

STATE BIRTH DEFECTS SURVEILLANCE PROGRAMS 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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Alabama***Alabama Birth Defects Surveillance and Prevention Program (ABDSPP)***

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

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

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1998

Organizational location: University

Population covered annually: 8,000 for 1998-2000 data; 18,000 for 2001 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

Current legislation or rule: none

Case Definition

Outcomes covered: major birth defects and genetic disorders

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

Age: up to one year after delivery

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

Surveillance methods

Case ascertainment: active case ascertainment, population-based

Case finding/identification sources:

Vital records: birth certificates, death certificates, fetal death certificates

Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/ pathology logs, Congenital Anomaly reporting form

Pediatric & tertiary care hospitals: disease or discharge index, ICU/NICU logs or charts, pediatric logs, postmortem/ pathology logs, Congenital Anomaly reporting form

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any birth certificate with a birth defect box checked,

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths up to 2 years, ocular conditions,

auditory/hearing conditions, any infant with a codable defect

Coding: California's coding system based on BPA

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: MS Access, Epi-Info, Clipper

Data Analysis

Data analysis software: Epi-Info, SPSS, Hypercube

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

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

Funding

Funding source: other federal funding 80%, University 20%

Other

Web site: www.usouthal.edu/genetics/

Additional information on file: Birth Defects Syndromes fact sheets

Comments: Site linked to international birth defect information systems.

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Alaska
Alaska Birth Defects Registry (ABDR)

Purpose: surveillance

Partner: local health departments, hospitals, community nursing services, environment agencies/organizations, early childhood prevention programs

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1996

Organizational location: Department of Health (MCH)

Population covered annually: 10,000

Statewide: yes

Current legislation or rule: 7 AAC 27.012

Legislation year enacted: 1996

Case Definition

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

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

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

Residence: Alaska residents

Surveillance methods

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

Case finding/identification sources:

Vital records: birth certificates, fetal death certificates

Other state based registries: programs for children with special needs, newborn biochemical screening program, Infant Learning Programs, Genetics Clinics, Specialty Clinics (Heart, Cleft Lip/Palate, Neurodevelopmental), MIMR (FIMR), Public Health Nursing

Delivery hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child treated or diagnosed with a reportable ICD-9 code.

Pediatric & tertiary care hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child treated or diagnosed with a reportable ICD-9 code.

Third party payers: Medicaid databases, Indian Health Services

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease; 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.

Conditions warranting a chart review beyond the newborn period: all infant deaths (excluding prematurity)

Coding: ICD-9-CM

Data Collected

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

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

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

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

System Integration

System links: final birth file

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

Funding

Funding source: CDC grant 100%

Other

Web site: www.hss.state.ak.us/dph/mcfh/epi/ABDR/default.htm

Surveillance reports on file: Family Health Dataline, MCH Fact Sheet on Folic Acid Knowledge and Use in Alaska

Procedure manual available: yes

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

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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

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

Partner: local health departments, universities, hospitals, early childhood prevention programs, advocacy groups

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1986

Organizational location: Arizona Department of Health Services/Bureau of Public Health Statistics/Office of Health Registries

Population covered annually: 87,106 in 2002

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 the BPA/MACDP codes.

Pregnancy outcome: live births (all gestational ages and birth weights); fetal deaths (stillbirths and abortions) at 20 weeks gestation and greater (1986-2001), fetal deaths (stillbirths and abortions) at all gestational ages/birth weights starting with 2002 data.

Age: up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review (which occurs 2 -4 years after the child's birth or fetal death), then the more precise diagnosis is used.

Residence: in-state birth to state resident

Surveillance methods

Case ascertainment: active case ascertainment, population based

Case finding/identification sources:

Vital records: birth certificates, death certificates, fetal death certificates

Other state based registries: programs for children with special needs (Children Rehabilitation Services Clinics, Newborn Metabolic Screening, and the Newborn Intensive Care Program, in the Office for Children with Special Health Care Needs).

Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, ultrasound reports, cytogenetic reports, stillborn logs, mother's charts for stillborns

Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, ultrasound reports, cytogenetic reports, stillborn logs, mother's charts for still borns

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

Other sources: none.

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions (i.e., abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all elective abortions, 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 info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic info

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

Father: identification info (name, address, date-of-birth, etc.), demographic info (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

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, grant proposals, education/public awareness, prevention projects

Funding

Funding source: general state funds 44%, genetic screening revenues 21%, CDC grant 35%

Other

Web site: www.hs.state.az.us/phs/phstats/bdr/index.htm

Surveillance reports on file: Annual Reports, 1986 - 1997

Procedure manual available: yes

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

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Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

Purpose: surveillance, research, referral to prevention/intervention programs
Partner: local health departments, universities, hospitals, advocacy groups, legislators
Program status: Currently collecting data
Start year: 1980
Earliest year of available data: 1980
Organizational location: University, Arkansas Children's Hospital
Population covered annually: 37,000
Statewide: yes
Current legislation or rule: Senate Bill Act 214
Legislation year enacted: 1985

Case Definition

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

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any birth certificate with a birth defect box checked, all stillborn infants, all elective abortions occurring in a hospital setting
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 info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic info
Mother: identification info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal diagnostic info, family history

Father: identification info (name, address, date-of-birth, etc.), demographic info (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: re-abstraction of cases, double-checking of assigned codes, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, 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

Funding

Funding source: general state funds 100%

Other

Web site: www.ARbirthdefectsresearch.uams.edu
Surveillance reports on file: Annual reports

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California

California Birth Defects Monitoring Program (CBDMP)

Purpose: surveillance, research

Partner: local health departments, universities

Program status: Currently collecting data

Start year: 1983

Earliest year of available data: 1983

Organizational location: Occupational and Environmental Disease Control, March of Dimes under contract with the State Department of Health Services, Environmental and Occupational Disease Control

Population covered annually: 60,000

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

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

Legislation year enacted: 1982

Case Definition

Outcomes covered: Serious structural birth defects, primarily encompassed within ICD9-CM codes 740-759

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: one year

Residence: In-state births to residents of 1 of 8 counties. Does not include births in military hospitals.

Surveillance methods

Case ascertainment: Active case ascertainment, population based

Case finding/identification sources:

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

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

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

Case Ascertainment

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

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions

Coding: CDC coding system based on BPA

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: FoxPro

Data Analysis

Data analysis software: SAS

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

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

System Integration

System links: final birth file

Funding

Funding source: general state funds 34%, MCH funds 20%, CDC grant 15%, other federal funding 16% DHS/UC Pass through 15%

Other

Web site: www.cbdmp.org

Surveillance reports on file: Current data on web site.

