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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 defects 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). 2005. State Birth Defects Surveillance Program Directory. Birth Defects Research Part A 73:700-757.

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Alabama

Alabama Birth Defects Surveillance and Prevention Program (ABDSPP)

Purpose: surveillance, research, prevention
Partner: university, hospital, child program, advocacy
Program status: currently collecting data
Start year: 1995
Earliest year of available data: 1998
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
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 and 2003 data: add Barbour, Butler, Pike, and Russell counties to 2001 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. (<20 weeks gestation, 20 weeks gestation and greater), elective terminations
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 and 2003 data: add Barbour, Butler, Pike, and Russell counties to 2001 counties

Surveillance Methods

Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, obstetrics logs (e.g. 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 genetic facilities
Data sharing agreements with other states: yes

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, infant low birth weight or gestation (<2500 Gms), all stillborn infants, all neonatal deaths, all elective abortions, all infants in NICU or special care nursery, all prenatally diagnosed or suspected cases, 5 minute apgar <7
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), occular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: California's coding system based on BPA

Data Collected

Infant/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

Database storage/management: MS Access

Data Analysis

Data analysis software: SPSS, MS 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: CDC grant 80%, University 20%

Other

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

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Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: surveillance
Partner: Department of Health, hospital, nursing, child program, advocacy
Program status: currently collecting data
Start year: 1996
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Maternal and Child 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, 740-760, 760.71
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: birth to age one; birth to age six for alcohol-related birth defects (including fetal alcohol syndrome)
Residence: Alaska residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population based; active case ascertainment for alcohol-related birth defects (including fetal alcohol syndrome)
Case finding/identification sources:
Vital records: birth certificates
Other state-based registries: programs for children with special needs, newborn biochemical screening program, infant learning programs, genetics clinics, specialty clinics (heart, cleft lip/palate, neurodevelopmental), MIMR (FIMR), public health nursing
Delivery hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child treated or diagnosed with a reportable ICD-9 code.
Pediatric & tertiary care hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child treated or diagnosed with a reportable ICD-9 code.
Third party payers: Medicaid databases, Indian health services
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting a chart review beyond the newborn period: any chart with an ICD-9 code of 760.71 or 742.1 and other birth defects as selected for review by the ABDR Program Manager, all fetal and infant deaths (excluding prematurity)
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

Database storage/management: MS Access

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS, MS Access, Excel
Quality assurance: validity checks, re-abstraction of cases, 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: final birth file
System integration: The ABDR is developing a system to match birth defects data the Infant Learning Program (IDEA/Part C) to help identify gaps in services and referrals for children with birth defects.

Other

Web site:
http://www.epi.hss.state.ak.us/mchepi/ABDR/default.stm
Surveillance reports on file: Family Health Datalines, ABDR Surveillance Updates, MCH Fact Sheets (ex: Folic Acid Knowledge and Use in Alaska), Alaska Maternal and Child Health Data Book 2003
Procedure manual available: yes
Additional information on file: results of the Alaska Folic Acid Surveys conducted in 1999 and 2000
Comments: A follow-up survey on folic acid knowledge, attitudes and behavior will be conducted during February/March 2005.

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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: surveillance, service, prevention
Partner: Department of Health, university, hospital, nursing, child program, advocacy
Program status: currently collecting data
Start year: 1986
Earliest year of available data: 1986
Organizational location: Department of Health (Epidemiology/Environment), Bureau of Public Health Statistics/Office of Health Registries
Population covered annually: 93,843 in 2004
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 composite categories covering the major birth defects and genetic diseases, as defined by BPA/CDC codes
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), <20 weeks gestation included if infant $\geq$500 gms, elective terminations (20 weeks gestation and greater), <20 weeks gestation included if infant $\geq$500 gms
Age: up to 1 year after delivery; if nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review (which occurs 2-4 years after the child's birth or fetal death), then the more precise diagnosis is used.
Residence: in-state birth to state resident

Surveillance Methods

Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Other state based registries: programs for children with special needs, newborn biochemical screening program, cases identified through Children Rehabilitation Services Clinic in the Office for Children with Special Health Care Needs
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs, pediatric logs, postmortem/pathology logs, mothers' charts for stillborns
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs, pediatric logs, postmortem/pathology logs, mothers' charts for stillborns
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with 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 (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all prenatally diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, occular 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, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), 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

Database storage/management: MS Access, Oracle

Data Analysis

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

Funding

Funding source: general state funds 30%, MCH funds 3%, genetic screening revenues 27%, CDC grant 40%

Other

Web site: http://www.azdhs.gov/phs/phstats/bdr/index.htm
Surveillance reports on file: Annual Reports, 1986-1997
Procedure manual available: yes
Additional information on file: copy of legislation, case record form, case finding log, abstraction forms, quality assurance procedures
Comments: Contact 3: Bichtram Nguyen, ABDMP, AZ Dept. of Health Services, 150 N. 18th Avenue, Suite 550, Phoenix, AZ 85007; Phone: 602-364-1302; E-mail: nguyenb@azdhs.gov

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Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

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

Case Definition

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

Surveillance Methods

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

Case Ascertainment

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

System Integration

System links: final birth file
System integration: no

Funding

Funding source: general state funds 100%

Other

Web site: http://ARbirthdefectsresearch.uams.edu
Surveillance reports on file: annual reports

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California

California Birth Defects Monitoring Program (CBDMP)

Purpose: surveillance, research
Partner: Department of Health, university
Program status: currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: Occupational and Environmental Disease Control, March of Dimes under contract with State Department of Health Services
Population covered annually: 60,000
Statewide: no; CBDPM currently monitors a sampling of CA births demographically similar to CA as a whole and whose birth defects rates and trends have been reflective of those throughout CA; CBDPM has statutory authority to conduct active surveillance anywhere in CA when warranted by environmental incidents or concerns
Current legislation or rule: Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855
Legislation year enacted: effective 1982, recodified 1996

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. (<20 weeks gestation, ≥20 weeks gestation), elective terminations (≥20 weeks gestation)
Age: one year
Residence: in-state births to residents of 1 of 8 counties; does not include births in military hospitals

Surveillance Methods

Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. 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 (ultrasound, etc.), genetic counseling/clinical genetic, and maternal serum screening facilities; cytogenetic laboratories

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 (e.g. abnormal facies, congenital heart disease), all stillborn infants, all neonatal deaths, all elective abortions, all prenatally diagnosed or suspected cases, apgar 0-0
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, GI condition (e.g. intestinal blockage), cardiovascular condition, all infant deaths (excluding prematurity), occular conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: FoxPro

Data Analysis

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

System Integration

System links: final birth file

Funding

Funding source: general state funds 35%, MCH funds 20%, CDC grant 20%, other federal funding 15%, DHS/UC Pass through 10%

Other

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

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Colorado

Colorado Responds To Children with Special Needs (CRCSN)

Purpose: surveillance, service, prevention
Partner: Department of Health, university, hospital association, local public health, environment, maternal and child health programs, advocacy
Program status: currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 68,798 (2004)
Statewide: yes
Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101 - 25-1.5-105
Legislation year enacted: 1985

