Case Definition
Outcomes covered: major structural birth defects and chromosomal anomalies of medical, surgical or cosmetic significance
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc., reportable fetal deaths-- (>=20 weeks gestation or >=350 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: combination of active and passive case ascertainment, population based
Vital Records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, postmortem/pathology logs
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics
Other sources: physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, all stillborn infants, all neonatal deaths
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, all infant deaths (excluding prematurity), auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

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

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

Data Analysis
Data analysis software: SAS, Access, Excel
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs. expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, education/public awareness, 1) selected cases from surveillance are eligible for CDC's National Birth Defects Prevention Study 2) Down syndrome and cardiovascular defects used for CDC grant to determine cost of these defects

System Integration
System links: 1) link case finding data to final birth file, 2) link case finding data to final fetal death file, 3) Massachusetts Pregnancy to Early Life Longitudinal (PELL) Linkage Project
System integration:

Funding
Funding Source: 100% General State Funds

Other
Web site: www.mass.gov/birthdefectscenter
Surveillance reports on file: visit www.mass.gov/birthdefectscenter to view or download annual surveillance reports.

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Michigan

Michigan Birth Defects Registry (MBDR)

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

Case Definition

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

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 6, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SPSS, Access, Fox-pro, Excel
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs. expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: link to other state registries/databases, link case finding data to final birth file, CSHCS, WIC
System integration: No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

Funding

Funding Source: 20% CDC grant, 80% Vital Records Fees

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Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 2005
Earliest year of available data: 2006
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 73,000
Statewide: No, the statewide surveillance system will be phased in over a number of years. Data is currently being collected in the two largest counties in Minnesota Hennepin and Ramsey counties). These two counties account for approximately 50 percent of the births.
Current legislation or rule: MS 144.2215-2219
Legislation year enacted: 2004

Case Definition
Outcomes covered: major "reported birth defects" as defined by CDC and ICD-9 codes up to 1 year of age; age 6 for FAS
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: up to 1 year after delivery
Residence: in-state data

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

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a CDC/BPA code, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive
Coding: CDC coding system based on BPA

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

Data Collection Methods and Storage
Data Collection: electronic file/report filled out by staff at facility (laptop, web-based, etc.), laptops encrypted and data downloaded regularly
Database storage/management: Access, final production format/platform to be determined based on collaborative partners

Data Analysis
Data analysis software: SAS, Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, timeliness, physician review as needed;
Data use and analysis: public health program evaluation, baseline rates, needs assessment, referral, grant proposals, education/public awareness, prevention projects, full system implementation in 2005; many of these listed above will be used when full data sets are available

System Integration
System links: link case finding data to final birth file
System integration: program plans to integrate with Newborn Screening/Hearing and collaborate with other regional programs.

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

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Mississippi

Mississippi Birth Defects Registry (MBDR)

Purpose: surveillance
Partner: local health departments, hospitals
Program status: currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health), Department of Health (Division of Genetic Services)
Population covered annually: 42,000
Statewide: Yes
Current legislation or rule: Section 41-21-205 of 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), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 350 grams or more)
Age: 0 to 21
Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment
Vital Records: birth certificates, death certificates
Other state based registries: newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Other sources: physician reports, community health centers

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.)

Data Collection Methods and Storage

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

Data Analysis

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

Funding

Funding Source: 100% genetic screening revenues

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Missouri

Missouri Birth Defects Registry

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1985
Earliest year of available data: 1980
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 78,000
Statewide: Yes

Case Definition

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

Surveillance Methods

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

Case Ascertainment

Coding: ICD-9-CM, ICD-10

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs. expected analyses, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: link case finding data to final birth file

Funding

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

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

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

Case Definition

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

Funding

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

Other

Comments: Due to lack of funding, MBOMS is no longer an active surveillance system. We have data for 2000 through 2004, but no valid data since December 31, 2004.