Procedure manual available: yes

Additional information on file: Publications Index, summaries of research findings, Collaboration Protocol, Confidentiality Procedures, Cluster Investigation Protocol, statutes, video

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

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

Partner: local health departments, universities, early childhood prevention programs, advocacy groups

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1989

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 67,006 (2001)

Statewide: yes

Current legislation or rule: Colorado Revised Statutes (CRS) 25-1-107

Legislation year enacted: 1985

Case Definition

Outcomes covered: Structural, genetic and selected metabolic birth defects; selected developmental disabilities; very low birth weight (less than 1500 grams); others with medical and maternal risk factors for developmental delay

Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc., any gestational age, diagnoses made prenatally are ascertained

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

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

Surveillance methods

Case ascertainment: Passive, population based, multiple sources; active for special projects including 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, Infectious disease reporting database (meningitis, congenital infections)

Delivery hospitals: disease index or discharge index

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

Third party payers: Medicaid databases

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: 14 selected conditions for CUSUM monitoring (newborn and up to age 3) and fetal alcohol syndrome (newborn and up to age 7)

Coding: ICD-9-CM, Extended code utilized to describe syndromes and further specify condition

Data Collected

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

birth measurements (weight, gestation, Apgars, etc.), birth defect diagnostic info

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

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: SAS, ArcView (GIS software), Maptitude

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

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

System Integration

System links: final birth file, Newborn Hearing Screening and Newborn Genetic Screening

Funding

Funding source (2002): general state funds 48%, CDC grant 47%, other federal funding 5%

Other

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

Procedure manual available: yes

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

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Connecticut***Children With Special Health Care Needs Registry (CSHCN REGISTRY)***

Purpose: surveillance, referral to services, referral to prevention/ intervention programs, reporting for MCH Block Grant

Partner: hospitals, early childhood prevention programs, advocacy groups

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2003

Organizational location: Department of Health (MCH)

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; for special health care needs < 19 years.

Residence: in and out of state births to state residents

Surveillance methods

Case ascertainment: Passive, population-based

Case finding/identification sources:

Vital records: birth certificates, death certificates, matched birth/death file, inpatient hospitalizations, ambulatory surgery and emergency room visits

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

Delivery hospitals: disease or discharge index, reports from health care professionals in newborn nurseries and NICUs.

Pediatric & tertiary care hospitals: disease index or discharge index, reports from health care professionals in pediatric inpatient and outpatient services planned for future.

Midwifery facilities:

Other sources: physician reports, mandatory reporting by health care providers and facilities; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, cases from birth admissions where the reporting form is the sole source of case ascertainment; cases of multiple anomalies

without a specified syndrome; cases where diagnoses are qualified as 'preliminary' or 'rule-out'; all cases of chromosomal anomalies lacking confirmation by karyotype, and a 10% random sample, stratified on birth hospital, of all obvious birth defects that were not reported from birth admission but documented from pediatric reports or in the CHIME database.

Coding: ICD-9-CM

Data Collected

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

Mother: identification info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), gravidity/parity, prenatal care, pregnancy/delivery complications

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle

Data Analysis

Data analysis software: SAS

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

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

System Integration

System links: final birth file

Funding

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

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Delaware
Delaware Birth Defects Surveillance Project

Program status: Currently collecting data
Organizational location: Department of Health (MCH)
Population covered annually: 10,574
Statewide: yes
Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the DE Code relating to Birth Defects. Birth defects legislations established in March 2003 requiring medical providers to report diagnosed birth defects up to age 5.
Legislation year enacted: 1997

Case Definition

Outcomes covered: Birth Defects Registry - All birth defects for passive surveillance, selected birth defects for active surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections
Pregnancy outcome: live births (all gestational ages and birth weights), Any gestation for live birth, greater than 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: Active and passive surveillance, population-based.
Case finding/identification sources:
Vital records: birth certificates, death certificates
Other: birth defects reporting form

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: electronic birth certificate

Data Analysis

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

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

Purpose: surveillance, research, referral to services
Partner: Local health departments, universities, hospitals, early childhood prevention programs, advocacy groups
Program status: Currently collecting data
Start year: July 2003 (Some data will be collected retroactive to January 2003.)
Organizational location: Department of Health (MCH)
Population covered annually: 15000 (approximately half are to District residents)
Statewide: yes

Case Definition

Outcomes covered: major birth defects and genetic disorders.

Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), >500gm
Age: Up to one year after birth except in the case of Fetal Alcohol Syndrome which is up to six years.
Residence: State resident at the time of diagnosis

Surveillance methods

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

Case finding/identification sources:

Vital records: birth certificates, death certificates, fetal death certificates

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

Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs/charts, pediatric logs

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, ICD9-CM 740-741.9, 742.3, 743.1, 744-748.8, 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 info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.),

tests and procedures, infant complications, birth defect diagnostic info

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

Father: identification info (name, address, date-of-birth, etc.), demographic info (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, fetal and infant death files

Funding Funding source: MCH funds 5%, CDC grant 95%

Other

Procedure manual available: yes

Additional information on file: Procedures manual is in development. However, it will be available for sharing once completed.

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Florida
Florida Birth Defects Registry (FBDR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention programs, educate health care professionals

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

Program status: Currently collecting data

Start year: 1998

Earliest year of available data: 1996

Organizational location: Department of Health (Epidemiology/Environment), Florida Department of Health, Bureau of Community Environmental Health

Population covered annually: 204,125 in 2000

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 (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: until age 1

Residence: Florida

Surveillance methods

Case ascertainment: Population-based passive case ascertainment

Case finding/identification sources:

Vital records: birth certificates, matched birth/death file, fetal death certificates

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

Delivery hospitals: discharge summaries

Pediatric & tertiary care hospitals: discharge summaries

Third party payers: Medicaid databases

Other sources: physician reports

Case Ascertainment

Coding: ICD-9-CM

Data Collected

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

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

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

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, comparison/verification between multiple data sources, timeliness

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

Funding

Funding source: general state funds 100%

Other

Web site: <http://fbdr.hsc.usf.edu>

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

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: surveillance, research, referral to services

Partner: universities, hospitals

Program status: Currently collecting data

Start year: 1967

Earliest year of available data: 1968

Organizational location: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Population covered annually: 50746

Statewide: no, Births to mothers residing within one of five counties in the metropolitan Atlanta area of the state of Georgia

Current legislation or rule: State Laws Official Georgia Code Annotated (OCGA) 31-12-2

Case Definition

Outcomes covered: Major structural or genetic birth defects

Pregnancy outcome: live births, ≥ 20 weeks, fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)

Age: Before 6 years of age

Residence: Births to mothers residing in one of five metropolitan Atlanta counties

Surveillance methods

Case ascertainment: Active case ascertainment; population-based; Combination of active and passive case ascertainment for cases ascertained only at perinatal offices.

Case finding/identification sources:

Vital records: birth certificates, fetal death certificates

Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, Induction logs and miscarriage logs

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

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

Case Ascertainment

Conditions warranting chart review in newborn period:

any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, birth weight < 2500 grams or < 36 weeks gestation, all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (ie seizure), GI condition (ie intestinal blockage), cardiovascular condition, ocular conditions, auditory/hearing conditions, any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: Epi-Info, Mainframe

Data Analysis

Data analysis software: SPSS, SAS, MS Access

Quality assurance: validity checks, double-checking of assigned codes, data/hospital audits, clinical review, timeliness

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, service delivery, prevention projects

System Integration

System links: state registry, final birth file

Funding

Funding source: other federal funding 100%

Other

Web site: www.cdc.gov/ncbddd/bd

Surveillance reports on file: numerous reports and bibliography

Procedure manual available: yes

Additional information on file: rate tables by defect by year

Comments: For surveillance reports and other information regarding the MACDP, contact CDC.

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Hawaii

Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance, research, referral to services, and referral to prevention/intervention programs.