Case Definition

Outcomes covered: structural birth defects, genetic and selected metabolic conditions; selected developmental disabilities; very low birth weight (<1500 grams); others with medical and maternal risk factors for developmental delay
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), any gestational age from selected diagnoses made prenatally
Age: up to the 3rd birthday (up to 7th birthday for FAS)
Residence: events occurring in-state or out-of-state to Colorado residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population-based; active for selected data sources and for special projects like fetal alcohol syndrome
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Other state based-registries: newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, specialty outpatient clinics, selected postmortem pathology sites
Pediatric & tertiary care hospitals: disease index or discharge index, specialty outpatient clinics, selected postmortem pathology sites
Other specialty facilities: prenatal diagnostic facilities (ultrasound, cytogenetics, etc.), cytogenetic laboratories, genetic clinics
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: selected chart reviews for prenatal to age 3, statistical trends monitoring (20 conditions - categories), selected death and fetal deaths, fetal alcohol syndrome (to age 7), 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
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

System Integration

System links: final vital records birth file, Newborn Hearing Screening and Newborn Genetic Screening; Integrated Registration Information System (IRIS) (an MCH based system)

Funding

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

Other

Web site: http://www.cdphe.state.co.us/dc/crcsn/crcsnhome.asp
Additional information on file: CRCSN Reference Guide; CRCSN Community Notification and Referral Program Site Manual; Fact sheets (available on web site)

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Connecticut

Connecticut Birth Defects Registry (CTBDR)

Purpose: surveillance, service, prevention, reporting for MCH Block Grant
Partner: hospital, child program, advocacy
Program status: currently collecting data
Start year: 2002
Earliest year of available data: to be determined
Organizational location: Department of Public Health (Maternal and Child Health)
Population covered annually: 45,000
Statewide: yes
Current legislation or rule: Sec. 19a-56a. (Formerly Sec. 10a-132b). Birth defects surveillance program.; Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children.
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
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, inpatient hospitalizations, ambulatory surgery and emergency room visits
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, developmental disabilities surveillance
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
Other sources: physician reports, mandatory reporting by health care providers and facilities; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, cases from birth admissions where the reporting form is the sole source of case ascertainment, cases of multiple anomalies without a specified syndrome, cases where diagnoses are qualified as 'preliminary' or 'rule-out', all cases of chromosomal anomalies lacking confirmation by karyotype, and a 10% random sample, stratified on birth hospital, of all obvious birth defects that were not reported from birth admission but documented from pediatric reports or in the CHIME database
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, provider education

System Integration

System links: final birth file

Funding

Funding source: MCH funds 100%

Other

Procedure manual available: yes

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Delaware

Delaware Birth Defects Surveillance Project

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

Case Definition

Outcomes covered: Birth Defects Registry - all birth defects for passive surveillance, selected birth defects for active surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections
Pregnancy outcome: live births (any gestation for live birth, >20 weeks for fetal death.), fetal deaths – stillbirths, spontaneous abortions, etc.
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
Case finding/identification sources:
Vital records: birth certificates, death certificates, hospital discharge records/data
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn metabolic screening program, cancer registry, HIV/AIDS registry
Delivery hospitals: disease index or discharge index
Pediatric & tertiary care hospitals: disease index or discharge index

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: electronic birth certificate

Data Analysis

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

System Integration

System links: link to Newborn Screening
System integration: initial check into Newborn Screening records with a link, which pulls info to Birth Defects Registry from Newborn Screening system

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District of Columbia

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

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, child program, advocacy
Program status: currently collecting data
Start year: 603
Earliest year of available data: 03
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 15,000 (approximately half are to District residents)
Statewide: yes

Case Definition

Outcomes covered: major birth defects and genetic disorders.
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), >500gm
Age: up to one year after birth except in the case of FAS, which is up to six years
Residence: state resident at the time of diagnosis

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs
Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports
Data sharing agreements with other states: yes

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatally diagnosed or suspected cases, ICD9-CM 740-741.9, 742.3, 743.1, 744-748.5, 749-749.25,750-751.6, 758-758.2, 760.71, 389, 243, 270.1, 270.3, 271.1, 282.2, 282.4-.63, 282.69, 282.7
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, developmental delay, all infant deaths (excluding prematurity), auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Database storage/management: Oracle

Data Analysis

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

System Integration

System links: state registry, final birth file

Funding

Funding source: MCH funds 100%

Other

Procedure manual available: yes

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Florida

Florida Birth Defects Registry (FBDR)

Purpose: surveillance, research, service, prevention, educate health care professionals
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator, federal and state agencies
Program status: currently collecting data
Start year: 1998
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment), Florida Department of Health, Bureau of Community Environmental Health, University
Population covered annually: 212,243 in 2003
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 one
Residence: Florida

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, matched birth/death file, fetal death certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs
Third party payers: Medicaid databases, health maintenance organizations (HMOs)
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetic facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected procedure codes, any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease)
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), auditory/hearing conditions
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Database storage/management: MS Access, Excel

Data Analysis

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

System Integration

System links: state registry, final birth file, environmental

Funding

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

Other

Web site: http://www.fbdr.org
Surveillance reports on file: 1996 Annual Report, Neural Tube Defects Report, Data Quality Assurance Report, Active Surveillance Report, Website
Procedure manual available: yes
Additional information on file: grants, progress reports, educational and health promotion materials, and video tapes

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Georgia

Centers for Disease Control and Prevention, Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: surveillance, research, service
Partner: university, hospital
Program status: currently collecting data
Start year: 1967
Earliest year of available data: 1968
Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities
Population covered annually: 51676
Statewide: no, births to mothers residing within one of five central counties in the metropolitan Atlanta area of the state of Georgia
Current legislation or rule: State Laws Official Georgia Code Annotated (OCGA) 31-12-2

Case Definition

Outcomes covered: major structural or genetic birth defects
Pregnancy outcome: live births (≥20 weeks), fetal deaths – stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (<20 week gestation, 20 weeks gestation and greater)
Age: before 6 years of age
Residence: births to mothers residing in one of five central metropolitan Atlanta counties

Surveillance Methods

Case ascertainment: active case ascertainment; population-based; combination of active and passive case ascertainment for cases ascertained only at perinatal offices
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. 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 an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, infant low birth weight or gestation (birth weight <2500 grams or <36 weeks gestation), all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatally diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), cardiovascular condition, occular 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

Database storage/management: Epi-Info, Mainframe

Data Analysis

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

System Integration

System links: state registry, final birth file, environmental, National Death Index

Funding

Funding source: other federal funding 100%

Other

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

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Georgia

Georgia Birth Defects Reporting and Information System (GBDRIS)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, advocacy
Program status: currently collecting data
Start year: 2003
Earliest year of available data: 2004
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 135,000
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. (<20 weeks gestation, 20 weeks gestation and greater), elective terminations
Age: up to 6 years of age
Residence: in and out of state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Third party payers: Medicaid databases
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

System Integration

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

Funding

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

Other

Web site:
http://health.state.ga.us/epi/mch/birthdefects/gbdris/index.asp
Procedure manual available: yes
Comments: Contact 3: Nicole Tucker, MPH, GA Division of Public Health, MCH Epidemiology Section, 2 Peachtree Street, NW, Suite 14-414, Atlanta, GA 30303, Phone: 404-651-5196, E-mail: ntucker@dhr.state.ga.us

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Hawaii

Hawaii Birth Defects Program (HBDP)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, nursing, environment, child program, advocacy, legislator
Program status: currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: combination of DOH/Children with Special Health Needs Branch and the Research Corporation of the University of Hawaii
Population covered annually: ~19,684 average over last 17 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 BPA Classification of Diseases (1979) and WHO ICD-9 CM (1977).
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (<20 week gestation, 20 weeks gestation and greater), elective terminations (all gestational ages), data collected on all elective medical terminations carried out because a screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect and the parents elected not to bring the baby to term
Age: up to one year after delivery
Residence: all in-state Hawaii births (resident and non-resident)

Surveillance Methods

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

Case Ascertainment

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

Database storage/management: MS Access

Data Analysis

Data analysis software: MS Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, education/public awareness, prevention projects, publication of 38 articles (as of 12/31/04) in peer-review professional journals

System Integration

System links: The HBDP is in the process of implementing a GIS statistical mapping project.