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Nebraska

Nebraska Birth Defects Registry

Purpose: surveillance, research, We are in the process of exploring a program of referral to services and prevention programs.
Partner: hospitals, Nebraska Department of Health and Human Services and MCH
Program status: currently collecting data
Start year: 1973
Earliest year of available data: 1973
Organizational location: Department of Health (Nebraska Department of Health and Human Services, Public Health, Office of Health Statistics)
Population covered annually: Statewide, 27,000+ births annually
Statewide: Yes
Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §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
Vital Records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, Nebraska Birth Defects Prevention Program Congenital Defects Case Record
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics, Nebraska Birth Defects Prevention Program Congenital Defects Case Record
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), cardiovascular condition, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), defects taken from paper copies of birth certificates submitted to the Vital Statistics Office.
Database storage/management: Netsmart

Data Analysis

Data analysis software: SAS, Reports from Netsmart.
Quality assurance: re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, case finding, data coding and entry.
Data use and analysis: baseline rates, monitoring outbreaks and cluster investigation, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, incidence rates, trend analysis, birth defect registry.

System Integration

System links: Netsmart.
System integration: integrated with births, fetal deaths, deaths and hearing screening.

Funding

Funding Source: 100% MCH funds

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Nevada

Nevada Birth Outcomes Monitoring System

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: hospitals, early childhood prevention programs, Bureau of Child, Family, & Community Wellness
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2005
Organizational location: State Division of Health, Bureau of Health Statistics, Planning, and Emergency Response
Population covered annually: 40,703 in 2007
Statewide: Yes
Current legislation or rule: NRS 442.300 - 442.330 - Birth Defects Registry Legislation *** Regulation = NAC 442
Legislation year enacted: 1999

Case Definition

Outcomes covered: major birth defects and genetic diseases
Pregnancy outcome: live births (20 weeks of gestation and greater with all birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 20 weeks gestation and greater)
Age: cover from 0-7 years of age
Residence: in-state births

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population based
Vital Records: birth certificates, death certificates, matched birth/death file, hospital medical records, diagnostic/laboratory reports
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, cancer registry
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), pediatric logs, postmortem/pathology logs, surgery logs, cardiac catherization laboratories, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, development delay, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), cardiovascular condition, any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff
Database storage/management: Access

Data Analysis

Data analysis software: SPSS, SAS, Access
Quality assurance: double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: link to other state registries/databases, birth registry data is manually linked to birth defect data, but the actual databases are not linked.
System integration: No

Funding

Funding Source: 100% service fees

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New Hampshire

New Hampshire Birth Conditions Program (NHBCP)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 2003
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health, Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, Department of Environmental Services Bureau of Environmental Health), University
Population covered annually: 14,500
Statewide: Yes
Current legislation or rule: RSA 141:J, NH DHHS Administrative Rules currently under review.
Legislation year enacted: 2008

Case Definition

Outcomes covered: all major birth defects and genetic diseases recommended by the CDC/NBDPN
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)
Age: currently collecting birth to age 2
Residence: all New Hampshire residents, those born in-state as well as out of state

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Vital Records: birth certificates, fetal death certificates, elective termination certificates, hospital ICD-9 codes for admissions, discharges and transports, fetal pathology reviews at Dartmouth Hitchcock Medical Center
Other state based registries: programs for children with special needs, newborn hearing screening program
Delivery hospitals: discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics, medical records abstraction of charts of selected ICD 9 Codes
Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics, cytogenetic laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic labs, genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, elective terminations that have confirmed birth conditions
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

Infant/fetus: identification information except for termination cases (name, address, date-of birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, apgars, etc.), birth defect diagnostic information
Mother: identification information except for termination cases (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
Father: date of birth

