TERATOLOGY 64:S47–S116 (2001)

STATE BIRTH DEFECTS SURVEILLANCE PROGRAMS DIRECTORY

Updated May 2001

Prepared by the National Center on Birth Defects and Developmental Disabilities, CDC

Acknowledgement: State health officers provided the information for this directory. Their names can be found under the “contact” section of each state profile.

Alabama
Alabama Birth Defects Program (ABDP)

Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1998
Organizational location: University
Population covered annually: 8,000
Statewide: no
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), elective terminations (<20 week gestation, ≥20 weeks gestation)

Age: up to one year after delivery

Residence: Mobile and Baldwin 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: chart review, 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: chart review, disease index or discharge index, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, Congenital Anomaly reporting form

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

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 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, 5 minute apgar <7

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (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: California's coding system based on BPA

Data Collected

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

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

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

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff

Database storage/management: Epi-Info, Clipper

Data Analysis

Data analysis software: Epi-Info

Quality assurance: double-checking of assigned codes, 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

Other

Web site: www.usouthal.edu/genetics/ (Site linked to international birth defect information systems.)

Procedure manual available: yes

Additional information on file: Birth Defects Syndromes fact sheets

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Alaska

Alaska Birth Defects Registry (ABDR)

Program status: Currently collecting data
Start year: 1996
Earliest year of available data: 1996
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 10,000
Statewide: yes
Current legislation or rule: 7 AAC 27.012
Legislation year enacted: 1996

Case Definition
Outcomes covered: ICD-9 Codes 237.7, 243, 255.2, 277, 279, 282, 284.0, 331, 334, 335, 343, 359, 362.74, 740-760, 760.71
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20 weeks gestation)
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 and fetal death certificates
Other state based registries: programs for children with special needs
Delivery hospitals: reportable ICD-9 code reports are received from the health information management department
Pediatric & tertiary care hospitals: reportable ICD-9 code reports are received from the health information management department
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 an ICD-9 code of 760.71 or 742.1
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.)
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Data Collection Methods and Storage
Data collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: MS Access
Data Analysis
Data analysis software: Epi-Info, SPSS, SAS, MS Access
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), needs assessment, service delivery, grant proposals, education/public awareness, prevention projects
Funding
Funding source: MCH funds 80%, other federal funding (non-CDC) 20%
Other
Web site: in development
Surveillance reports on file: Family Health Dataline
Procedure manual available: yes

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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1986
Organizational location: Bureau of Public Health Statistics/Office of Health Registries
Population covered annually: 80,000
Statewide: yes
Current legislation or rule: ARS $ 36-133 statute Title 9, Chapter 4, Articles 1 and 5, Adopted effective 1991
Legislation year enacted: 1988

<u>Case Definition</u>
Outcomes covered: 44 composite categories covering the major birth defects and genetic diseases, as defined by the BPA/MACDP codes
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20 weeks gestation)
Age: up to one year after delivery
Residence: in-state birth to state residents
<u>Surveillance methods</u>
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, specifically these are the Children Rehabilitation Services facilities, which is part of the Office for Children with Special Health Care Needs
Delivery hospitals: chart review, disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, ultrasound reports, cytogentic reports, stillborn logs, mother's charts for stillborns
Pediatric & tertiary care hospitals: chart review, disease index or discharge index, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, laboratory logs, ultrasound reports, cytogentic reports, stillborn logs, mother's charts for stillborns
Other specialty facilities: cytogenetic laboratories
Other sources: children receiving services from Children Rehabilitation Services (CRS) facilities, whose diagnosis falls within the ABDMP case-finding criteria.

<u>Case Ascertainment</u>
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 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, ICD-9-CM
<u>Data Collected</u>
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, prenatal care, pregnancy/delivery complications, exposures, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), exposures, family history
<u>Data Collection Methods and Storage</u>
Data collection: printed abstract/report filled out by staff
Database storage/management: Oracle
<u>Data Analysis</u>
Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources, clinical review
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, epidemiologic studies (using only program data), grant proposals
<u>Funding</u>
Funding source: general state funds 57%, genetic screening revenues 43%
<u>Other</u>
Web site:
www.hs.state.az.us/phs/phstats/bdr/index.htm
Surveillance reports on file: Annual Reports, 1986 through 1992.
Procedure manual available: yes
Additional information on file: procedures 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)

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. (<20 week gestation, ≥20 weeks gestation), elective terminations (<20 week gestation, ≥20 weeks gestation)
Age: two years after delivery
Residence: in/out of state births to state residents