Funding

Funding source: general state funds 54%, CDC grant 31%, other federal funding 5%, private foundations 4%, Special Fund funding 6%

Other

Web site: http://www.hawaiibirthdefects.org
Surveillance reports on file: 12 Hawaii Birth Defects Program Statewide Surveillance Data Reports: 1) 1989-1991, 2) 1988-1993, 3) 1988-1994, 4) 1988-1995, 5) 1987-1996, 6) 1986-1997, 7) 1986-1998, 8) 1986-1999, 9) 1986-2000, 10) 1986-2001, 11) 1986-2002, and 12) 1986-2003 (to be published soon)
Procedure manual available: yes

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

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Idaho

Program status*:* No surveillance program

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Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: surveillance, service, prevention
Partner: Department of Health, hospital, environment, child program, advocacy, legislator
Program status: currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 182,000
Statewide: yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)
Legislation year enacted: 1985

Case Definition

Outcomes covered: ICD-9-CM codes 740.0 through 759.9; infants positive for controlled substances; serious congenital infections; congenital endocrine, metabolic or immune disorders; congenital blood disorders; other conditions such as retinopathy of prematurity, fetal alcohol
Pregnancy outcome: live births, fetal deaths – stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: end of newborn hospitalization
Residence: in-state births mandatory

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population-based; birth defect diagnoses are confirmed in a review of medical records by APORS staff.
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
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, hospitals mandated to report newborns discharged from any to the NICU or specialty units

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), infant low birth weight or gestation (<1500 grams), all neonatal deaths
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, FoxPro, Mainframe

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, public health program evaluation, 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: final birth file
System integration: no

Funding

Funding source: general state funds 73%, CDC grant 27%

Other

Web site: http://www.idph.state.il.us/about/epi/aporsrpt.htm
Surveillance reports on file: available on website

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Indiana

Indiana Birth Defects and Problems Registry (IBDPR)

Purpose: surveillance, research, service
Partner: universities, hospitals, early childhood prevention programs, advocacy groups, legislators, state and federal agencies
Program status: currently collecting data
Start year: 2002
Earliest year of available data: 2003 birth data will be available in 2006
Organizational location: Department of Health (Maternal and Children's Special Health Care Services)
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), fetal deaths – stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (20 weeks gestation and greater)
Age: up to 5 years
Residence: in- and out-of-state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment, population-based, combined with selected active confirmation
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates
Other state-based registries: newborn hearing screening program, cancer registry, newborn biochemical screening lab data
Delivery hospitals: disease index or discharge index, chart audits of 45 targeted birth defects
Pediatric & tertiary care hospitals: discharge summaries, chart audits of 45 targeted birth defects
Other specialty facilities: genetic counseling/clinical genetic facilities, prenatal diagnostic facilities (ultrasound, etc.) (planning)
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart whose ICD-9-CM falls within the 45 targeted medical conditions
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.), birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness

System Integration

System links: state registry, final birth file
System integration: The database is linked with births, deaths, fetal deaths, and newborn screening data.

Funding

Funding source: Genetic Implementation Grant 25%, MCH funds 75%

Other

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

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Iowa

Iowa Registry for Congenital and Inherited Disorders (IRCID)

Purpose: surveillance, research, service, prevention, prevention education programs
Partner: Department of Health, university, hospital, environment, legislator
Program status: currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: university
Population covered annually: 37,831 avg 10 yr
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
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (<20 week gestation, ≥20 weeks gestation), elective terminations
Age: 1 year
Residence: maternal residence in Iowa at time of delivery

Surveillance Methods

Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Vital records: birth, death, and fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, specialty outpatient clinics
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports, outpatient surgery facilities
Data sharing agreements with other states: yes

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, a selected list of ICD9-CM codes outside 740-759, a CDC/BPA code, selected procedure codes, selected defects or medical conditions (e.g. abnormal facies, CHD); any birth certificate with a birth defect box checked; all stillborn infants, neonatal deaths, elective abortions, prenatally diagnosed or suspected cases; muscular dystrophy
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), cardiovascular condition, all infant deaths (excluding prematurity), occular 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

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

Data Analysis

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

System Integration

System links: state registry, final birth file, environmental
System integration: no

Funding

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

Other

Web site: http://www.public-health.uiowa.edu/ircid
Surveillance reports on file: registry reports for 2000, 2002, 2005
Procedure manual available: yes
Comments: former name: Iowa Birth Defects Registry

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Kansas

Birth Defects Reporting System

Purpose: registry
Partner: hospital
Program status: currently collecting data
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 39,353 (Year 2003)
Statewide: yes
Current legislation or rule: KSA 65-102; KSA 75-3715a (Senate Bill No. 418)
Legislation year enacted: 1979; 2004

Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics, but are not used as part of a birth defects surveillance system. Twenty-four anomalies are listed on the birth certificate and are reported; however, these are not linked to ICD codes.
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (<20 weeks gestation, 20 weeks gestation and greater), elective terminations (all gestational ages)
Age: passive reporting on congenital malformation reports continues through the first year of life
Residence: in- and out-of-state births to Kansas residents and in-state births to out of state residents

Surveillance Methods

Case ascertainment: passive case ascertainment, hospital-based
Case finding/identification sources:
Vital records: birth certificates
Pediatric & tertiary care hospitals: congenital malformations reporting form - sent by hospitals for infants up to one year of age
Data sharing agreements with other states: yes

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

Database storage/management: Mainframe

Data Analysis

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

System Integration

System links: state registry
System integration: program has a link with vital statistics records

Funding

Funding source: MCH funds 100%

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Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: surveillance, service, prevention of birth defects
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator
Program status: currently collecting data
Start year: 1996
Earliest year of available data: 1998
Organizational location: Department for Public Health, Division of Adult and Child Health Improvement, Early Childhood Branch
Population covered annually: 54,500
Statewide: yes
Current legislation or rule: KRS 211.651-211.670
Legislation year enacted: 1992

Case Definition

Outcomes covered: major birth defects, genetic diseases, fetal mortality
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. ($\geq$20 weeks gestation), 20 weeks or 350 gms., elective terminations ($\geq$20 weeks gestation), elective terminations prior to 20 weeks are identified in pilot active surveillance project at eight hospitals in Kentucky which represent 36% of births
Age: up to fifth birthday
Residence: all in-state births; out-of-state births to state residents

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population-based
Case finding/identification sources:
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 biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics, laboratory records
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, laboratory records
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities
Other sources: physician reports, local health departments