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

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

Funding

Funding Source: 100% CDC grant

Other

Web site: www.nhbcp.org

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New Jersey

Special Child Health Services Registry (SCHS REGISTRY)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health & Senior Services - Special Child, Adult, and Early Intervention Services
Population covered annually: 113,000
Statewide: Yes
Current legislation or rule: NJSA 26:8 et seq., NJAC 8:20 - Enacted 08-04-1983, with effective date of 03-04-1985. Changes to legislation 1990, 1991, 1992, 2005. Readopted 05/2005.
Legislation year enacted: 1983

Case Definition

Outcomes covered: All birth defects, including structural, genetic, and biochemical are required to be reported. While not mandated, all special needs and any condition which places a child at risk, e.g. prematurity, asthma, cancer, developmental delay, are also reported.
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: mandated reporting of birth defects diagnosed through age 5, voluntary reporting of birth defects diagnosed > age 6 and all children diagnosed with Special Needs conditions who are <= 22 yrs. of age
Residence: in/out-of-state NJ births to NJ residents; because of our link to the SCHS Case Management system, we also enroll anyone becoming NJ resident.

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population based
Vital Records: birth certificates, death certificates, matched birth/death file
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, 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 catherization 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 catherization laboratories, specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period
Midwifery facilities: Midwifery facilities
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetics facilities
Other sources: physician reports, special child health services county based case management units, parents, medical examiners

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, all neonatal deaths, all death certificates for < 3 year of age
Conditions warranting chart review beyond the newborn period: GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness, merge registry with birth certificate registry and the death certificate registry
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time-space cluster analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: link to other state registries/databases, link case finding data to final birth file, link to hearing screening registry
System integration: hearing screening registry provides direct feed into SCHS Registry.

Funding

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

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New Mexico

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

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators, private providers
Program status: currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 29,000
Statewide: Yes
Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regulations.
Legislation year enacted: January 1, 2000

Case Definition

Outcomes covered: 740-760.71, Currently focused on major birth defects of interest to Environmental Public Health Tracking.
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), elective terminations (all gestational ages)
Age: birth through age 4 years--this was just changed April 2006.
Residence: births to New Mexico residents. Due to a change in vital records procedures, we only receive birth records for nm residents with births occurring in-state.

Surveillance Methods

Case ascertainment: passive case ascertainment, population based
Vital Records: birth certificates, death certificates, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, medical chart review
Pediatric & tertiary care hospitals: disease index or discharge index, specialty outpatient clinics, specialty outpatient clinics, including neurosurgery, plastic surgery, pediatric surgical specialists, prenatal diagnostic providers
Third party payers: Medicaid databases, health maintenance organization (HMOs), Indian health services, Children's Medical Services (CMS)
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, charts with a list of other ICD9-CM codes selected by CMS
Coding: CDC coding system based on BPA, ICD-9-CM, ICD10 for deaths

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: Stata
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, grant proposals, education/public awareness, prevention projects

System Integration

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

Funding

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

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New York

New York State Congenital Malformations Registry (CMR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention, community outreach and education
Partner: universities, hospitals, early childhood prevention programs, March Of Dimes
Program status: Currently collecting data
Start year: 1982
Earliest year of available data: 1983
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 250,000 - 300,000
Statewide: Yes
Current legislation or rule: Public Health Law Art. 2, Title, II, Sect 225(5)(t) and Art. 2 Title I, sect 206(1) (j): Codes, Rules and Regulations, Chap 1, State Sanitary Code, part 22.3
Legislation year enacted: 1982

Case Definition

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

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population based
Other state based registries: NYS Dept. of Health statewide hospital discharge database
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catherization laboratories, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics
Other specialty facilities: cytogenetic laboratories
Other sources: physician reports, hospital discharge data

Case Ascertainment

Conditions warranting chart review in newborn period: charts with major malformations - a detailed list is available upon request
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data Collection: electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Sybase

Data Analysis

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

System Integration

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

Funding

Funding Source: 24% general state funds, 12% MCH funds, 3% genetic screening revenues, 44% CDC grant, 17% other federal funding (non-CDC grants)