Surveillance methods

Case ascertainment: active case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates
Delivery hospitals: chart review, 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: chart review, disease 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.), 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, all stillborn infants, and neonatal deaths
Conditions warranting a chart review beyond the newborn period: all infant deaths (excluding prematurity), any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, Access
Quality assurance: re-abstraction of cases, clinical review, timeliness
Data use and analysis: baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, education/public awareness, prevention projects

Funding

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

Other

Web site: under development
Surveillance reports on file: Annual reports

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California

California Birth Defects Monitoring Program (CBDMP)

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: 251,000
Statewide: no
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: major structural birth defects, primarily encompassed within ICD codes 740-759
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. ($<$20 week gestation, $\geq$20 weeks gestation), elective terminations ($<$20 week gestation, $\geq$20 weeks gestation)
Age: one year
Residence: In-state births to residents of 1 of the 11 registry counties. Does not include births in military hospitals.

Surveillance methods

Case ascertainment: active case ascertainment, population based
Case finding/identification sources:
Delivery hospitals: chart review, 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: chart review, 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 information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, exposures, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff, computerized reporting system
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
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, grant proposals, education/public awareness, prevention projects

Funding

Funding source: general state funds 64%, CDC grant 19%, other federal funding (non-CDC) 15%, private foundations 2%

Other

Web site: www.cbdmp.org

Surveillance reports on file: Birth Defects in California (1983-90 data); Birth Defects in 11 California Counties (1990-92 data); Birth Defects in California Counties (1995 data); 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.
Comments: 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 do active surveillance anywhere in the state when warranted by environmental incidents or concerns.

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Colorado

Colorado Responds to Children with Special Needs: Colorado's Public Health Program for Monitoring and Preventing Birth Defects (CRCSN)

Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 60,000
Statewide: yes
Current legislation or rule: Colorado Revised Statutes (CRS) 25-1-107
Legislation year enacted: 1985

Case Definition

Outcomes covered: all birth defects, some genetic diseases, developmental disabilities, very low birth weight (less than 1500 grams), others with medical and maternal risk factors for developmental delay
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (<20 week gestation, ≥20 weeks gestation), fetal deaths (diagnoses made prenatally are ascertained), elective terminations (<20 week gestation, ≥20weeks gestation)
Age: 3 years of age (7 yrs for fetal alcohol syndrome)
Residence: State resident at time of diagnosis

Surveillance methods

Case ascertainment: passive, population based, multiple sources; active for special projects
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Other state based registries: newborn genetic screening program, newborn hearing 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
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: 14 selected conditions for CUSUM monitoring or other designated reason. Review is performed for 12 additional conditions based on a data quality analysis.

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

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, ArcView (GIS software)
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

Funding

Funding source: general state funds 61%, CDC grant 31%, other federal funding (non-CDC) 8%

Other

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

Connecticut Birth Defect Prevention and Surveillance Program (CBDPSP)

Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1993
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 45,000
Statewide: yes
Current legislation or rule: Sec. 10a-132b transferred to Sec 19a-56a in 1999
Legislation year enacted: 1991

Case Definition
Outcomes covered: 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
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, ambulatory surgery and emergency room visits during first year
Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, newborn biochemical screening program, cancer registry, AIDS/HIV registry
Delivery hospitals: disease index or discharge index
Pediatric & tertiary care hospitals: disease index or discharge index
Case Ascertainment
Conditions warranting chart review in newborn period: any birth certificate with a birth defect box checked, first three years did various combinations of chart review . No longer have resources to continue and the three years of data identified the sensitivity and specificity of the data sources.
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.)
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Data Collection Methods and Storage
Data collection: electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: SPSS
Data Analysis
Data analysis software: SPSS
Quality assurance: 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, prevention projects, provider education

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Delaware

Delaware Birth Defects Surveillance Project

Program status: Currently collecting data
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 10,574
Statewide: yes
Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects
Legislation year enacted: 1997

<u>Case Definition</u>

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 that cause birth defects, neural tube defects.
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. ($\geq$20 weeks gestation)
Age: up to one year after delivery
Residence: in-state and out-of-state birth to state resident, and in-state birth to state non-resident

<u>Surveillance methods</u>

Case ascertainment: active and passive surveillance, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates

<u>Case Ascertainment</u>

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

<u>Data Collected</u>

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

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

Data collection: electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: electronic birth certificate

<u>Data Analysis</u>

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

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District of Columbia

Program status: No surveillance program

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Florida

Florida Birth Defects Registry (FBDR)

Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: ~ 200,000
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)
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
Delivery hospitals: discharge summaries
Pediatric & tertiary care hospitals: discharge summaries
Other sources: physician reports
Case Ascertainment
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, pregnancy/delivery complications, exposures
Father: identification information (name, address, date-of-birth, etc.)
Data Collection Methods and Storage
Data collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, SAS, Excel
Data Analysis
Data analysis software: SPSS, SAS, 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: fbdr.med.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)

Program status: Currently collecting data
Start year: 1967
Earliest year of available data: 1968
Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities
Population covered annually: 44933
Statewide: no
Current legislation or rule: Official Code of Georgia (OCGA) 31-12-2
Legislation year enacted: 1994

Case Definition

Outcomes covered: major structural or genetic birth defects
Pregnancy outcome: live births (≥20 weeks or birth weight ≥500 grams), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20 weeks gestation), elective terminations (≥20 weeks gestation)
Age: before 6 years of age
Residence: Births to mothers resident in five metropolitan Atlanta counties

Surveillance methods

Case ascertainment: active surveillance; 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, surgery logs, cardiac catheterization laboratories, Stillbirth reports
Pediatric & tertiary care hospitals: disease index or discharge index, postmortem/pathology logs, surgery logs, Laboratory logs
Other specialty facilities: 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 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, >=20 weeks or birth weight >=500 grams, all stillborn infants, all neonatal deaths, all infants with low APGAR scores, all infants in NICU or special care nursery, Elective abortions occurring >=20 weeks
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, developmental delay, recurrent infections, 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, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff, electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic report filled out by staff at facility as of 2/1/2000
Database storage/management: MS Access, SAS, Mainframe

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS, MS Access
Quality assurance: 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, time trends, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies

Funding

Funding source: 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)

Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: University
Population covered annually: 17,000+
Statewide: yes
Current legislation or rule: Hawaii Revised Statutes, Sections 321-31 and 338-2 in conjunction per Executive Chamber ruling by Governor on June 16,1989. Hawaii Revised Statutes 324-1 and 324-2 (1990 Amendments) for additional legislative authority.
Legislation year enacted: 1989

Case Definition

Outcomes covered: all 1154+ recommended by CDC
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (<20week gestation, ≥20weeks gestation), elective terminations (<20week gestation, ≥20weeks gestation)
Age: up to one year after delivery
Residence: all in-state births (resident and non-resident)

Surveillance methods

Case ascertainment: active case ascertainment, population-based
Case finding/identification sources:
Vital records: Vital records are used to supplement information collected from other data sources but are not used to identify potential cases.
Delivery hospitals: chart review, disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: chart review, disease index or discharge index, discharge summaries
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, all stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

Funding

Funding source: general state funds 7%, CDC grant 65%, private foundations 5%, Contractual- State 11%, Contractual- Regional 1%

Other

Web site:
http://members.aol.com/entropynot/hbdp.html
Surveillance reports on file: (7) Hawaii Birth Defects Program Statewide Surveillance Data Reports - 1) = 1989-1991, 2) = 1988-1993, 3) = 1988-1994, 4) = 1988-1995, 5) = 1987-1996, 6) = 1986-1997, 7) = 1986-1998, with 8) 1986-1999 to be published in summer 2000.
Procedure manual available: yes

Additional information on file: HBDP informational brochure; organizational chart; copy 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 report (completeness, accuracy, timeliness); special study reports (4).

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Idaho

Program status: No surveillance program

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Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1988
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 182,000
Statewide: yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)
Legislation year enacted: 1985

Case Definition
Outcomes covered: ICD-9-CM Codes 740.0 through 759.9; infants positive for controlled substances; serious congenital infections; congenital endocrine, metabolic or immune disorders; congenital blood disorders; other conditions such as retinopathy of prematurity, fetal alcohol syndrome, intrauterine growth retardation; very low birth weights; neonatal or fetal deaths
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20weeks gestation)
Age: end of newborn hospitalization
Residence: in-state births mandatory
Surveillance methods
Case ascertainment: passive case ascertainment with mandatory hospital reporting
Case finding/identification sources:
Vital records: fetal death certificates, mandatory hospital reporting
Other state based registries: newborn genetic screening program, newborn hearing screening program, newborn biochemical screening program, cancer registry, AIDS/HIV registry, Childhood lead poisoning, Occupational Disease
Delivery hospitals: Maternal charts with 5% of infants reviewed for clarification not case ascertainment
Case Ascertainment
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.)
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, pregnancy/delivery complications, exposures
Father: identification information (name, address, date-of-birth, etc.)
Data Collection Methods and Storage
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: MS Access, FoxPro, Mainframe
Data Analysis
Data analysis software: MS Access, SAS
Quality assurance: timeliness
Data use and analysis: routine statistical monitoring, time trends, epidemiologic studies (using only program data), service delivery, referral
Funding
Funding source: general state funds 78%, CDC grant 19%, other federal funding (non-CDC) 5%
Other
Web site: idph.state.il.us/about/epi/aporsrpt.htm
Surveillance reports on file: Epi Report 94:8-Birth Defects Surveillance Report Epi Report 97:6-Birth Defects in Illinois: A report on mortality and county-specific prevalence at birth Epi Report 99:4-Trends in the Prevalence of Birth Defects in Illinois and Chicago 1989 to 1997 Epi Report 2000:4-Adverse Pregnancy Outcomes in Illinois: County-specific Prevalence and Related Infant Mortality-1989-1998
Comments: APORS is transition to more active ascertainment and expand case age to 2 years.