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 (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all prenatally diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (e.g. seizure), cardiovascular condition, any infant with a codable defect
Coding: ICD-9-CM, ICD-10 for Vital Statistics death data

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Mainframe

Data Analysis

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

System Integration

System links: final birth file

Funding

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

Other

Web site: http://chfs.ky.gov/dph/ach/kbsr.htm
Surveillance reports on file: legislation and regulation, Hospital Reporting Administrative Manual, draft confidentiality guidelines, conditions definitions, KBSR fact sheet, KBSR brochure
Procedure manual available: yes

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Louisiana

Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: surveillance, service
Partner: university, hospital, child program, advocacy
Program status: currently collecting data
Start year: 2005
Earliest year of available data: 2005
Organizational location: Office of Public Health, Children's Special Health Services
Population covered annually: 21,000 (for 2005)
Statewide: no; covering Bossier, Caddo, Calcasieu, Cameron, East Baton Rouge, and Orleans parishes in 2005
Current legislation or rule: 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, selected genetic diseases and metabolic disorders
Pregnancy outcome: live births (20 weeks gestation and greater or birth weight $\geq$350gms.)
Age: up to third birthday
Residence: in- and out-of-state births to state residents

Surveillance Methods

Case ascertainment: active case ascertainment
Case finding/identification sources:
Vital records: in progress
Other state-based registries: in progress
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: in progress
Third party payers: in progress
Other sources: in progress

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD-9-CM code 740-759, 760.71, or 762.8, plus selected codes for endocrine, metabolic, immune and blood disorders
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, 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

Database storage/management: in progress

Data Analysis

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

System Integration

System links: in progress

Other

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

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Maine

Maine Birth Defects Program (MBDP)

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

Case Definition

Outcomes covered: selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21 and major heart defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. ($\geq$20 weeks gestation), 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
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: programs for children with special needs, Newborn Hearing and Newborn Screening Programs
Delivery hospitals: disease index or discharge index, specialty outpatient clinics (Spina Bifida, Cleft lip and palate, high-risk OB)
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts, pediatric logs, specialty outpatient clinics
Midwifery facilities: Ballard House
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatally diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, 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

Database storage/management: MS Access, Citrix, University of Maine/Center for Excellence in Developmental Disabilities ChildLINK database system electronic abstraction record/hospital case reports/electronic submission of hospital discharge data. On-line hospital case report form.

Data Analysis

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

System Integration

System links: state registry, final birth file

Funding

Funding source: Currently, MCH funds pending additional funding sources

Other

Web site: http://www.maine.gov/dhhs/boh/cshn/home.html
Additional information on file: program manual in draft form/newsletter/brochure

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Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

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

Case Definition

Outcomes covered: selected birth defects: anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), or ≥500 grams weight; reports accepted on fetal deaths <500 grams or <20 weeks gestation, elective terminations, reports accepted on terminations
Age: newborn
Residence: all in-state births

Surveillance Methods

Case ascertainment: passive case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, Sickle Cell Disease
Delivery hospitals: obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form
Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form
Other specialty facilities: genetic counseling/clinical genetic facilities, maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with selected defects or medical conditions (e.g. 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, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

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

Funding

Funding source: general state funds 100%

Other

Web site: http://www.fha.state.md.us/genetics (then select Birth Defects Reporting Information)
Surveillance reports on file: provisional surveillance reports 1984-1992; 1995-2002
Procedure manual available: yes
Additional information on file: copies of publications, legislation, miscellaneous booklets and other information related to birth defects surveillance in Maryland

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Massachusetts

Massachusetts Center for Birth Defects Research and Prevention (MCBDRP), Birth Defect Monitoring Program, MA Dept. of Public Health

Purpose: surveillance, research, service, prevention
Partner: university, hospital, environment, advocacy
Program status: currently collecting data
Start year: 1997
Earliest year of available data: 1999 for statewide data
Organizational location: Bureau of Family and Community Health
Population covered annually: 81,000
Statewide: yes
Current legislation or rule: Massachusetts General Laws, Chapter 111, Section 67E. In 2002 the Massachusetts Legislature amended this statute, expanding the birth defects monitoring program. The new law: 1) increases mandated reporting up to age three; 2) requires physicians to report to MDPH within 30 days of diagnosis; 3) sets out requirements for the use of this data; 4) requires MDPH to promulgate regulations governing the operation of the Birth Defects Monitoring Program.
Legislation year enacted: 1963

Case Definition

Outcomes covered: major structural birth defects and chromosomal anomalies of medical, surgical or cosmetic significance
Pregnancy outcome: live births, reportable fetal deaths (≥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: population-based, state-wide, combination of active case ascertainment and administrative review
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, postmortem/pathology logs
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts, postmortem/pathology logs
Other sources: physician reports
Data sharing agreements with other states: yes

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 (e.g. abnormal facies, congenital heart disease), all stillborn infants
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: SAS, MS 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 investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, selected cases from surveillance are eligible for CDC's National Birth Defects Prevention Study

System Integration

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

Funding

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

Other

Web site: http://www.mass.gov/dph/fch/birthdefects/bdefects.htm
Surveillance reports on file: first surveillance report published in November 2001, available online at http://www.mass.gov/dph/fch/birthdefects/bdefects.htm or by calling contacts; MCBDRP Prevention and Resource Booklet at http://www.mass.gov/dph/fch/birthdefects/bdefects.htm
Procedure manual available: yes
Comments: statewide coverage started October 1998

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Michigan

Michigan Birth Defects Registry (MBDR)

Purpose: surveillance, research, service, prevention, incidence and mortality statistics
Partner: Department of Health, university, hospital, environment, advocacy, legislator
Program status: currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics)
Population covered annually: 135,000
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)
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
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death reporting, cytogenic laboratories, genetics clinics, hospital discharge data
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry, 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
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: FoxPro

Data Analysis

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

System Integration

System links: state registry, final birth file, final mortality file
System integration: no; data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

Funding

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

Other

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

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Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, child program, advocacy, legislator
Program status: currently collecting data
Start year: 2005
Earliest year of available data: 2005
Organizational location: Environmental Health
Population covered annually: 71,000
Statewide: no; the surveillance system will be phased in over a number of years. Implementation will begin in the two largest counties in Minnesota Hennepin and Ramsey counties, which account for approximately 50 percent of the births.
Current legislation or rule: MS 144.2215-2219
Legislation year enacted: 2004

Case Definition

Outcomes covered: major "reported birth defects" as defined by CDC and ICD-9 codes
Pregnancy outcome: live births (up to one year; FAS cases will include children up to 6 years of age)
Age: up to 1 year after delivery
Residence: in-state data

Surveillance Methods

Case ascertainment: active surveillance will be phased in based on resources; passive sources will also be used after validation
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, infant death records
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), ICU/NICU logs or charts, surgery logs, 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 organizations (HMOs)
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all infants in NICU or special care nursery
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies
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
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle, format/platform to be determined based on collaborative partners

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness, physician review as needed; additional quality control checks may be added after start-up
Data use and analysis: public health program evaluation, baseline rates, epidemiologic studies (using only program data), referral, grant proposals, education/public awareness, prevention projects, full system implementation in 2005; many of these listed above will be used

System Integration

System links: final birth file
System integration: Program plans to integrate with Newborn Screening/Hearing and collaborate with other regional programs.