Partner: Local health departments, universities, hospitals, community nursing services, environment agencies/organizations, early childhood prevention programs, advocacy groups, legislators.

Program status: Currently collecting data.

Start year: 1988.

Earliest year of available data: 1986.

Organizational location: DOH/Children With Special Health Needs Branch, Research Corporation of the University of Hawaii.

Population covered annually: ~19,906 average over 16 years.

Statewide: Yes.

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 - 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+ recommended by CDC in their May 1987 Birth Defects Branch Six Digit Code for Reportable Congenital Anomalies, based on B.P.A. Classification of Diseases (1979) and W.H.O. ICD9 CM (1977).

Pregnancy outcome: Live births (all gestational ages and birth weights), fetal deaths (stillbirths and spontaneous abortions less than and greater than 20 week gestation), and elective terminations. Data collected on all elective medical terminations that were carried out because a screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect and the parents elected not to bring the baby to term.

Age: Up to one year after delivery.

Residence: All in-state Hawaii births (resident and non-resident).

Surveillance methods

Case ascertainment: Statewide, active case ascertainment, and 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; these entities do not supply data to the HBDP.

Delivery hospitals: Disease index or discharge index, discharge summaries, and postmortem/pathology logs. Note: Information from specific logs, laboratories, clinics, etc. is usually found in the medical record when doing chart review.

Pediatric & tertiary care hospitals: Disease index or discharge index, and discharge summaries. Information

from specific logs, laboratories, clinics, etc. is usually found in the medical record when doing chart review.

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

Case Ascertainment**Conditions warranting chart review in newborn period:**

Any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, all stillborn infants, all neonatal deaths, all prenatally diagnosed or suspected cases, and 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 years, and any infant with a codable defect.

Coding: CDC coding system based on BPA.

Data Collected

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

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

Father: Identification info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, age, etc.), illnesses/conditions, family history, etc.

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, and timeliness.

Data use and analysis: Routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessments, grant proposals, education/public awareness, prevention projects, legislative queries, and publication of articles in professional peer-reviewed professional journals.

System Integration

System links: Although not initiated yet, the HBDP is in the planning stages of embarking on a GIS project ultimately linking to other federal and state databases.

Funding

Funding source: General state funds 57.8%, CDC grants 26.7%, other federal/state/special fund funding 11.4%, and private foundations 4.1%.

Other

Web site: <http://members.aol.com/entropynt/hbdp.html>

Surveillance reports on file: Ten (10) Hawaii Birth Defects Program Statewide Surveillance Data Reports each over 130 pages - 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)=986-2001, and 11)=1986-2002 to be published in late 2003.

Procedure manual available: Yes.

Additional information on file: HBDP informational brochure; organizational chart; copies of legislation; original abstraction forms; revised abstraction forms; revised mini-manual; annual report (FY 88-89); sample of quarterly reports; slides of HBDP data; quality assurance reports (completeness, accuracy, timeliness); and special study reports (e.g. Cluster investigations).

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Idaho

Program status: No surveillance program

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Illinois***Adverse Pregnancy Outcomes Reporting System (APORS)***

Purpose: surveillance, referral to services
Partner: Local health departments, universities, hospitals, advocacy groups, legislators
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1988
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 184,022
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: Population-based, passive ascertainment of newborn cases. Active ascertainment of major birth defects diagnosed up to 2 years of age began 7/01
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, Hospitals are mandated to identify newborn cases and report to IDPH.

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease,
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, FoxPro, Mainframe

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: re-abstraction of cases, comparison/

verification between multiple data sources, data/hospital audits, timeliness

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

Funding

Funding source: general state funds 76%, CDC grant 21%, other federal funding 3%

Other

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

Surveillance reports on file: See Web Site

Additional information on file:

Comments: APORS is transition to more active case ascertainment and expand case age to 2 years.

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Indiana

Indiana Birth Defects Surveillance System/Indiana Birth Problems Registry (IBDSS/BPR)

Purpose: surveillance, research, referral to services

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

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 2003

Organizational location: Department of Health (Epidemiology/Environment), Department of Health (MCH)

Population covered annually: 83,000

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, low birth weight, 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: Less than 3 years of age

Residence: In and out of state births to state residents

Surveillance methods

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

Case finding/identification sources:

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

Other state based registries: newborn genetic screening program, newborn hearing screening program, cancer registry

Delivery hospitals: disease index or discharge index, random chart audits

Pediatric & tertiary care hospitals: discharge summaries, random chart audits

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Randomly selected charts of targeted medical conditions.

Coding: ICD-9-CM

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

Data analysis software: Oracle, SAS

Quality assurance: validity checks, comparison/verification between multiple data sources, data/hospital audits, timeliness

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: state registry, final birth file

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

Funding

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

Other

Web site: www.in.gov/isdh/programs/ibpr

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Iowa

Iowa Birth Defects Registry (IBDR)

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

Partner: Local health departments, university, hospitals, environment agencies/organizations, legislators

Program status: Currently collecting data

Start year: 1983

Earliest year of available data: 1983

Organizational location: University

Population covered annually: 37,831 avg 10 yr

Statewide: yes

Current legislation or rule: Administrative Code of Iowa, Volume I, Chapter 135.37, Section 40, Division III

Legislation year enacted: 1986; Revised 2001

Case Definition

Outcomes covered: Major Birth Defects and Metabolic Disorders

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

Age: 1 year

Residence: Maternal residence in Iowa at time of delivery

Surveillance methods

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

Case finding/identification sources:

Vital records: birth, death, and fetal death certificates

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

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

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

Other sources: physician reports, Outpatient Surgery Facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage),

cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect

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

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: Access, Oracle, Mainframe

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS, Access, Oracle

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

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster 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

Funding

Funding source: general state funds 30%, CDC grant 38%, other federal funding 32%

Other

Web site: <http://www.public-health.uiowa.edu/birthdefects>

Surveillance reports on file: Iowa Birth Defects Registry Annual Report 2000, 2002

Procedure manual available: yes

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Kansas
Birth Defects Reporting System

Purpose: registry
Partner: hospitals
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Vital Statistics), Department of Health (MCH)
Population covered annually: 38,832 (Year 2001)
Statewide: yes
Current legislation or rule: KSA 65-102
Legislation year enacted: 1979

Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics, but are not used as part of a birth defects surveillance system. Twenty-four anomalies are listed on the birth certificate and are reported, however, these are not linked to ICD codes.

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

Age: Passive reporting on congenital malformation reports continues through the first year of life.

Residence: In and out of state births to Kansas residents and in-state births to out of state residents.

Surveillance methods

Case ascertainment: Passive, population-based, 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 Collected

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

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

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

Data Analysis

Data analysis software: Ad-hoc SAS reports and Standard analytical summary reports; ad-hoc summary reports developed as needed from Crystal Reports.

Quality assurance: Office of Vital Statistics conducts verification on birth certificate data.

Data use and analysis: routine statistical monitoring, rates by demographic and other variables, monitoring outbreaks and cluster investigations, Ad-hoc upon request.

System Integration

System links: state registry

System integration: Our program has a link with vital statistics records.