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Indiana

Indiana Birth Problems Registry

Program status: Interested in developing a surveillance program

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Iowa

Iowa Birth Defects Registry (IBDR)

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

<u>Case Definition</u>

Outcomes covered: major birth defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (<20week gestation, ≥20weeks gestation), elective terminations (<20week gestation, ≥20weeks gestation)
Age: 1 year
Residence: maternal residence in Iowa at time of delivery

<u>Surveillance methods</u>

Case ascertainment: population based, active case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: chart review, 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: chart review, 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
Other sources: physician reports

<u>Case Ascertainment</u>

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a ICD9-CM codes in addition to 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, CNS condition (ie seizure), GI condition (ie intestinal blockage), cardiovascular condition, childhood deaths between 1 and 6, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

<u>Data Collected</u>

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

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

Data collection: printed abstract/report filled out by staff, electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: MS Access, Oracle, SAS, Mainframe

<u>Data Analysis</u>

Data analysis software: Epi-Info, SAS, MS Access, Oracle
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, 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

Funding

itFunding source: general state funds 7%, CDC grant 69%, other federal funding (non-CDC) 24%

Other

Web site: http://www.public-health.uiowa.edu/birth.html

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

Procedure manual available: yes

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Kansas

Birth Defects Reporting system

Program status: No surveillance program
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 38,000
Statewide: yes
Current legislation or rule: KSA 65-102

Surveillance methods

Case ascertainment: No surveillance system is in place, sources below relate to birth defect reporting system.

Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
Pediatric & tertiary care hospitals: Birth Defect reporting form - sent by hospitals for infants up to one year of age.

Case Ascertainment

Coding: 25 conditions/categories are listed on the birth certificate and birth defect reporting form.

Data Collected

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

Data Collection Methods and Storage

Data collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: AS 400 / Crystal Reports

Data Analysis

Data analysis software: SAS, ad-hoc summary reports developed as needed from Crystal Reports and SAS.
Quality assurance: No surveillance program is in place. Verification is conducted on birth certificate data.
Data use and analysis: routine statistical monitoring, identification of potential cases for other epidemiologic studies, ad-hoc upon request.

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Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Program status: Currently collecting data
Start year: 1996
Earliest year of available data: 1997
Organizational location: Department for Public Health, Division of Adult and Child Health
Population covered annually: 52,000
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 and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20weeks gestation or 350 gms)
Age: up to fifth birthday
Residence: In-state births to state residents
Surveillance methods
Case ascertainment: combination of active and passive, hospital 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 genetic screening program, newborn hearing screening program
Delivery hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts
Other specialty facilities: 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 ICD9-CM codes in addition to 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, small for gestational age, 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
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures, family history
Data Collection Methods and Storage
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: MS Access, Mainframe
Data Analysis
Data analysis software: SAS, MS Access
Quality assurance: 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, education/public awareness, prevention projects
Funding
Funding source: general state funds 60%, CDC grant 40%
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)

Program status: Program has not started collecting data yet
Start year: 2002
Earliest year of available data: 2003–2005
Organizational location: Department of Health (Maternal and Child Health, 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
Pregnancy outcome: in progress
Age: up to 3 years
Residence: in and out of state births to state residents (tentative criteria)
Surveillance methods
Case ascertainment: active case ascertainment
Case finding/identification sources: in progress

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Maine

Maine Birth Defects Program

Program status: Program has not started collecting data yet
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 13,800
Statewide: yes
Current legislation or rule: 22 MRSA c. 1687
Legislation year enacted: 1999