Funding

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

Other

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

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Mississippi

Mississippi Birth Defects Registry (MBDR)

Purpose: surveillance
Partner: Department of Health, hospital
Program status: currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health), Division of Genetic Services, Mississippi Department of Health
Population covered annually: 42,000
Statewide: yes
Current legislation or rule: section 41-21-205 of the Mississippi Code
Legislation year enacted: 1997

Case Definition

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

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Other state-based registries: newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, occular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

Funding

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

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Missouri

Missouri Birth Defects Registry

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator
Program status: currently collecting data
Start year: 1985
Earliest year of available data: 1980
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 75,000
Statewide: yes

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment, multi-source
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: discharge summaries
Pediatric & tertiary care hospitals: discharge summaries, specialty outpatient clinics
Other sources: enrollment data, Missouri Department 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

Database storage/management: SAS (Unix)

Data Analysis

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

System Integration

System links: final birth file

Funding

Funding source: MCH funds 37%, service fees 54%, private foundations 9%

Other

Surveillance reports on file: Missouri Birth Defects 1995-99

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

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

Case Definition

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

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: cardiovascular condition
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, ClusterSeer 2
Quality assurance: double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: state registry
System integration: integrated with Children with Special Health Care Needs database

Funding

Funding source: CDC grant 100%

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Nebraska

Nebraska Birth Defects Registry

Purpose: surveillance, research; in the process of developing a program of referral to services and prevention programs
Partner: hospital, Department of Health and Human Services and MCH
Program status: currently collecting data
Start year: 1973
Earliest year of available data: 1973
Organizational location: Nebraska Health and Human Services Regulation & Licensure Data Management Section
Population covered annually: statewide, 24,000+ births annually
Statewide: yes
Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §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 (>20 weeks and >500 grams), fetal deaths – stillbirths, spontaneous abortions, etc. (≥20 weeks gestation)
Age: birth to one year
Residence: in-state and out-of-state birth to state resident

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, ICU/NICU 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 genetic facilities
Other sources: physician reports
Data sharing agreements with other states: yes

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 (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, occular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Key-entry 3

Data Analysis

Data analysis software: SAS
Quality assurance: re-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 investigations, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, Incidence rates, trend analysis, birth defect registry

Funding

Funding source: MCH funds 100%

Other

Surveillance reports on file: 2003 report in Vital Statistics Report. 2004 report will be available in published form in November of 2005.
Procedure manual available: yes
Additional information on file: copy of legislation, congenital defects case record form
Comments: State legislation introduced to allow release of patient-identifying information to approved researcher for the purpose of research; development of a system so that hospitals may use the electronic birth certificate to initially alert the surveillance program of the birth of a child with an anomaly.

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Nevada

Nevada Birth Defects Registry

Purpose: surveillance, service, prevention
Partner: Bureau of Health Planning and Statistics
Program status: currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: State Division of Health, Bureau of Family Health Services (MCH)
Population covered annually: 33,000 in 2003
Statewide: no; year 2000 data is for Las Vegas only, statewide data completed for year 2001
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 (all gestational ages and birth weights), fetal deaths (20 weeks gestation and greater), elective terminations (20 weeks gestation and greater)
Age: cover 0-7 years of age
Residence: in-state births

Surveillance Methods

Case ascertainment: combination of active and passive ascertainment initially; restarted active case ascertainment in July 2004
Case finding/identification sources:
Vital records: birth certificates, matched birth/death file, hospital medical records - for year 2000
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: disease index or discharge index
Pediatric & tertiary care hospitals: disease index or discharge index
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with 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 (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle, Mainframe

Data Analysis

Data analysis software: SPSS, SAS, MS Access
Quality assurance: double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, education/public awareness

System Integration

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

Funding

Funding source: service fees 100%

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New Hampshire

New Hampshire Birth Conditions Program (NHBCP)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator
Program status: currently collecting data
Start year: 2003
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health), Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, Department of Environmental Services Bureau of Environmental Health, University
Population covered annually: 14,000
Statewide: yes; currently collecting 2003 and 2004 data for all birth hospitals in the state
Current legislation or rule: Currently working toward a legislative rules revision that would include birth defects. Draft rules have been written and provided to NH's Department of Health and Human Services for inclusion in a 2005 NH DHHS Administrative Rules change proposal.

Case Definition

Outcomes covered: all major birth defects and genetic diseases recommended by CDC/NBDPN
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. ($\geq$20 weeks gestation), elective terminations
Age: fetuses >20 weeks gestation, newborns/infants up to 1 year
Residence: all NH residents (born in- and out-of-state)

Surveillance Methods

Case ascertainment: active case ascertainment, population based
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates, fetal pathology reviews at Dartmouth Hitchcock Medical Center
Other state-based registries: newborn hearing screening program
Delivery hospitals: discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, medical records abstraction of charts of selected ICD 9 Codes
Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics, cytogenetics laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all stillborn infants, all infants in NICU or special care nursery, all prenatally diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA, 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 diagnostic information
Father: identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

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, MS Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review
Data use and analysis: Statewide data collection began January 2005 for calendar years 2003-2004. No data use or analysis has occurred in the previous 12 months; however, we anticipate preliminary analysis to begin in the summer of 2005.

System Integration

Integrated into the NH DHHS Newborn Hearing Screening Program registry, a statewide universal hearing program for all NH infants.

Funding

Funding source: CDC grant 100%

Other

Web site: in production (to be completed 9/2005)
Surveillance reports on file: not at this time
Procedure manual available: yes
Additional information on file: abstract for a pilot study on the comparison between birth certificate data and ICD-9 code data alone and with the use of medical chart abstraction for NH birth defects surveillance

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New Jersey

Special Child Health Services Registry (SCHS REGISTRY)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator
Program status: currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health & Senior Services – Special Child, Adult, and Early Intervention Services
Population covered annually: 114,500
Statewide: yes
Current legislation or rule: NJSA 26:8 et seq., NJAC 8:20
Legislation year enacted: 1983; effective date March 4, 1985; legislation changes 1990, 1991, 1992; readopted March 2005

Case Definition

Outcomes covered: all birth defects (including structural, genetic, and biochemical) 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 ≤ age 2, voluntary reporting of birth defects diagnosed > age 2 and all children diagnosed with Special Needs conditions ≤ 22 years
Residence: in/out NJ births to NJ residents; because of our link to the SCHS Case Management system, we also enroll anyone becoming NJ residents

Surveillance Methods

Case ascertainment: passive, population-based reporting system with annual quality assurance visits by BDR staff to birthing hospitals, birthing centers and pediatric care facilities; medical providers contacted to confirm 'questionable' diagnoses; medical chart review conducted on all children registered with any of the defects eligible for participation in the NBDPS
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, AIDS/HIV registry
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/ pathology logs, surgery logs, cardiac catheterization laboratories, specialty outpatient clinics, quality assurance visit consisting of chart review of 3-month period
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics, quality assurance visit consisting of chart review of 3-month period
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetic facilities
Other sources: physician reports, Special Child Health Services county-based Case Management units, parents, schools, 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 <1 year of age
Conditions warranting a chart review beyond the newborn period: GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), occular 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.)
Father: identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Database storage/management: SAS