Funding

Funding source: MCH and CHES (Center for Health & Environmental Statistics) funds 100%

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Kentucky
Kentucky Birth Surveillance Registry (KBSR)

Purpose: surveillance, referral to services, prevention of birth defects

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

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1998

Organizational location: Department for Public Health, Division of Adult and Child Health, Maternal and Child Health Branch

Population covered annually: 55,000

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 & birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 wks gestation & greater), 20wks or 350gms

Age: up to fifth birthday

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

Surveillance methods

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

Case finding/identification sources:

Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, Medical laboratory reporting is mandated; voluntary outpatient reporting

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

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

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

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

Other sources: physician reports, Local health departments

Case Ascertainment

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

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

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

Data Collected

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

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

Father: identification info (name, address, DOB, etc.), demographic info (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage

Database storage/management: Access, Mainframe, SQL server

Data Analysis

Data analysis software: SAS, MS Access

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

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

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

Funding

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

Other

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

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

Procedure manual available: yes

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Louisiana
Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: surveillance, referral to services
Partner: universities, hospitals, early childhood prevention programs, advocacy groups
Program status: Program has not started collecting data yet
Start year: 2003
Earliest year of available data: 2004-2005
Organizational location: Children's Special Health Services
Population covered annually: 65,000 +
Statewide: yes
Current legislation or rule: R.S. 40:31.41 - 40:31.48, Act No. 194
Legislation year enacted: 2001

Case Definition

Outcomes covered: major structural, functional, or genetic birth defect
Age: in progress
Residence: in and out of state births to state residents (tentative criteria)

Surveillance methods

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

Case Ascertainment

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

Data Collection Methods and Storage

Database storage/management: MS Access, in progress

Data Analysis

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

System Integration

System links: in progress

Other

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

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Maine
Maine Birth Defects Program (MBDP)

Purpose: surveillance, referral to services, referral to prevention/intervention programs
Partner: universities, hospitals, community nursing services, early childhood prevention programs, advocacy groups
Program status: Currently collecting data- May 1, 2003
Start year: 1999
Earliest year of available data: not available yet
Organizational location: Department of Health (MCH)
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 and Omphalocele, major heart defects, Trisomy 21
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), prenatally diagnosed at any gestation, elective terminations (20 weeks gestation and greater), 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 screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), NBN/NICU logs or charts, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts, pediatric logs, specialty outpatient clinics
Other specialty facilities: genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, cardiovascular condition, 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 info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic info
Mother: identification info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, family history, occupation
Father: identification info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), occupation

Data Collection Methods and Storage

Database storage/management: MS Access, Citrix

Data Analysis

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

System Integration

System links: state registry, final birth file

Funding

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

Other

Web site: developing

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Maryland
Maryland Birth Defects Reporting and Information System (BDRIS)

Purpose: surveillance, research, referral to services
Partner: Local health departments, universities, hospitals, environment agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1984
Organizational location: Family Health Administration, Office for Genetics & CSHCN
Population covered annually: 68,000
Statewide: yes
Current legislation or rule: Health-General Article, Section 18-206; Annotated Code of Maryland
Legislation year enacted: 1982

Case Definition

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

Surveillance methods

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

Case Ascertainment

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

Data Collected

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

Mother: identification info (name, address, DOB, etc.), demographic info (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, family history
Father: identification info (name, address, DOB, etc.), demographic info (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, 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://mdpublichealth.org/genetics> (then select Birth Defects Reporting Information System)

Surveillance reports on file: Provisional surveillance reports 1984-1992; 1995-1999

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, Birth Defect Monitoring Program, Massachusetts Department Of Public Health (MCBDRP)**

Purpose: surveillance, research

Partner: universities, hospitals, environment agencies/ organizations, advocacy groups

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: 80,866 for 1999; 81,582 for 2000

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 these data; 4) requires MDPH to promulgate regulations governing the operation of the Birth Defects Monitoring Program.

Legislation year enacted: 1963

Case Definition

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

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

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 or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/ NICU logs or charts, postmortem/pathology logs

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions e.g. facial dysmorphism, all stillborn infants

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

Coding: Six digit coding system based on a combined ICD9/BPA

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: SAS, MS Access, Microsoft Excel
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness

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

System Integration

System links: birth file, link case finding data to fetal death file

Funding

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

Other

Web site: website in development

Surveillance reports on file: First surveillance report published in November 2001; available online at <http://www.state.ma.us/dph/bhsre/birthdefects/surv rpt99.pdf> or by calling contacts; MCBDRP Prevention and Resource Booklet at <http://www.state.ma.us/dph/bhsre/birthdefects/2002prevbklt.pdf>

Procedure manual available: yes

Comments: Statewide coverage started October 1998

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Michigan
Michigan Birth Defects Registry (MBDR)

Purpose: surveillance, research, referral to services, referral to prevention/intervention programs
Partner: Local health departments, universities, hospitals, legislators, Children's Special Health Care, Newborn Screening, EHDI
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 135,400
Statewide: yes
Current legislation or rule: Public Act 236 of 1988
Legislation year enacted: 1988

Case Definition

Outcomes covered: Congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: up to two years after delivery
Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

Surveillance methods

Case ascertainment: passive, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, cytogenetic laboratories, genetics clinics, hospital discharge data
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: disease index or discharge index, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, specialty outpatient clinics
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment

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

Data Collected

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

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

Data Collection Methods and Storage

Database storage/management: FoxPro

Data Analysis

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

System Integration

System links: final birth file
System integration: No, data from vital records and other sources are extracted and loaded in the registry as opposed to truly integrated database structures.

Funding

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

Other

Web site: <http://www.michigan.gov/mdch>
Surveillance reports on file: birth defects incidence and mortality annual reports
Procedure manual available: yes

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Minnesota

Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 2002
Organizational location: Environmental Health
Population covered annually: 66,000
Statewide: yes
Current legislation or rule: MS 144.2215
Legislation year enacted: 1996

Case Definition

Outcomes covered: Initial system will analyze neural tube defects and oro-facial clefts; additional conditions may be added in the future.
Pregnancy outcome: live births, fetal deaths—stillbirths, spontaneous abortions, etc.
Age: Initial proposal of up to 1 year after delivery; will be examined collaboratively and adjusted as needed.
Residence: Initial proposal of only using in-state data; will be examined collaboratively and adjusted as needed.

Surveillance methods

Case ascertainment: Initial system will be passive combined with selected active confirmation; will be examined collaboratively and adjusted as needed.
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, Infant death records
Third party payers: Medicaid databases, health maintenance organizations (HMOs)

Case Ascertainment

Conditions warranting chart review in newborn period: any birth certificate with a birth defect box checked
Coding: ICD-9-CM, only for selected data retrieval; functioning system not yet in place.

Funding

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

Other

Web site: www.health.state.mn.us
Comments: Formal program currently being developed; data collected, data collection and storage methods, and data analysis methods will be determined during start-up phase. State has access/expertise in SAS, Epi-Info, Access, FoxPro, and Oracle databases.

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Mississippi
Mississippi Birth Defects Registry (MBDR)

Purpose: surveillance

Partner: Local health departments, hospitals

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: Department of Health (MCH),
Division of Genetics, Mississippi State Department of
Health

Population covered annually: 44,000

Statewide: yes

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

Legislation year enacted: 1997

Case Definition

Outcomes covered: A birth defect is an abnormality of structure, function or metabolism, whether genetically determined or a result of environmental influences during embryonic or fetal life. A birth defect may present from the time of conception through one year after birth, or later in life.