Other

Web site: http://www.health.state.ny.us/diseases/congenital_malformations/cmrhome.htm
Surveillance reports on file: Reports for 1983-2005

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North Carolina

North Carolina Birth Defects Monitoring Program (NCBDMP)

Purpose: surveillance, research, referral to services, referral to prevention/intervention, education, advocacy
Partner: local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 1987
Earliest year of available data: 1989
Organizational location: Department of Health (State Center for Health Statistics)
Population covered annually: 130,000
Statewide: Yes
Current legislation or rule: NCGS 130A-131
Legislation year enacted: 1995

Case Definition

Outcomes covered: major birth defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (all gestational ages)
Age: up to one year after delivery
Residence: NC resident births, in-state and out-of-state occurrence

Surveillance Methods

Case ascertainment: active case ascertainment, population based
vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any birth certificate with a birth defect box checked, all stillborn infants, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

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

Funding

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

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North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

Purpose: surveillance
Partner: universities, March of Dimes
Program status: currently collecting data
Start year: 2002
Earliest year of available data: 1994
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health), ND Department of Health (Childrens Special Health Services)
Population covered annually: 8807
Statewide: Yes
Current legislation or rule: North Dakota Century code 23-41
Legislation year enacted: 1941

Case Definition

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

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Coding: ICD-9-CM, ICD 10

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

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

Funding

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

Other

Web site: http://www.health.state.nd.us/cshs/docs/birth-defects-report.pdf
Surveillance reports on file: North Dakota Birth Defects Monitoring System -Summary Report 1995-1999

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Ohio

Ohio Connections For Children With Special Needs (OCCSN)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 2006
Earliest year of available data: N/A
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 150,000
Statewide: Yes
Current legislation or rule: Ohio Revised Code (ORC) 3705.30 - 3705.36, signed into law in July, 2000.
"The Director of Health shall establish and, if funds for this purpose are available, implement a statewide birth defects information system for the collection of information concerning congenital anomalies, stillbirths, and abnormal conditions of newborns." Administrative rules became effective June 3, 2005.
Legislation year enacted: 2000

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment, hospital based
Vital Records: birth certificates
Other state based registries: programs for children with special needs
Delivery hospitals: hospital electronic data systems for medical records and billing
Pediatric & tertiary care hospitals: hospital electronic data systems for medical records and billing
Other specialty facilities: genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any birth certificate with a birth defect box checked, children from birth to 5 years with at least one of reportable ICD-9 codes
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS
Quality assurance: comparison/verification between multiple data sources, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation

System Integration

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

Funding

Funding Source: 100% CDC grant

Other

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Oklahoma

Oklahoma Birth Defects Registry (OBDR)

Purpose: surveillance, referral to prevention/intervention
Partner: hospitals, early childhood prevention programs, legislators, cytogenetics & medical genetics
Program status: currently collecting data
Start year: 1992; statewide 1994
Earliest year of available data: 1992
Organizational location: Department of Health (Other, please specify):, Family Health Services
Population covered annually: 55,000
Statewide: Yes
Current legislation or rule: 63 O.S. Section 1-550.2
Legislation year enacted: 1992

Case Definition

Outcomes covered: modified 6-digit ICD-9-CM codes for birth defects and genetic diseases (CDC/BPA)
Pregnancy outcome: live births (>= 20 weeks gestation), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (20 weeks gestation and greater)
Age: 2 years
Residence: in-state births to state residents

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Vital Records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, 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, ICU/NICU logs or charts, pediatric logs, surgery logs, specialty outpatient clinics
Midwifery facilities: midwifery facilities
Third party payers: Indian health services, military hospitals delivering babies
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code
Conditions warranting chart review beyond the newborn period: any infant with a 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, pregnancy/delivery complications, maternal risk factors, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff
Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access, ArcView GIS
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, timeliness, editing of all completed abstracts
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, needs assessment, referral, grant proposals, education/public awareness, prevention projects, program quality assurance