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, 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 investigations, time-space cluster analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: state registry, final birth file, link to hearing screening registry
System integration: hearing screening registry provides direct feed into SCHS Registry

Funding

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

Other

Web site: http://www.state.nj.us/health/fhs/scregis.htm
Surveillance reports on file: Special Child Health Services Registry (1985-1989, 1985-1991, 1985-1994, 1990-1999 [in press])
Additional information on file: information sheet, case record form, copy of legislation, quality assurance audit information

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New Mexico

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

Purpose: surveillance, research, service, prevention
Partner: university, hospital, child program, legislature
Program status: currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 27,500
Statewide: yes
Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regulations.
Legislation year enacted: January 1, 2000

Case Definition

Outcomes covered: 740-760.71
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths and terminations included in NTD counts
Age: birth through age 14 years
Residence: in-state births to New Mexico residents (since 2001); previous years included out-of-state births to NM residents

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759 and 760.71, any birth certificate with a birth defect box checked, all prenatally diagnosed or suspected cases, any chart with a list of other ICD9-CM codes selected by CMS
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Excel

Data Analysis

Data analysis software: SAS
Quality assurance: validity checks, reabstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, grant proposals, education/public awareness, prevention projects, Mar03-Mar04 NM BDPASS did not have epidemiology staff; prevention teams developed teaching modules

System Integration

System links: state registry, final birth file
System integration: BDPASS is integrated with the Children's Chronic Conditions Registry

Funding

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

Other

Web site: http://www.health.state.nm.us
Surveillance reports on file: Birth Defects in New Mexico 1997-1998; Birth Defects in New Mexico 1995-1999

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New York

New York State Congenital Malformations Registry (CMR)

Purpose: surveillance, research, service, prevention
Partner: university, hospital, child program, March of Dimes
Program status: currently collecting data
Start year: 1982
Earliest year of available data: 1983
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 260,000
Statewide: yes
Current legislation or rule: Public Health Law Art. 2, Title, II, Sect 225(5)(t) and Art. 2 Title I, sect 206(1)(j): Codes, Rules and Regulations, Chap 1, State Sanitary Code, part 22.3
Legislation year enacted: 1982

Case Definition

Outcomes covered: major malformations, detailed list available upon request
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: 2 years
Residence: in- and out-of-state birth to state residents; in-state birth to nonresidents; 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
Case finding/identification sources:
Delivery hospitals: disease index or discharge index, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts
Other sources: physician reports, hospital discharge data

Case Ascertainment

Conditions warranting chart review in newborn period: charts with selected ICD-9CM codes in the 740-759
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

Database storage/management: MS Access, FoxPro, Sybase

Data Analysis

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

System Integration

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

Funding

Funding source: general state funds 15%, MCH funds 24%, CDC grant 45%, other federal funding 16%

Other

Web site:
http://www.health.state.ny.us/nysdoh/cmr/cmrhome.htm
Surveillance reports on file: reports for 1983-2001.
Procedure manual available: yes

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North Carolina

North Carolina Birth Defects Monitoring Program (NCBDMP)

Purpose: surveillance, research, service, prevention, education, advocacy
Partner: Department of Health, university, hospital, child program, advocacy, legislator
Program status: currently collecting data
Start year: 1987
Earliest year of available data: 1989
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 118,000
Statewide: yes
Current legislation or rule: NCGS 130A-131
Legislation year enacted: 1995

Case Definition

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

Surveillance Methods

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

Case Ascertainment

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

Data Collected

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

Database storage/management: MS Access, Mainframe, SAS

Data Analysis

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

System Integration

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

Funding

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

Other

Web site: http://www.schs.state.nc.us/SCHS
Surveillance reports on file: annual reports, special studies

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North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

Purpose: surveillance
Partner: university, March of Dimes
Program status: currently collecting data
Start year: 2002
Earliest year of available data: 1994
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health), ND Department of Human Services (Children's Special Health Services)
Population covered annually: 7676
Statewide: yes
Current legislation or rule: North Dakota Centry code 50-10
Legislation year enacted: n/a

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry, AIDS/HIV registry, FAS
Delivery hospitals: birth certificate completion
Pediatric & tertiary care hospitals: specialty outpatient clinics
Third party payers: Medicaid databases, health maintenance organizations (HMOs), private insurers
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports
Data sharing agreements with other states: yes

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 (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked
Coding: ICD-9-CM, ICD 10

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

Funding

Funding source: SSDI Grant

Other

Web site: http://www.vitalnd.com
Procedure manual available: yes

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Ohio

Ohio Connections for Children with Special Needs (OCCSN)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, child program, advocacy, legislator
Program status: program has not started collecting data
Start year: 2004
Earliest year of available data: n/a
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: system in development
Statewide: system in development
Current legislation or rule: Ohio Revised Code (ORC) 3705.30 - 3705.36. "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."
Legislation year enacted: 2000, administrative rules became effective June 3, 2005

Case Definition

Outcomes covered: 45 disorders recommended by NBDPN

Surveillance Methods

Case ascertainment: passive reporting

Funding

Funding source: CDC grant 100%

Other

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Oklahoma

Oklahoma Birth Defects Registry (OBDR)

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

Case Definition

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

Surveillance Methods

Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, surgery logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, pediatric logs, surgery logs, specialty outpatient clinics
Third party payers: Indian Health Services, military hospitals delivering babies
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities
Data sharing agreements with other states: yes

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 a chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: SAS, MS 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 investigations, time-space cluster analyses, needs assessment, referral, grant proposals, education/public awareness, prevention projects, program quality assurance

System Integration

System links: 9/2003 awarded Environmental Public Health Tracking Grant to link health outcomes & environmental contamination data – in planning stages

Funding

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

Other

Surveillance reports on file: 1992 & 1993 Annual Report - combined for Oklahoma, Tulsa and Cleveland Counties; 1994-1998 Annual Report; Congenital Malformations Tables & Prevalence Rates/1994-2002
Procedure manual available: yes
Additional information on file: PRAMS Gram Vol 8 No 3: Folic Acid Knowledge and Multivitamin Use Among Oklahoma Women; provisional rate tables for 1994-2002.
Comments: Statewide data collection began in 1994. Additional information for case definitions residence: 1995 began abstraction of Oklahoma residents born in Fort Smith, Arkansas.