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

Age: 0 to 21

Residence: In and out of state births to state residents

Surveillance methods

Case ascertainment: combination of active and passive case ascertainment

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, cancer registry

Delivery hospitals: disease index or discharge index, discharge summaries, regular nursery logs, pediatric logs, postmortem/pathology logs

Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any birth certificate with a birth defect box checked

Conditions warranting a chart review beyond the newborn period: CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, ocular conditions, auditory/hearing conditions, any infant with a codable defect

Coding: ICD-9-CM

Data Collected

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

Mother: identification info (name, address, date-of-birth, etc.), demographic info (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, baseline rates, rates by demographic and other variables, 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, referral to services, referral to prevention/intervention programs
Partner: Local health departments, universities, hospitals, environment agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1980
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 75,000
Statewide: yes

Case Definition

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

Surveillance methods

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

Case Ascertainment

Coding: ICD-9-CM, ICD-10

Data Collected

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

Data Collection Methods and Storage

Database storage/management: SAS (Unix)

Data Analysis

Data analysis software: SAS

Quality assurance: validity checks, double-checking of

assigned codes, comparison/verification between multiple data sources

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

System Integration

System links: final birth file

Funding

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

Other

Surveillance reports on file: MO Birth Defects 1995-99

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

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

Partner: hospitals, advocacy groups, private practice physicians

Program status: Currently collecting data

Start year: 1999

Earliest year of available data: 2000

Organizational location: Department of Health (MCH)

Population covered annually: 11,000

Statewide: yes

Current legislation or rule: none

Legislation year enacted:

Case Definition

Outcomes covered: Selected major birth defects: neural tube defects, cleft lip/palate, congenital heart defects, musculoskeletal defects; chromosomal anomalies; congenital hypothyroidism

Pregnancy outcome: live births, >20 weeks gestation & 500 grams, fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), more than 500grams, elective terminations

Age: Birth to 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

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 birth certificate with a birth defect box checked, cytogenetic charts with ICD9-CM code 758.0-758.2

Conditions warranting a chart review beyond the newborn period: cardiovascular condition

Coding: ICD-9-CM

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS

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, and in the process of developing a program of referral to services & prevention

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, Greater than 20 weeks and greater than 500 grams., fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Birth to 1 year

Residence: In-state and out-of-state birth to state resident

Surveillance methods

Case ascertainment: Combination of active and passive case ascertainment

Case finding/identification sources:

Vital records: birth certificates, death certificates, fetal death certificates

Delivery hospitals: disease index or discharge index, discharge summaries, ICU/NICU 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

Case Ascertainment

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

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

Coding: CDC coding system based on BPA

Data Collected

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

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

Father: identification info (name, address, date-of-birth, etc.), demographic info (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: 2001 report in Vital Statistics Report. 2002 report will be available in published form in summer of 2003.

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

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Nevada
Nevada Birth Defects Registry

Purpose: surveillance

Partner: universities

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: Department of Health (MCH), Maternal and Child Health is a Bureau - under the umbrella of the State Health Division, State Department of Human Resources

Population covered annually: 31,000

Statewide: no, Year 2000 data is for Las Vegas only. Year 2001 - Las Vegas data complete, Reno area in the process of being completed. Anticipate completion of statewide 2000 data by March of 2003.

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 from 0-7 years of age

Residence: In-state births

Surveillance methods

Case ascertainment: Combination of active and passive ascertainment initially. Currently - system is a "passive" system; "active" component being resumed in the fall of 2003.

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, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts

Pediatric & tertiary care hospitals: disease index or discharge index

Third party payers: Medicaid databases

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: physician reports

Case Ascertainment

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

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

Coding: ICD-9-CM

Data Collected

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

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle, Mainframe

Data Analysis

Data analysis software: SPSS, SAS

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, monitoring outbreaks and cluster investigations, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: final birth file

System integration: 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: MCH funds 5%

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New Hampshire
New Hampshire Birth Defects Monitoring and Prevention Program (NH BDMPP)

Program status: Program has not started collecting data yet

Start year: 2002

Earliest year of available data: 2003

Organizational location: Department of Health and Human Services, (Bureau of Vital Records; Bureau of Special Medical Services; Bureau of Nutrition and Health Promotion), University

Population covered annually: 13,560

Statewide: yes

Current legislation or rule: None

Case Definition

Outcomes covered: All major birth defects and multiple congenital anomaly syndromes

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: all fetuses >20 weeks gestation and newborns to the time of discharge from birthing hospital or ICN

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

Surveillance methods

Case ascertainment: active case ascertainment and population based

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, cancer registry, AIDS/HIV registry

Delivery hospitals: discharge summaries, regular nursery logs, ICU/NICU logs or charts, postmortem/pathology logs

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 a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases

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

Data Collected

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

birth measurements (weight, gestation, Apgars, etc.),

infant complications, birth defect diagnostic info

Mother: identification info (name, address, date-of-birth,

etc.), demographic info (race/ethnicity, sex, etc.),

gravidity/parity, illnesses/conditions, prenatal care,

prenatal diagnostic info, pregnancy/delivery

complications, family history

Father: identification info (name, address, date-of-birth,

etc.), demographic info (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Database storage/management: MS Access, investigating web-based data base solutions

Data Analysis

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

Quality assurance: validity checks, re-abstraction of

cases, double-checking of assigned codes, comparison/

verification between multiple data sources, clinical

review, timeliness

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables,

monitoring outbreaks and cluster investigations, time

trends, epidemiologic studies (using only program data),

identification of potential cases for other epidemiologic

studies, needs assessment, service delivery, referral,

grant proposals, education/public awareness, prevention

projects

Funding

Funding source: CDC grant 77%, private foundations 23%

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New Jersey
Special Child Health Services Registry (SCHS REGISTRY)

Purpose: surveillance, research, referral to services, referral to prevention/intervention programs
Partner: Local health departments, universities, hospitals, environmental agencies/organizations, early childhood prevention programs, advocacy groups, legislators
Program status: Currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health & Senior Services – Family Health Services Division - Special Child, Adult, and Early Intervention Services
Population covered annually: 113,500
Statewide: yes
Current legislation or rule: NJSA 26:8 et seq., NJAC 8:20 - Enacted 08-04-1983, with effective date of 03-04-1985. Changes to legislation 1990, 1991, 1992. Readopted 05/2000.
Legislation year enacted: 1983

Case Definition

Outcomes covered: All birth defects, including structural, genetic, and biochemical are required to be reported. While not mandated, all special needs and any condition which places a child at risk, eg. prematurity, asthma, cancer, developmental delay, are also reported.
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: mandated reporting of birth defects diagnosed \leq age 1, voluntary reporting of birth defects diagnosed $>$ age 1 and all children diagnosed with Special Needs conditions who are \leq 21 yrs. of age
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 chart review is conducted on all children registered with any of the defects eligible for participation in the National Birth Defects Prevention Study; hospital-based, medical providers are contacted to confirm 'questionable' diagnoses.
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, AIDS/HIV registry
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, cardiac catheterization laboratories, specialty outpatient clinics, Quality Assurance visit consisting of chart review of 3 month period
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs,

surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics, Quality Assurance visit consisting of chart review of 3 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, sub-specialty clinics, pediatric urologists, cardiologists, and ophthalmologists

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, all neonatal deaths, all death certificates for $<$ 1 year of age

Conditions warranting a chart review beyond the newborn period: GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions

Coding: ICD-9-CM

Data Collected

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

Mother: identification info (name, address, DOB, etc.)