System Integration

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

Funding

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

Other

Web site:
http://www.ok.gov/health/Child_and_Family_Health/Screening,_Special_Services_and_Sooner_Start/Oklahoma_Birth_Defects_Registry_/index.html

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Oregon

Program status: No surveillance program

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Pennsylvania

Pennsylvania Birth Defects Surveillance Database

Purpose: surveillance, referral to services, referral to prevention/intervention
Partner: universities, hospitals, community nursing services, advocacy groups
Program status: currently collecting data
Start year: 2003
Earliest year of available data: 2001
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 148,706 total live births in 2001; 142,388 total live births in 2002; 145,952 total live births in 2003; 144,499 total live births in 2004.
Statewide: Yes
Current legislation or rule: Not applicable

Case Definition

Outcomes covered: 740-759.9 and 760.71 ICD-9
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (16 weeks gestation and greater)
Age: birth to 24 months of age
Residence: in-state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population based
Vital Records: birth certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, cancer registry, AIDS/HIV registry
Delivery hospitals: discharge summaries
Pediatric & tertiary care hospitals: discharge summaries

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SPSS, SAS, Access
Quality assurance: validity checks, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

Funding

Funding Source: 100% MCH funds

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Puerto Rico

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

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, community nursing services, early childhood prevention programs, advocacy groups
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: 50,000
Statewide: Yes
Current legislation or rule: Yes, Law 351
Legislation year enacted: September 16th, 2004

Case Definition

Outcomes covered: selected birth defects - neural tube defects, cleft lip and/or cleft palate, talipes equinovarus, limb defects, ventral wall defects, ambiguous genitalia, trisomy 13, 18 and 21, conjoint twins, albinism, congenital heart defects, hypospadias, epispadias, Jarcho-Levin syndrome, anotia, microtia, anophthalmia, microphthalmia and bladder extrophy.
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (all gestational ages)
Age: up to 6 years after delivery
Residence: in-state birth to state residents

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Vital Records: birth certificates, death certificates, fetal death certificates
Other state based registries: programs for children with special needs
Delivery hospitals: discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs
Third party payers: Medicaid databases
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetics facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all elective abortions, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, cardiovascular condition, 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, prenatal diagnostic information, pregnancy/delivery complications
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access

Data Analysis

Data analysis software: SPSS, Excel
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

Funding

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

Other

Web site: http://www.salud.gov.pr
Surveillance reports on file: PR Birth Defects Databook 2008

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Rhode Island

Rhode Island Birth Defects Surveillance Program

Purpose: surveillance, referral to services, referral to prevention/intervention
Partner: hospitals, community nursing services, environmental agencies/organizations, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 2000
Earliest year of available data: 1997
Organizational location: Department of Health (Maternal and Child Health)
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: birth-4 years
Residence: RI residents

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: chart reviews are conducted for infants born at the regional perinatal center who were identified with an ICD-9 code 740-759
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

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

Funding

Funding Source: 25% MCH funds, 75% CDC grant

Other

Web site: http://www.health.ri.gov/family/birthdefects/index.php
Surveillance reports on file: 2008 Rhode Island Birth Defects Data Book

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South Carolina

South Carolina Birth Defects Program (SCBDP)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, legislators, Greenwood Genetic Center (GGC)
Program status: currently collecting data
Start year: GGC began monitoring in 1992; transitioned to SC DHEC and expanded in 2006
Earliest year of available data: via GGC, for 3 categories of defects, since 1993
Organizational location: SC Department of Health and Environmental Control, Maternal and Child Health
Population covered annually: 55,317
Statewide: Yes
Current legislation or rule: A281,R308,H4115
Legislation year enacted: 2004

Case Definition

Outcomes covered: neural tube defects, cardiovascular defects, musculoskeletal defects, orofacial clefts
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)
Age: up to two years of age
Residence: currently monitoring in-state births to persons residing in South Carolina