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Oregon

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Pennsylvania

Pennsylvania Follow-Up, Outreach, Referral and Education for Families (PA FORE FAMILIES)

Purpose: surveillance, service
Partner: university, hospital, nursing, advocacy
Program status: currently collecting data
Start year: 2003
Earliest year of available data: 2001
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 142,380 resident live births in 2002; 145,485 resident live births in 2003
Statewide: yes

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
Case finding/identification sources:
Vital records: birth certificates, matched birth/death file, fetal death certificates, hospital discharge data collected by the Pennsylvania Health Care Cost Containment Council (PHC4--a state agency).
Delivery hospitals: PHC4 data is based on hospital discharge summaries
Pediatric & tertiary care hospitals: PHC4 data is based on hospital discharge summaries

Case Ascertainment

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

Data Collected

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

Database storage/management: MS Access, Mainframe

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, comparison/verification between multiple data sources, data/hospital audits
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: MCH funds 100%

Other

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

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Puerto Rico

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

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, nursing, child program, advocacy
Program status: currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Division of Children with Special Health Care Needs
Population covered annually: 56,000
Statewide: yes
Current legislation or rule: Law 351
Legislation year enacted: September 16, 2004

Case Definition

Outcomes covered: neural tube defects (anencephaly, encephalocele, myelomeningocele and meningocele), cleft lip and/or cleft palate, gastroschisis, club foot, limb reduction defects, Down syndrome, omphalocele, ambiguous genitalia, trisomy 13, trisomy 18, conjoint twins, albinism, and congenital heart defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (<20 weeks gestation, 20 weeks gestation and greater), elective terminations
Age: up to 6 years after delivery
Residence: in-state birth to state residents

Surveillance Methods

Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: programs for children with special needs
Delivery hospitals: obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: ICU/NICU logs or charts, pediatric logs, surgery logs, laboratory logs
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), genetic counseling/clinical genetic 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 (e.g. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all elective abortions, all infants in NICU or special care nursery, all prenatally diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: 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, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

Funding

Funding source: MCH funds 59%, CDC grant 41%

Other

Web site: http://www.salud.gov.pr/AF/AFindex.htm
Surveillance reports on file: description of registry development, case report form, manual for case report form
Procedure manual available: yes

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Rhode Island

Rhode Island Birth Defects Surveillance Program

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

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program; RI has an integrated database called KIDS NET, which links data from 9 programs (Universal Newborn Developmental Risk Screening, Universal Newborn Hearing, Newborn Bloodspot Screening, Early Intervention, Immunization, Lead Poisoning, WIC, Home Visiting, Vital Records)
Delivery hospitals: discharge summaries, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: specialty outpatient clinics
Other specialty facilities: genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: chart reviews conducted for every newborn identified with a birth defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle

Data Analysis

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

System Integration

System links: state registry, KIDSNET (Universal Newborn Developmental Risk Screening, Universal Newborn Hearing, Newborn Bloodspot Screening, Early Intervention, Immunization, Lead Poisoning, WIC, Home Visiting, Vital Records), hospital discharge database

Funding

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

Other

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

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South Carolina

South Carolina Birth Defects Surveillance and Prevention Program

Purpose: surveillance, research, service
Partner: Department of Health, university, hospital
Program status: currently collecting data
Start year: 1992
Earliest year of available data: 1993
Organizational location: Greenwood Genetic Center
Population covered annually: 56,182
Statewide: yes

Case Definition

Outcomes covered: neural tube defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (<20 weeks gestation, 20 weeks gestation and greater), elective terminations (<20 weeks gestation, 20 weeks gestation and greater)
Age: up to one year after delivery
Residence: in- and out-of-state births to residents of South Carolina

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, autopsy
Delivery hospitals: disease index or discharge index, discharge summaries, postmortem/pathology logs, specialty outpatient clinics, ICD-9 codes
Pediatric & tertiary care hospitals: discharge summaries, specialty outpatient clinics
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports
Data sharing agreements with other states: yes

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 (e.g. abnormal facies, congenital heart disease), all prenatally diagnosed or suspected cases
Coding: ICD-9-CM

Data Collected

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

Database storage/management: MS Access

Data Analysis

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

Funding

Funding source: general state funds 65%, institutional funding 25%, March of Dimes 10%

Other

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

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South Dakota

Program status: No surveillance program

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Tennessee

Tennessee Birth Defects Registry (TBDR)

Purpose: surveillance, research, service, prevention
Partner: hospital, child program, advocacy, legislator
Program status: currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: research
Population covered annually: 80,000
Statewide: yes
Current legislation or rule: TCA 68-5-506
Legislation year enacted: 2000

Case Definition

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

Surveillance Methods

Case ascertainment: passive case ascertainment supplemented with active case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catheterization laboratories, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, infant low birth weight or gestation (active review sample infants with no known diagnosis and oversample for low birth weight), ICD9-CM code 760.71
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, SQL Server

Data Analysis

Data analysis software: SAS, MS Access, SQL Server
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, observed vs expected analyses, needs assessment, service delivery, education/public awareness, prevention projects

Funding

Funding source: general state funds 100%

Other

Surveillance reports on file: Birth Defects in Tennessee 2000-2002

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Texas

Texas Birth Defects Monitoring Division (TBDMD)

Purpose: surveillance, research, service, prevention
Partner: university, hospital, advocacy
Program status: currently collecting data
Start year: 1994
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 377,000
Statewide: yes
Current legislation or rule: Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87
Legislation year enacted: 1993

Case Definition

Outcomes covered: all major structural birth defects and FAS
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths – stillbirths, spontaneous abortions, etc. (<20 weeks gestation, ≥20 weeks gestation), elective terminations
Age: up to one year after delivery; FAS to any age
Residence: in-state births to state residents

Surveillance Methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), infant low birth weight or gestation (<34 weeks GA), all stillborn infants
Conditions warranting a chart review beyond the newborn period: CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. 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, etc.), gravidity/parity, illnesses/conditions, prenatal diagnostic information, pregnancy/delivery complications, maternal risk factors, family history
Father: identification information (name, date-of-birth, etc.), demographic information (race/ethnicity, etc.)

Data Collection Methods and Storage

Database storage/management: SQL Server

Data Analysis

Data analysis software: SAS, MS Access, SPSS
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, clinical review, timeliness, re-casefinding, re-review of medical records
Data use and analysis: baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, epidemiologic studies, identification of potential cases for other epidemiologic studies, referral, grant proposals, education/public awareness

System Integration

System links: link registry to vital records for demographic data

Funding

Funding source: general state funds 51%, MCH Title V funds 33%, Preventive Health Block Grant 16% *Note: does not include CDC-funded Texas Center for Birth Defects Research and Prevention

Other

Web site: http://www.dshs.state.tx.us/birthdefects
Surveillance reports on file: 1996 Birth Defects in the Lower Rio Grande Valley; Report of Birth Defects Among 1995 Deliveries, Among 1996 and 1997 Deliveries, Among 1998 and 1999 Deliveries, Among 1999 and 2000 Deliveries, and Among 1999-2001 Deliveries
Procedure manual available: yes
Additional information on file: copy of legislation, FAS brochure (English and Spanish), Pregnancy Outcome Patterns for Various Defects, Impact of Including Induced Pregnancy Terminations Before 20 Weeks Gestation on Birth Defect Rates, Cluster Investigation Reports, Birth Defects Glossary, Recent Trends in Neural Tube Defects in Texas, Birth Defects Risk Factor Series
Comments: Statewide as of 1999 deliveries. Until 2000, the Texas Department of Health also had the Texas Neural Tube Defect Surveillance and Intervention Project along the Texas border with Mexico, which conducted active surveillance and research on neural tube defects for 14 counties.