Case Definition

Outcomes covered: selected major birth defects: NTD, clefts, gastroschisis, major heart defects, trisomy 13,18 and 21
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20weeks gestation), fetal deaths (prenatally diagnosed at any gestation), elective terminations (≥20weeks gestation), elective terminations (prenatally diagnosed at any gestation)
Age: through age one
Residence: all in-state births

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 genetic screening program
Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/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, 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)

Funding

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

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Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1984
Organizational location: Community & Public Health Administration, Office for Genetics & Children with Special Health Care Needs
Population covered annually: 68,000
Statewide: yes
Current legislation or rule: Health-General Article, Section 18-206; Annotated Code of Maryland
Legislation year enacted: 1982

Case Definition

Outcomes covered: selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft Lip, cleft lip with cleft palate, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper limb, reduction deformity - lower limb, congenital dislocation of the hip, and Down syndrome
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20weeks gestation, or ≥500 grams weight. We do accept reports on fetal deaths =500 grams weight.) We do accept reports on terminations <500grams or <20 weeks if reported to us.
Age: Newborn
Residence: All in-state births

Surveillance methods

Case ascertainment: passive surveillance, 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, Infant newborn screening (for metabolic disorders)
Delivery hospitals: obstetrics logs (i.e., labor & delivery), regular nursery logs, Sentinel Birth Defects hospital report form is our primary source.
Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, midwifery facilities, Sentinel Birth Defects hospital report form is our primary source.
Other specialty facilities: 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 selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, Law mandates reporting of 12, All fetal death certificates
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Funding

Funding source: general state funds 100%

Other

Web site: http://mdpublichealth.org (then select Hereditary Disorders)

Surveillance reports on file: Provisional surveillance reports 1984-1992; 1995-1998

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 Monitoring Program, Massachusetts Department of Public Health (MCBDRP)

Program status: Currently collecting data
Start year: 1997
Earliest year of available data: 1998
Organizational location: Bureau of Health Statistics, Research and Evaluation
Population covered annually: 81,404 for 1998
Statewide: yes, statewide coverage started October 1998
Current legislation or rule: Massachusetts General Laws, Chapter 111, Section 67E. March of Dimes has introduced an amendment in 2000 to expand ascertainment sources from birthing hospitals to physicians. Waiting approval.
Legislation year enacted: 1963

<u>Case Definition</u>
Outcomes covered: major birth defects and chromosomal anomalies
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20weeks gestation, or ≥350 gms)
Age: up to one year
Residence: in and out of state births to state residents
<u>Surveillance methods</u>
Case ascertainment: population based, state-wide, combination of active case ascertainment and administrative review
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Delivery hospitals: chart review, disease index or discharge index, regular nursery logs, ICU/NICU logs or charts, postmortem/pathology logs
Pediatric & tertiary care hospitals: chart review, disease index or discharge index, ICU/NICU logs or charts, postmortem/pathology logs
<u>Case Ascertainment</u>
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, all charts that have selected ICD9-CM codes within the range of 740-759, all charts of infants reported from nursery or NICU with an identified birth defect, all stillborn infants
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM
<u>Data Collected</u>
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
<u>Data Collection Methods and Storage</u>
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic scanning of printed records, Data from printed hospital reporting form is entered into electronic surveillance data base.
Database storage/management: MS Access, SAS, Mainframe, Microsoft Excel
<u>Data Analysis</u>
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 study, National Birth Defects Prevention Study

Funding
Funding source: CDC grant 100%
Other
Web site: website in development
Surveillance reports on file: first surveillance report to be published in July 2001
Procedure manual available: yes

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Michigan

Michigan Birth Defects Registry (MBDR)

Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 133,500
Statewide: yes
Current legislation or rule: Public Act 236 of 1988
Legislation year enacted: 1988

Case Definition

Outcomes covered: congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc (≥20weeks gestation)
Age: up to two years after delivery
Residence: resident births, 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, fetal death certificates, cytogenic laboratories
Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, cancer registry
Delivery hospitals: chart review, disease index or discharge index, specialty outpatient clinics
Pediatric & tertiary care hospitals: chart review, disease index or discharge index
Other specialty facilities: 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
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Funding

Funding source: general state funds 85%, CDC grant 15%

Other

Web site:
www.mdch.state.mi.us/PHA/OSR/index.htm
Surveillance reports on file: birth defects incidence and mortality
Procedure manual available: yes

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Minnesota

Program status: Interested in developing a surveillance program
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: not determined at this time

Surveillance methods
Case ascertainment: not determined at this time

Other
Web site: www.health.state.mn.us
Comments: no formal program currently in place