Surveillance Methods

Case ascertainment: active case ascertainment
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates
Other state based registries: programs for children with special needs, autopsy
Delivery hospitals: disease index or discharge index, discharge summaries, postmortem/pathology logs, ICD-9 codes
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities.
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, all prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

System links: link case finding data to final birth file, SC Vital Records
System integration: SC Vital Records

Funding

Funding Source: 100% general state funds

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South Dakota

Program status: No surveillance program

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Tennessee

Tennessee Birth Defects Registry (TBDR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: local health departments, universities, hospitals, community nursing services, early childhood prevention programs, advocacy groups, legislators
Program status: currently collecting data
Start year: 2000
Earliest year of available data: 1999
Organizational location: Department of Health (Health Research Division in the Office of Policy, Planning and Assessment)
Population covered annually: 80,000
Statewide: Yes
Current legislation or rule: TCA 68-5-506
Legislation year enacted: 2000

Case Definition

Outcomes covered: 44 major structural birth defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (500 grams or more, or in the absence of weight, of 22 completed weeks of gestation or more)
Age: diagnosed up to one year after delivery
Residence: in and out state births to state resident

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population based, hospital based
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catherization laboratories, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catherization laboratories, specialty outpatient clinics
Third party payers: Medicaid databases

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, infants with low birth weight or low gestation, please specify:, active review sample infants with no known diagnosis and oversample for low birth weight, ICD9-CM code 760.71
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, Access, SQL Server, Arc-GIS
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, time-space cluster analyses, observed vs. expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, education/public awareness, prevention projects

System Integration

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

Funding

Funding Source: 100% general state funds

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Texas

Texas Birth Defects Epidemiology And Surveillance Branch (TBDES)

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: universities, hospitals, advocacy groups
Program status: currently collecting data
Start year: 1994
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: **385,537 live births in 2005 finalized data**
Statewide: Yes
Current legislation or rule: Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87.
Legislation year enacted: 1993

Case Definition

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

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, infants with low birth weight or low gestation, please specify:, (<34 weeks GA), all stillborn infants
Conditions warranting chart review beyond the newborn period: CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), cardiovascular condition, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, clinical review, timeliness, re-case finding, re-review of medical records
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, observed vs. expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, referral, grant proposals, education/public awareness

System Integration

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

Funding

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

Other

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

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Utah

Utah Birth Defect Network (UBDN)

Purpose: surveillance, research, referral to services, referral to prevention/intervention, education
Partner: university, hospitals, environmental agencies/organizations, advocacy groups, legislators
Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1994
Organizational location: Department of Health (CSHCN), University of Utah
Population covered annually: >50,000
Statewide: Yes
Current legislation or rule: Birth Defect Rule (R398-5)
Legislation year enacted: 1999

Case Definition

Outcomes covered: 742.000 - 759.000
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (all gestational ages)
Age: 2
Residence: maternal residence in Utah at time of delivery

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population-based; all medical records are reviewed for all reported potential cases
Vital Records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics, champions report live births delivered at their respective hospitals
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, postmortem/pathology logs, surgery logs, specialty outpatient clinics
Midwifery facilities: midwifery facilities
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetics facilities
Other sources: physician reports, lay midwives

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, all fetal deaths certificates, NICU reports, infant deaths are reviewed
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 6, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SPSS, SAS, Access, Stata
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness, logical checks, duplicate check in tracking and surveillance module, case record form checked for completeness, timeliness through system, manual review of subset of surveillance module case data compared to case record form.
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, referral, grant proposals, education/public awareness, prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention, International Clearinghouse for Birth Defects, Local Studies

System Integration

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

Funding

Funding Source: 100% general state funds

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Vermont

Birth Information Network (BIN)