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Utah

Utah Birth Defect Network (UBDN)

Purpose: surveillance, research, service, prevention, education
Partner: university, hospital, environment, advocacy
Program status: currently collecting data
Start year: 1994
Earliest year of available data: 1994
Organizational location: university, Department of Health
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), stillbirths (20 weeks gestation or greater), elective terminations
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
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. 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
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities
Other sources: physician reports, lay midwives

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 (e.g. 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 prenatally diagnosed or suspected cases, all fetal deaths certificates, NICU reports, infant deaths are reviewed
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Database storage/management: MS Access

Data Analysis

Data analysis software: SPSS, SAS, MS Access, Epi2000, Stata 8
Quality assurance: 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, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, referral, grant proposals, education/public awareness, prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention

System Integration

System links: link to birth records

Funding

Funding source: MCH funds 80%, CDC grant 20%

Other

Web site: http://health.utah.gov/birthdefect
Surveillance reports on file: 1994 NTD Surveillance report, 1994-1996 registry report, Scientific Collaboration Protocol - Data Sharing Agreement
Procedure manual available: yes
Additional information on file: Newsletters, brochure

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Vermont

Birth Information Network

Purpose: surveillance, service, prevention
Partner: university, hospital, nursing, advocacy
Program status: program has not started collecting data
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 (<1500 grams)
Age: up to one year after delivery
Residence: in- and out-of-state births to state residents

Funding

Funding source: CDC grant 100%

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Virginia

Virginia Congenital Anomalies Reporting and Education System (VACARES)

Purpose: surveillance
Partner: university, hospital, child program
Program status: currently collecting data
Start year: 1985
Earliest year of available data: 1987
Organizational location: Pediatric Screenings and Genetic Services, Division of Child and Adolescent Health
Population covered annually: calendar year 2003 – 100,561
Statewide: yes
Current legislation or rule: Health Law 32.1-69.1,-69.1:1,-69.2
Legislation year enacted: 1985; amended 1986, 1988

Case Definition

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

Surveillance methods

Case ascertainment: passive case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
Other state-based registries: newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: discharge summaries, medical records abstracts codes from charts
Pediatric & tertiary care hospitals: discharge summaries, medical records abstracts codes from charts
Other specialty facilities: genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with anxz 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 (e.g. 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 a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM, ICD-10 for death certificate

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

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

System Integration

System links: state registry
System integration: The current system, Virginia Infant Screening and Infant Tracking System (VISITS), is an integrated database for VaCARES and the Virginia Newborn Hearing Screening Program. A pilot of the At Risk Referral Service is currently being evaluated.

Funding

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

Other

Web site: http://www.vahealth.org/genetics
Surveillance reports on file: 10-year report (1989-1998) published in 2002
Procedure manual available: yes
Additional information on file: Oracle database
Comments: As of January 2005, hospitals are entering data directly into the Virginia Infant Screening and Infant Tracking Program (VISITS), a web-based tracking and data management system. Additional case ascertainment via state contracted genetic centers is currently being piloted in one center.

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Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: surveillance, service
Partner: university, hospital
Program status: currently collecting data
Start year: 1986 – active; 1991 – passive
Earliest year of available data: 1987
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 80,000
Statewide: yes
Current legislation or rule: Notifiable Conditions: WAC 246-101
Legislation year enacted: 2000

Case Definition

Outcomes covered: From 1987 to 1991 (active surveillance), and from 1991 to the 2000 (passive surveillance), the cases reportable to the Birth Defects Registry included those with ICD-9-CM codes 740-759, selected primary cancers, selected metabolic conditions, and FAS/FAE. Since the adoption of the Notifiable Conditions law in 2000, conditions subject to mandatory reporting are neural tube defects, orofacial clefts, limb deficiencies, abdominal wall defects, hypospadias/epispadias and Down syndrome. FAS/FAE, Cerebral Palsy and Autism Spectrum Disorder 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; transitioning to ascertainment through 1 year of age for structural defects and to age 10 for FAS/FAE, Cerebral Palsy and Autism Spectrum Disorder
Residence: resident births; children born or diagnosed in-state

Surveillance Methods

Case ascertainment: passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates, elective termination 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 clinic
Data sharing agreements with other states: yes

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

Database storage/management: Web-based SQL server

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, re-abstraction of cases, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, service delivery, grant proposals, education/public awareness, prevention projects

System Integration

System links: final birth file, CSHCN program participant file
System integration: Member of the Environmental Health Tracking Grant project.

Funding

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

Other

Surveillance reports on file: Brighter Futures report available for 1987-1988 data; Washington State Birth Defects Surveillance System: Status Report 1995-2004

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West Virginia

Birth Defects Surveillance System

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

Case Definition

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

Surveillance Methods

Case ascertainment: active/passive case ascertainment combination
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates
Other state-based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, developmental disabilities surveillance, cancer registry, AIDS/HIV registry, SIDS
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (e.g. labor & delivery), regular nursery logs, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: specialty outpatient clinics, physicians complete birth defect reporting forms for those diagnosed after delivery
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports, pediatric referrals of children diagnosed after delivery and discharge
Data sharing agreements with other states: yes

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with an ICD9-CM code 740-759, a selected list of ICD9-CM codes outside 740-759, selected procedure codes, selected defects or medical conditions (e.g. abnormal facies, congenital heart disease); any birth certificate with a birth defect box checked; infant low birth weight or gestation (<2500 grams or <37 weeks); all stillborn infants, neonatal deaths, elective abortions; all infants with low APGAR scores; all infants in NICU or special care nursery; all prenatally diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1-6, occular 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, Apgar, etc.), tests and procedures, infant complications, birth defect diagnostic info
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal 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

Database storage/management: MS Access, Mainframe, Visual D-Base

Data Analysis

Data analysis software: MS Access, custom
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, observed vs expected analyses, epidemiologic studies (using only program data), needs assessment, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: state registry; plans are underway to link several programs housed in the Office of Maternal, Child and Family Health

Funding

Funding source: Title V and State appropriations 100%

Other

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

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Wisconsin

Wisconsin Birth Defects Registry (WBDR)

Purpose: surveillance, research, service
Partner: Department of Health, university, hospital, child program, advocacy
Program status: currently collecting data
Start year: 2004
Earliest year of available data: 2004
Organizational location: Department of Health and Family Services (CSHCN)
Population covered annually: ~68,000
Statewide: yes
Current legislation or rule: Statute 253.12 HFS 116--Took effect April 1, 2003
Legislation year enacted: 2000

Case Definition

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

Surveillance methods

Case ascertainment: passive case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state-based registries: newborn hearing screening program, newborn biochemical screening program
Pediatric & tertiary care hospitals: case reports from pediatric specialty clinics
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports, hospital discharge data through 2 years of age

Case Ascertainment

Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, *Note: Items above are the ones likely to be used.

System Integration

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

Funding

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

Other

Web site: https://wbdr.han.wisc.edu
Surveillance reports on file: Birth and Developmental Outcome Monitoring Program 1990-91, Birth and Developmental Outcome Monitoring Program 1990-94
Comments: The new program requires complete specification through an Advisory Council and Administrative Rule. The Council meets quarterly. Administrative rules took effect April 1, 2003.

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

Case Definition

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

Surveillance Methods

Case ascertainment: combination of active and passive case ascertainment, population-based; electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries
Case finding/identification sources:
Delivery hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data
Third party payers: all inpatient and outpatient encounters are captured in standardized DoD data
Other sources: validation of standardized electronic data 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 CDC/BPA code, 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
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Database storage/management: MS Access, SAS

Data Analysis

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

System Integration

System links: DoD databases
System integration: DoD databases

Funding

Funding source: other federal funding 100%

Other

Web site:
http://www.nhrc.navy.mil/rsch/code25/projects/birthdefects.htm
Surveillance reports on file: DoD/HA policy memorandum; annual reports

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