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Mississippi

Mississippi Birth Defects Registry (MBDR)

Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2001
Organizational location: Department of Health (Maternal and Child Health), Mississippi State Department of Health
Population covered annually: 42,000
Statewide: yes
Current legislation or rule: Section 41-21-205 of the Mississippi Code
Legislation year enacted: 1997

<u>Case Definition</u>

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. (≥20weeks gestation, ≥350 grams), elective terminations (≥20weeks gestation, ≥350 grams)
Age: 21
Residence: in and out of state births to state residents

<u>Surveillance methods</u>

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 genetic screening program, newborn hearing screening program, newborn biochemical screening program, cancer registry, birth and death certificates
Delivery hospitals: chart review, disease index or discharge index, discharge summaries, regular nursery logs, pediatric logs, postmortem/pathology logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: chart review, 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

<u>Case Ascertainment</u>

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a ICD9-CM codes in addition to 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 stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

<u>Data Collected</u>

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

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

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

<u>Data Analysis</u>

Data analysis software: MS Access
Quality assurance: validity checks, re-abstraction of cases, 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, 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

Funding

Funding source: general state funds 10%, MCH funds 90%

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Missouri

Missouri Birth Defect Registry

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

<u>Case Definition</u>
Outcomes covered: ICD9 codes 740-759, plus additional diagnoses
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20 weeks gestation, fetal death certificates are only source of data), elective terminations (<20week gestation, ≥20weeks gestation, surveillance of terminations currently limited to NTDs)
Age: up to one year after delivery
Residence: in and out of state births to state residents
<u>Surveillance methods</u>
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
Delivery hospitals: discharge summaries
Pediatric & tertiary care hospitals: discharge summaries
<u>Case Ascertainment</u>
Coding: ICD-9-CM
<u>Data Collected</u>
Infant/fetus: demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, pregnancy/delivery complications
Father: demographic information (race/ethnicity, sex, etc.)
<u>Data Collection Methods and Storage</u>
Data collection: electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: SAS
<u>Data Analysis</u>
Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects
<u>Funding</u>
Funding source: general state funds 24%, CDC grant 76%
<u>Other</u>
Surveillance reports on file: Missouri Birth Defects 1993-95

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

Program status: Program has not started collecting data yet
Start year: 2000
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 11,000
Statewide: yes

Case Definition
Outcomes covered: major birth defects
Pregnancy outcome: live births ($>$500g and 20 weeks gestation), fetal deaths-stillbirths, spontaneous abortions, etc. ($\geq$20 weeks gestation, $>$500g)
Age: 21 years
Residence: in-state births and out of state births to MT residents
Surveillance methods
Case ascertainment: passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates, referrals
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Case Ascertainment
Coding: ICD-9-CM
Data Collection Methods and Storage
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Oracle
Funding
Funding source: CDC grant 100%

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Nebraska

Nebraska Birth Defects Registry

Program status: Currently collecting data
Start year: 1973
Organizational location: Nebraska Health and Human Services Regulation & Licensure Data Management Section
Population covered annually: Statewide, 24,000+ births annually
Statewide: yes
Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §71-646, §71-647, §71-648, §71-649)
Legislation year enacted: 1972

Case Definition
Outcomes covered: all birth defects, exclusions according to CDC exclusion list
Pregnancy outcome: live births ($>$20 weeks and $>$500 grams), fetal deaths-stillbirths, spontaneous abortions, etc.($\geq$20 weeks gestation)
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: chart review, 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: chart review, disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics, Nebraska Birth Defects Prevention Program Congenital Defects Case Record
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports
Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Data Collection Methods and Storage
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: SAS, 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: 1998 report in Vital Statistics Report
Additional information on file: Copy of legislation, congenital defects case record form
Comments: State legislation introduced to allow release of patient-identifying information to approved researcher for the purpose of research; development of a system so that hospitals may use the electronic birth certificate to initially alert the surveillance program of the birth of a child with an anomaly.