Purpose: surveillance, referral to services, referral to prevention/intervention, prevention education
Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups, VT Department of Banking, Insurance, Securities & Healthcare Administration; VT Association of Hospitals and Health Systems.
Program status: currently collecting data
Start year: 2006
Organizational location: Department of Health (Statistics)
Population covered annually: 6500
Statewide: Yes
Current legislation or rule: Act 32 (TITLE 18 VSA §5087)
Legislation year enacted: 2003

Case Definition

Outcomes covered: major birth defects and genetic diseases, very low birth weight (less than 1500 grams)
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: up to one year after delivery
Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population based
Vital Records: birth certificates, death certificates, matched birth/death file
Other state based registries: programs for children with special needs, newborn hearing screening program
Delivery hospitals: discharge summaries, specialty outpatient clinics
Pediatric & tertiary care hospitals: discharge summaries, specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports from offices and clinics associated with Tertiary Care Hospital

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease
Conditions warranting chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access

Data Analysis

Data analysis software: SPSS, Access, Excel
Quality assurance: comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring

System Integration

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

Funding

Funding Source: 100% CDC grant

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Virginia

Virginia Congenital Anomalies Reporting And Education System (VACARES)

Purpose: surveillance, research
Partner: universities, hospitals
Program status: currently collecting data
Start year: 1985
Earliest year of available data: 1987
Organizational location: Department of Health (Pediatric Screening and Genetic Services, Div. of Child and Adolescent Health)
Population covered annually: 105,890
Statewide: Yes
Current legislation or rule: Health Law 32.1-69.1,-69.1:1,-69.2
Legislation year enacted: 1985, amended 1986, 1988, 2006

Case Definition

Outcomes covered: major birth defects and genetic diseases
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: below 24 months of age
Residence: in and out-of-state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population based, active component includes periodic on site QA monitoring of eligible cases by VaCARES staff.
Vital Records: birth certificates, death certificates, matched birth/death file
Other state based registries: newborn hearing screening program, newborn metabolic screening program
Delivery hospitals: discharge summaries, medical records abstracts codes from charts
Pediatric & tertiary care hospitals: discharge summaries, medical records abstracts codes from charts
Other specialty facilities: genetic counseling/clinical genetics facilities

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, needs assessment, service delivery, referral, grant proposals, prevention projects

System Integration

System links: link to other state registries/databases
System integration: The current system, Virginia Infant Screening and Infant Tracking System (VISITS), is an integrated database for VaCARES and the Virginia Early Hearing Detection and Intervention Program

Funding

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

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Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: surveillance, referral to services
Partner: universities, hospitals, environmental agencies/organizations
Program status: currently collecting data
Start year: 1986- active and 1991- passive
Earliest year of available data: 1987
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 86,000
Statewide: Yes
Current legislation or rule: Notifiable Conditions: WAC 246-101
Legislation year enacted: 2000

Case Definition

Outcomes covered: From 1987 to 1991 (active surveillance), and from 1991 to the 2000 (passive surveillance), the cases reportable to the Birth Defects Registry included those with ICD-9-CM codes 740-759, selected primary cancers, selected metabolic conditions, and FAS/FAE. Since the adoption of the Notifiable Conditions law in 2000, conditions subject to mandatory reporting are neural tube defects, orofacial clefts, limb deficiencies, abdominal wall defects, hypospadias/epispadias and Down Syndrome. FAS/FAE, Cerebral Palsy and Autism are designated as reportable with systems being established to ascertain cases outside the hospital setting.
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: to age 4 years historically, We are transitioning to ascertainment through 1 year of age for structural defects and to age ten for FAS/FAE, Cerebral Palsy and Autism.
Residence: resident births; children born, diagnosed or treated in-state

Surveillance Methods

Case ascertainment: passive case ascertainment
Vital Records: birth certificates, fetal death certificates
Other state based registries: programs for children with special needs
Delivery hospitals: disease index or discharge index
Pediatric & tertiary care hospitals: disease index or discharge index
Other sources: university-based FAS/FAE and Autism specialty centers

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, Access, Stata
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, monitoring outbreaks and cluster investigation, time trends, observed vs. expected analyses, education/public awareness