Father: identification info (name, address, DOB, 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, 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 electronic birth certificate files, final birth data file

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

Funding

Funding source: MCH funds 85%, CDC grant 10%, dedicated state funds 5%

Other

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

Surveillance reports on file: Special Child Health Services Registry 1985-1989; Special Child Health Services Registry 1985-1991; Special Child Health Services Registry 1985-1994; Special Child Health Services Registry 1990-1999 (in press).

Procedure manual available: yes

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

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New Mexico

New Mexico Birth Defects Prevention and Surveillance System (NMBDPASS)

Purpose: surveillance, research, referral to services, referral to prevention/intervention programs
Partner: hospital, early childhood prevention programs, legislators
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (MCH)
Population covered annually: 27,000
Statewide: yes
Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regs.
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—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)
Age: age 14
Residence: In and out of state births to state residents, NM

Surveillance methods

Case ascertainment: Active case ascertainment for NTDs and oral facial clefts; passive for other defects, population-based, hospital-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, cancer registry, Children's Chronic Conditions Registry
Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics, Office of the Medical Investigator
Pediatric & tertiary care hospitals: ICU/NICU logs or charts, specialty outpatient clinics, Abstractors contact neurosurgeons quarterly to identify all NTD cases. Also contact plastic surgeons to identify children with OFCs.
Third party payers: Medicaid databases, health maintenance organizations (HMOs), Indian health services, Children's Medical Services
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 a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases, Charts with ICD code 760.71

Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, We are in the process of rebuilding our database in SQL server.

Data Analysis

Data analysis software: Stata
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, needs assessment, grant proposals, education/public awareness, prevention projects, Beginning to develop linkage with early intervention services (IDEA Part C) and exploring ways to work with Medicaid to link children to medical home and case-management.

System Integration

System links: state registry, final birth file
System integration: Currently, BDPASS is integrated with the Children's Chronic Conditions Register. We are working on integrating with the IDEA Part C Program and Medicaid.

Funding

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

Other

Web site:
Surveillance reports on file: 1995-1996 Report of birth defects 1997-1998 Report of birth defects 1995-1999 Report of birth defects

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New York

New York State Congenital Malformations Registry (CMR)

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

Partner: universities, hospitals, early childhood prevention programs, March Of Dimes

Program status: Currently collecting data

Start year: 1982

Earliest year of available data: 1983

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 260,000

Statewide: yes

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

Legislation year enacted: 1982

Case Definition

Outcomes covered: Major malformations, detailed list available upon request.

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

Age: 2 years

Residence: In-state and out-of-state birth to state resident; in-state birth to nonresident; all children born in or residing in New York, up to age 2.

Surveillance methods

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

Case finding/identification sources:

Vital records:

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 info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic info

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

Father: identification info (name, address, date-of-birth, etc.), demographic info (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: final birth file, Statewide Hospital Discharge Database (SPARCS)

Funding

Funding source: general state funds 11%, MCH funds 31%, CDC grant 35%, other federal funding 23%

Other

Web site: <http://www.health.state.ny.us/nysdoh/cmr/cmrhome.htm>

Surveillance reports on file: Reports for 1983-1997.

Procedure manual available: yes

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North Carolina
North Carolina Birth Defects Monitoring Program (NCBDMP)

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

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

Program status: Currently collecting data

Start year: 1987

Earliest year of available data: 1989

Organizational location: Department of Health (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, combined active and passive ascertainment

Case finding/identification sources:

Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates

Other state based registries: programs for children with special needs

Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery)

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

Third party payers: Medicaid databases

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

Case Ascertainment

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

Conditions warranting 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 info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic info

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

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

Data Collection Methods and Storage

Database storage/management: MS Access, Mainframe

Data Analysis

Data analysis software: SAS, MS Access

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

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

System Integration

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

Funding

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

Other

Web site: 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)

Partner: March of Dimes

Program status: Program has not started collecting data yet

Start year: 2002

Earliest year of available data: 1994

Organizational location: Department of Health (Vital Statistics), Department of Health (MCH), ND Department of Human Services (Children's Special Health Services)

Population covered annually: 7676

Statewide: yes

Current legislation or rule: ND Century code 50-10

Case Definition

Outcomes covered: Selected birth defects (NTDs, congenital heart defects, cleft lip and palate) 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 (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 finding/identification sources:

Vital records: birth certificates

Other state based registries: programs for children with special needs

Delivery hospitals: Birth certificate completion

Pediatric & tertiary care hospitals: specialty outpatient clinics

Third party payers: Medicaid databases, health maintenance organizations (HMOs), private insurers

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: physician reports

Case Ascertainment

Coding: ICD-9-CM, ICD 10

Data Collected

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

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

Father: identification info (name, address, date-of-birth, etc.), demographic info (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

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

Funding

Funding source: SSDI Grant

Other

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

Procedure manual available: yes

Comments: Procedure manual being developed

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Ohio

Program status: Interested in developing a surveillance program

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

Legislation year enacted: 2000

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Oklahoma
Oklahoma Birth Defects Registry (OBDR)

Purpose: surveillance, referral to prevention/intervention programs

Partner: hospitals, Cytogenetics/ & Medical Genetics

Program status: Currently collecting data

Start year: -1992; statewide 1994

Earliest year of available data: 1992

Organizational location: Department of Health

Population covered annually: 50,000

Statewide: yes

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

Legislation year enacted: 1992

Case Definition

Outcomes covered: modified 6-digit ICD-9-CM codes for birth defects and genetic diseases

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

Age: 2 years

Residence: In-state births to state residents

Surveillance methods

Case ascertainment: population-based, active case ascertainment

Case finding/identification sources:

Vital records: birth certificates, death certificates, fetal death certificates

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

Pediatric & tertiary care hospitals: disease index or discharge index, pediatric logs, surgery logs, specialty outpatient clinics

Third party payers: Indian health services, Military hospitals delivering babies

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

Case Ascertainment

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

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

Coding: CDC coding system based on BPA

Data Collected

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

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

Father: identification info (name, address, date-of-birth, etc.), demographic info (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

Funding

Funding source: general state funds 10%, MCH funds 58%, CDC grant 32

Other

Surveillance reports on file: 1992 & 1993 Annual Report - combined for Oklahoma, Tulsa and Cleveland Counties 1994-1998 Annual Report

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 1994-1997.