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Nevada

Nevada Birth Defects Registry

Program status: Currently collecting data
Start year: 2000
Earliest year of available data: NA
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 29,000
Statewide: no, currently in Las Vegas only
Current legislation or rule: NRS 442.300 - 442.330 - Birth Defects Registry Legislation *** Regulation = NAC 442
Legislation year enacted: 1999

<u>Case Definition</u>
Outcomes covered: major birth defects and genetic diseases
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc (≥20 weeks gestation), elective terminations (≥20 weeks gestation)
Age: cover from 0-7 years of age
Residence: In-state births
<u>Surveillance methods</u>
Case ascertainment: Combination of active and passive ascertainment
Case finding/identification sources:
Vital records: birth certificates, matched birth/death file, Hospital medical records
Other state based registries: programs for children with special needs, newborn biochemical screening program, cancer registry
Delivery hospitals: chart review, disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports, state sponsored specialty clinics
<u>Case Ascertainment</u>
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions 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
<u>Data Collected</u>
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), prenatal care, pregnancy/delivery complications
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
<u>Data Collection Methods and Storage</u>
Data collection: printed abstract/report filled out by staff, electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: MS Access, Oracle, Mainframe
<u>Data Analysis</u>
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, education/public awareness, prevention projects
<u>Funding</u>
Funding source: general state funds 5%, CDC grant 95%

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New Hampshire

New Hampshire Birth Defects Registry (NHBDR)

Program status: Program has not started collecting data yet
Start year: 2000
Organizational location: Department of Health (Maternal and Child Health), Bureau of WIC Nutrition Services
Population covered annually: 14,150
Statewide: yes

Case Definition
Outcomes covered: neural tube defects, possibly other major defects
Pregnancy outcome: live births (all gestational ages and birth weights)
Surveillance methods
Case finding/identification sources:
Vital records: birth certificates, death certificates
Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, cancer registry, AIDS/HIV registry
Delivery hospitals: discharge summaries
Pediatric & tertiary care hospitals: discharge summaries
Other specialty facilities: genetic counseling/clinical genetic facilities
Case Ascertainment
Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, all prenatal diagnosed or suspected cases
Coding: ICD-9-CM
Data Collection Methods and Storage
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.)
Database storage/management: MS Access
Data Analysis
Data analysis software: MS Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, timeliness
Data use and analysis: baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, grant proposals, education/public awareness, prevention projects
Funding
Funding source: CDC grant 95%

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New Jersey

Special Child Health Services: Birth Defects and Special Needs Registry (SCHS Regis)

Program status: Currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health & Senior Services - Special Child, Adult, and Early Intervention Services
Population covered annually: 113,500
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: birth defects ≤ age 1, special Needs ≤ 21 yrs.
Residence: in/out NJ births to NJ res; anyone becoming NJ res

Surveillance methods

Case ascertainment: Passive, population based reporting system with annual quality assurance visits by BDR staff to birthing hospitals, birthing centers and, pediatric care facilities.
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
Delivery hospitals: chart review, 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: chart review, 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, physician reports
Other sources: Special Child Health Services county based Case Management units, parents, schools, medical examiners

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a ICD9-CM codes in addition to 740-759, any chart with a selected list of ICD9-CM codes outside 740-759
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

Funding

Funding source: MCH funds 90%, dedicated state funds 10%

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.
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)

Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 27,000
Statewide: yes
Current legislation or rule: None

Case Definition
Outcomes covered: 740-760.72
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (<20week gestation, ≥20weeks gestation), elective terminations (<20week gestation, ≥20weeks gestation)
Age: age 14
Residence: In and out of state births to state residents, New Mexico
Surveillance methods
Case ascertainment: active case ascertainment for NTDs and oral facial clefts; passive for other defects
Case finding/identification sources:
Vital records: birth certificates
Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, cancer registry
Delivery hospitals: chart review, obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics
Pediatric & tertiary care hospitals: chart review, ICU/NICU logs or charts, specialty outpatient clinics, midwifery facilities
Third party payers: Medicaid databases, health maintenance organizations (HMOs), Indian health services
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.)
Other sources: physician reports, Children's Chronic Condition's Register
Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Data Collection Methods and Storage
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: MS Access
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
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, capture-recapture analyses, observed vs expected analyses, needs assessment, grant proposals, education/public awareness, prevention projects
Funding
Funding source: general state funds 16%, MCH funds 25%, CDC grant 59%

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New York

New York State Congenital Malformations Registry (CMR)

Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1997
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 260,000
Statewide: yes
Current legislation or rule: Public Health Law Art. @, Tit, II, Sect 225(5)(t) and art. 2 Tit 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
Case finding/identification sources:
Delivery hospitals: disease index or discharge index, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts
Other sources: physician reports, hospital discharge data
Case Ascertainment
Conditions warranting chart review in newborn period: charts with selected ICD-9CM codes in the 740-759
Coding: CDC coding system based on BPA, ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, FoxPro, SAS, Sybase
Data Analysis
Data analysis software: Epi-Info, SAS, Access
Quality assurance: 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, 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
Funding
Funding source: MCH funds 48%, CDC grant 29%, other federal funding (non-CDC) 23%
Other
Web site:
www.health.state.ny.us/nysdoh/cmr/cmrhome.htm
Surveillance reports on file: Reports for '93-'95.
Procedure manual available: yes