System Integration

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

Funding

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

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West Virginia

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

Purpose: surveillance, research, referral to services, referral to prevention/intervention
Partner: universities, hospitals, early childhood prevention programs, advocacy groups
Program status: currently collecting data
Start year: 1989
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 21,000
Statewide: Yes
Current legislation or rule: State Statute Section 16-5-12a
Legislation year enacted: 1991Legislation updated: 2002

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment, monthly reports sent from birthing facilities across the state and reproductive outcome forms submitted by facilities and individual physicians
Vital Records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, development disabilities surveillance, cancer registry, AIDS/HIV registry, SIDS
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: discharge summaries, specialty outpatient clinics, physicians complete reproductive outcomes forms for those diagnosed after delivery
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports, pediatric referrals of children diagnosed after delivery and discharge

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, infants with low birth weight or low gestation (less than 2500 grams or less than 37 weeks), all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery
Conditions warranting chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, development delay, CNS condition (i.e. seizure), GI condition (i.e. recurrent blockage), GU condition (i.e. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 6, 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.), infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

Data Collection Methods and Storage

Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Mainframe

Data Analysis

Data analysis software: Access
Quality assurance: validity checks, comparison/verification between multiple data sources, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: link to other state registries/databases, link case finding data to final birth file, plans continue to link several programs housed in the Office of Maternal, Child and Family Health.

Funding

Funding Source: 100% Title V Block Grant funds

Other

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

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Wisconsin

Wisconsin Birth Defects Registry (WBDR)

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

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment, population based
Delivery hospitals: case reports from nursery managers
Pediatric & tertiary care hospitals: case reports from pediatric specialty clinics
Midwifery facilities: midwifery facilities
Third party payers: health maintenance organization (HMOs)
Other specialty facilities: genetic counseling/clinical genetics facilities
Other sources: physician reports, hospital discharge data through 2 yrs of age

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Data Collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.), organizations can report by uploading multiple records to the WBDR secure website.
Database storage/management: Oracle

Data Analysis

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

System Integration

System links: Legislation currently prohibits data linkage.

Funding

Funding Source: 50% General state Funds, 50% MCH funds

Other

Web site: https://wbdr.han.wisc.edu/index.html
Surveillance reports on file: http://dhs.wisconsin.gov/DPH_BFCH/cshcn/bdpsdesc/bdpssystem.htm
Comments: We have stopped printing reports as of 2008 and instead post them to our website.

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Wyoming

Program status: Interested in developing a surveillance program

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US Department of Defense

United States Department of Defense (DoD) Birth and Infant Health Registry

Purpose: surveillance, research
Partner: universities, hospitals, CDC
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: DoD Center for Deployment Health Research, Naval Health Research Center, San Diego, CA
Population covered annually: approximately 100,000 per year
Statewide: No - National/Worldwide; includes all DoD beneficiaries
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum
Legislation year enacted: 1998

Case Definition

Outcomes covered: Outcomes include those birth defects listed in the case definition of the National Birth Defects Prevention Network. For a birth defect to be represented, the diagnosis must appear at least once in an inpatient record, or at least twice on two separate dates for outpatient encounters. Same sex multiples are excluded from analysis.
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: birth to 1 year
Residence: worldwide; any birth to a US DoD beneficiary

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population based, electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries
Delivery hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Third party payers: all inpatient and outpatient encounters are captured in standardized DoD data
Other sources: validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from both military and civilian facilities

Case Ascertainment

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

Data Collected

Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, prenatal diagnostic information, pregnancy/delivery complications
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions

Data Collection Methods and Storage

Data Collection: electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, SAS

Data Analysis

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

System Integration

System links: DoD databases
System integration: DoD databases

Funding

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

Other

Web site: http://www.nhrc.navy.mil/department164/program.html
Surveillance reports on file: DoD/Health Affairs policy memorandum; annual reports

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