Comments: Statewide in 1994. Additional information for case definitions residence: 1995 began abstraction of Oklahoma residents born in Fort Smith

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Oregon

Program status: No surveillance program

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Pennsylvania

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

Partner: universities, hospitals, community nursing services, advocacy groups
Program status: Program implementation scheduled for July 1, 2003
Start year: 2003
Earliest year of available data: 2003 statewide data collected, but 4-county pilot
Organizational location: Department of Health (MCH), Division of Newborn Disease Prevention & Identification (division contained within the Bureau of Family Health, which is equivalent to the MCH Bureau in the PA Dept. of Health.
Population covered annually: 143,972 in 2001, the most recent year for which final figures are available.
Statewide: yes
Current legislation or rule: None applicable

Case Definition

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

Surveillance methods

Case ascertainment: population-based, passive
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, Hospital discharge data collected by the Pennsylvania Health Care Cost Containment Council—(HC4—a state agency).
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program. Those noted above will eventually be linked.
Delivery hospitals: discharge summaries, HC4 data is based on hospital discharge summaries
Pediatric & tertiary care hospitals: discharge summaries, HC4 data is based on hospital discharge summaries
Other specialty facilities: genetic counseling/clinical genetic facilities

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Mainframe

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, needs assessment, service delivery, referral, education/public awareness, prevention projects

Funding

Funding source: MCH funds 100%

Other

Comments: Pennsylvania is in the process of developing a plan for a demonstration project to identify children within the above-specified IC9 code range and link them with early intervention and other appropriate services. The project will collect data from birth

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

Purpose: surveillance, research, referral to services, referral to prevention/intervention programs
Partner: Local health departments, universities, community nursing services, early childhood prevention programs, advocacy groups
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Division of Children with Special Health Care Needs
Population covered annually: 56,000
Statewide: yes
Current legislation or rule: No

Case Definition

Outcomes covered: Neural Tube Defects (Anencephaly, Encephalocele, Myelomeningocele and Meningocele), Cleft Lip and/or Cleft Palate, Gastroschisis, Club Foot, Limb reduction defects, Down Syndrome. Starting January 2003, Congenital Heart Defects, Omphalocele, Ambiguous Genitalia, Albinism, Trisomy 13 and 18, conjoined twin.

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

Age: up to 1 year after delivery

Residence: In state birth to state residents

Surveillance methods

Case ascertainment: Active case ascertainment and population-based

Case finding/identification sources:

Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates

Other state based registries: programs for children with special needs

Delivery hospitals: obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, specialty outpatient clinics

Pediatric & tertiary care hospitals: ICU/NICU logs or charts

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 a ICD9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all elective abortions, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases

Conditions warranting a chart review beyond the newborn period: failure to thrive, cardiovascular

condition, all infant deaths (excluding prematurity), any infant with a codable defect

Coding: ICD-9-CM

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: SPSS, MS Access, Excel

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

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

Funding

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

Other

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

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

Procedure manual available: yes

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Rhode Island
Rhode Island Birth Defects Surveillance Program

Purpose: surveillance, referral to services, referral to prevention/intervention programs
Partner: hospitals, early childhood prevention programs, advocacy groups
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 1997
Organizational location: Department of Health (MCH)
Population covered annually: 12,500
Statewide: yes
Current legislation or rule: None (legislation is currently being developed)

Case Definition

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

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: Currently, chart reviews are conducted on a random basis for quality assurance and data verification. We are planning to review charts of all infants in the NICU. In addition, we are currently working with our Advisory Committee to identify a set of sentinel conditions for case management and outreach. All records of those infants with this set of conditions will be reviewed.
Coding: ICD-9-CM

Data Collected

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

gravidity/parity, illnesses/conditions, prenatal care, pregnancy/delivery complications, family history
Father: identification info (name, address, date-of-birth, etc.), demographic info (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
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

Funding

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

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South Carolina
South Carolina Birth Defects Surveillance and Prevention Program

Purpose: surveillance, research, referral to services
Partner: Local health departments, universities, hospitals
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1993
Organizational location: Greenwood Genetic Center
Population covered annually: 54,140
Statewide: yes

Case Definition

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

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 655.00-755.9, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, limb reduction defects, all prenatal diagnosed or suspected cases
Coding: ICD-9-CM

Data Collected

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

etc.), demographic info (race/ethnicity, sex, etc.), illnesses/conditions, family history

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review

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

Funding

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

Other

Web site: [Http://www.ggc.org](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, referral to services, referral to prevention/intervention programs
Partner: hospital, early childhood prevention programs, advocacy groups
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Research)
Population covered annually: 80,000
Statewide: yes
Current legislation or rule: TCA 68-5-506
Legislation year enacted: 2000

Case Definition

Outcomes covered: Major Birth Defects and fetal alcohol syndrome
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc., a fetal death 500 grams or more, or in the absence of weight, of 22 completed weeks of gestation or more. Induced abortions are not included.
Age: up to age 1
Residence: state residents

Surveillance methods

Case ascertainment: hospital based matched to vital records, passive
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn genetic screening program
Delivery hospitals: disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759
Coding: ICD-9-CM

Data Collected

Infant/fetus: identification info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic info
Mother: identification info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications
Father: identification info (name, address, date-of-birth, etc.), demographic info (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 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, needs assessment, service delivery, grant proposals, education/public awareness, prevention projects

Funding

Funding source: general state funds 100%

Other

Comments: Tennessee's Birth Defects Registry is in transition from a limited regional pilot project to full statewide data collection. We currently have statewide data and are preparing a statewide report, but full integration of the various elements will likely take another year. We also have plans to add active data collection and medical record reviews at randomly selected hospitals.

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Texas

Texas Birth Defects Monitoring Division (TBDMD)

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

Partner: university, March of Dimes

Program status: Currently collecting data

Start year: 1994

Earliest year of available data: 1995

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 365,000

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 fetal alcohol syndrome

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

Age: Up to one year after delivery - FAS up to 5 years

Residence: In-state births to state residents.

Surveillance methods

Case ascertainment: Active, population-based

Case finding/identification sources:

Vital records:

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:

Other sources: licensed birthing centers

Case Ascertainment

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

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 info (name, address, date-of-birth, etc.), demographic info (race/ethnicity, sex, etc.),

birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic info

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

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

Data Collection Methods and Storage

Database storage/management: SQL Server

Data Analysis

Data analysis software: SPSS, SAS, MS Access

Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, clinical review, timeliness, re-casefinding, re-review of medical records

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

System Integration

System links: Link registry to vital records for demographic data

Funding

Funding source: general state funds 51%, MCH funds 33%, Preventive Health block grant 16%

Note: does not include CDC-funded Texas Birth Defects Research Center funds

Other

Web site: <http://www.tdh.state.tx.us/tbdmd/index.htm>

Surveillance reports on file: Report of Birth Defects Among 1995 Deliveries. 1996 Birth Defects in the Lower Rio Grande Valley. Report of Birth Defects Among 1996 and 1997 Deliveries. Report of Birth Defects Among 1998 and 1999 Deliveries.

Procedure manual available: yes

Additional information on file: copy of legislation; Texas Birth Defects Monitoring Division brochure; Fetal Alcohol Syndrome brochure (English and Spanish); birth defect risk factor series; birth defects coding index; program operating plan; conference proceedings; glossary; impact of including induced pregnancy terminations before 20 weeks gestation on birth defects rates; pregnancy outcome patterns for various birth defects; cluster investigation annual reports

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.

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Utah
Utah Birth Defect Network (BDN)

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

Partner: universities, advocacy groups

Program status: Currently collecting data

Start year: 1994

Earliest year of available data: 1994

Organizational location: Department of Health (MCH), University of Utah

Population covered annually: 49,000

Statewide: yes

Current legislation or rule: Birth Defect Rule

Legislation year enacted: 1999

Case Definition

Outcomes covered: 740.000 - 759.000

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

Age: 2

Residence: Maternal residence in Utah at time of delivery

Surveillance methods

Case ascertainment: Combined active/passive all of which is population-based

Case finding/identification sources:

Vital records: birth certificates, death certificates, fetal death certificates

Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, 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 a ICD9 code 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, All fetal deaths certificates, NICU reports, infant deaths are reviewed

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, GI condition (i.e. intestinal blockage), cardiovascular condition, all infant deaths (excluding prematurity), any infant with a codable defect

Coding: CDC coding system based on BPA, also use codes for pregnancy termination (600s)

Data Collected

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

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

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: Epi-Info, SAS, Statview

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), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, case-control investigations, genetic studies

Funding

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

Other

Web site: health.utah.gov/birthdefect

Surveillance reports on file: 1994 NTD Surveillance, 1994-1996 registry report

Procedure manual available: yes

Additional information on file: Data Sharing Protocol

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Vermont

Program status: Interested in developing a surveillance program

Other

Comments: In 2002 a Birth Information Council was established to advise the Legislature on the need for, and implementation of, a birth information system. The Council recommended to the Legislature that a Birth Information Network be established with the purpose of identifying children with special health needs and ensuring they receive referrals to appropriate services. Based on the Council's recommendation legislation was passed in 2003 providing authorization for the Health Department to establish the Network. However, implementation of the system is dependent on the Health Department obtaining grants or other funding.

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Virginia
Virginia Congenital Anomalies Reporting and Education System (VACARES)

Purpose: surveillance
Partner: universities, hospitals, early childhood prevention programs
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1987
Organizational location: Pediatric Screenings and Genetic Services, Div. of Child and Adolescent Health
Population covered annually: Calendar Year 2002- 98,864
Statewide: yes
Current legislation or rule: Health Law 32.1-69.1,-69.1:1,-69.2
Legislation year enacted: 1985, amended 1986, 1988

Case Definition

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

Surveillance methods

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

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, timeliness

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

System Integration

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

Funding

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

Other

Web site: www.vahealth.org/genetics
Surveillance reports on file: A 10-Year report (1989-1998) has recently been completed.
Procedure manual available: yes
Additional information on file: Oracle database
Comments: As of September 2002, most hospitals are entering data directly into database from the hospital contacts via Virginia Infant Screening and Infant Tracking Program (VISITS), a web-based tracking and data management system.

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Washington
Washington State Birth Defects Registry

Program status: Currently collecting data
Start year: 1986- Active and 1991- Passive
Earliest year of available data: 1987
Organizational location: Department of Health (MCH)
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 since 1991 to the current time (passive surveillance), the Department of Health receive casefinding logs listing ICD-9-CM codes 740-759; specific primary cancers; specific metabolic conditions; FAS/FAE. Over t
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: to age 4 years historically, We are transitioning to ascertainment through 1 year of age currently.
Residence: resident births; child born or diagnosed in state

Surveillance methods

Case ascertainment: passive
Case finding/identification sources:
Delivery hospitals: discharge summaries, Casefinding Log completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff
Pediatric & tertiary care hospitals: discharge summaries, Casefinding Logs completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff

Case Ascertainment

Coding: ICD-9-CM

Data Collected

Infant/fetus: identification info (name, address, date-of-birth, etc.), birth defect diagnostic info
Mother: identification info (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Database storage/management: D-base

Data Analysis

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

Funding

Funding source: general state funds 20%, MCH funds 30%, CDC grant 50%

Other

Surveillance reports on file: Brighter Futures report available for 1987-1988 data
Procedure manual available: yes

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West Virginia
West Virginia Birth Defects Surveillance System

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

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

Program status: Currently collecting data

Start year: 1989

Earliest year of available data: 1989

Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Department of Health (MCH)

Population covered annually: 21,000

Statewide: yes

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

Legislation year enacted: 1991 State Statute Section 16-40-1, legislative updated: 2002

Case Definition

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

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

Age: 0-6

Residence: In and out of state births to state residents

Surveillance methods

Case ascertainment: passive case ascertainment transitioning to active 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, cancer registry, AIDS/HIV registry, SIDS

Delivery hospitals: Hospital personnel complete reporting forms, reports also sent from Genetics Program.

Pediatric & tertiary care hospitals: Hospital personnel and Genetics Programs complete reporting forms

Other specialty facilities: genetic counseling/clinical genetic facilities

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, less than 2500 grams or less than 37 weeks, all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI

condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 6, ocular conditions, auditory/hearing conditions, any infant with a codable defect

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

Data Collected

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

Mother: identification info (name, address, DOB, etc.), demographic info (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic info, pregnancy/delivery complications, family history

Father: identification info (name, address, DOB, etc.), demographic info (race/ethnicity, sex, etc.), illnesses/conditions, family history

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: custom

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

System Integration

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

Funding

Funding source: CDC grant 100%

Other

Web site: www.wvdhhr.org

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Wisconsin
Wisconsin Birth Defects Registry (WBDR)

Purpose: surveillance, research, referral to services
Partner: Local public health departments, universities, hospitals, early childhood prevention programs, advocacy groups
Program status: Program has not started collecting data yet
Start year: 2001
Earliest year of available data: 2003
Organizational location: Department of Health and Family Services (CSHCN)
Population covered annually: ~67,000
Statewide: yes
Current legislation or rule: Statute 253.12HFS 116—Estimate will be finalized by Spring 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 WI regardless of residence status.

Surveillance methods

Case ascertainment: population based, passive
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
Pediatric & tertiary care hospitals: Case reports from pediatric specialty clinics
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports, hospital discharge data through 2 yrs of age

Case Ascertainment

Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

Data analysis software: TBD

Quality assurance: TBD

Data use and analysis: baseline rates, rates by demographic and other variables, time trends, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, Items checked above are the ones likely to be used.

System Integration

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

Funding

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

Other

Web site: www.cbdds.state.wi.us/ www.dhfs.state.wi.us/DPH_BFCH/cshcn/bdpsdesc/bdpssystem.htm
Surveillance reports on file: Birth and Developmental Outcome Monitoring Program 1990-91, Birth and Developmental Outcome Monitoring Program 1990-94
Comments: The new program will require complete specification through an Advisory Council and Administrative Rule.

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Wyoming

Program status: Interested in developing a surveillance program

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US Department of Defense
United States Department Of Defense (Dod) Birth And Infant Health Registry

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

Case Definition

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

Surveillance methods

Case ascertainment: Electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries, combination, population
Case finding/identification sources:
Vital records:
Delivery hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, All inpatient and outpatient encounters are captured in standardized DoD data
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, All inpatient and outpatient encounters are captured in standardized DoD data
Third party payers: All inpatient and outpatient encounters are captured in standardized DoD data
Other sources: Validation of standardized electronic data is performed by active case ascertainment and chart review of all births at one of the largest DoD hospitals (Naval Medical Center, San Diego)

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a CDC/BPA code, Validation of standardized electronic data is performed by active case ascertainment and chart review of all births at one of the largest DoD hospitals (Naval Medical Center, San Diego)
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

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

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