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North Carolina

North Carolina Birth Defects Monitoring Program (NCBDMP)

Program status: Currently collecting data
Start year: 1987
Earliest year of available data: 1989
Organizational location: DOH (Vital Statistics)
Population covered annually: >110,000
Statewide: yes
Current legislation or rule: NCGS 130A-131
Legislation year enacted: 1995

Case Definition

Outcomes covered: major birth defects and genetic diseases

Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. ($\geq$ 20 weeks gestation), elective terminations ($<$ 20 week gestation, $\geq$ 20 weeks gestation, terminations for NTDs only)

Age: up to one year after delivery

Residence: NC resident births, both 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: chart review, disease index or discharge index, discharge summaries
Pediatric & tertiary care hospitals: chart review, disease 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 ICD9-CM codes in addition to 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: ICD-9-CM, modification of ICD-9-CM, ICD-10

Data Collected

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

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

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

Data Collection Methods and Storage

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

Database storage/management: Access, SAS, Mainframe, Mainframe used for file back-up

Data Analysis

Data analysis software: SAS, Access

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

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

Funding

Funding source: general state funds 67%, CDC grant 33%

Other

Web site: www.schs.state.nc.us/SCHS

Surveillance reports on file: Annual reports, Special studies

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North Dakota

Program status: Interested in developing a surveillance program
Organization location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health), ND Department of Human Services (Children's Special Health Services)
Population covered annually: 7675
Statewide: yes

<u>Case Definition</u>
Outcomes covered: Major Birth Defects and other risk factors that may lead to health and developmental problems.
Pregnancy outcome: live births (all gestational ages and birth weights, numbers collected and reported via Vital Records), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20 weeks gestation, numbers collected and reported via Vital Records), elective terminations (<20 week gestation, ≥20 weeks gestation, numbers collected and reported via Vital Records)
Age: Newborn period
Residence: In-state resident births
<u>Surveillance methods</u>
Case ascertainment: passive
Case finding/identification sources:
Vital records: birth certificates
Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, newborn biochemical screening program, cancer registry, AIDS/HIV registry, FAS
Delivery hospitals: Birth certificate completion
Pediatric & tertiary care hospitals: specialty outpatient clinics
Third party payers: Medicaid databases, health maintenance organizations (HMOs), private insurers
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports
<u>Case ascertainment</u>
Coding: ICD-9-CM, ICD 10
<u>Data Collected</u>
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures, family history
Father: identification information (name, address, date-of-birth, etc.)
<u>Data Collection Methods and Storage</u>
Data collection: printed abstract/report submitted by other agencies (hospitals, etc.)
Database storage/management: MS Access, Mainframe, Db2
<u>Data Analysis</u>
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
<u>Funding</u>
Funding source: No funding specifically directed to birth defects
<u>Other</u>
Web site:
www.health.state.nd.us/ndhd/admin/vital/
Procedure manual available: yes
Comments: Birth Review Program only

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Ohio

Program status: Interested in developing a surveillance program

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Oklahoma

Oklahoma Birth Defects Registry (OBDR)

Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 50,000
Statewide: yes
Current legislation or rule: 63 O.S. Sec. 1-550.2
Legislation year enacted: 1992

<u>Case Definition</u>

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

Pregnancy outcome: live births (≥ 20 weeks gestation), fetal deaths-stillbirths, spontaneous abortions, etc. (≥ 20 weeks gestation), elective terminations (≥ 20 weeks gestation)

Age: 2 years

Residence: in-state births to state residents

<u>Surveillance methods</u>

Case ascertainment: population based, active case ascertainment

Case finding/identification sources:

Vital records: birth certificates, death certificates

Delivery hospitals: chart review, 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: chart review, disease index or discharge index, pediatric logs, surgery logs, specialty outpatient clinics, midwifery facilities

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

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

<u>Case Ascertainment</u>

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

Coding: CDC coding system based on BPA

<u>Data Collected</u>

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

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

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

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

Data collection: printed abstract/report filled out by staff

Database storage/management: Access

<u>Data Analysis</u>

Data analysis software: SAS, Access, ArcView

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

<u>Funding</u>

Funding source: general state funds 25%, MCH funds 58%, CDC grant 17%

<u>Other</u>

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

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: 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 Birth Defects Surveillance System

Program status: Currently collecting data
Start year: 1999
Earliest year of available data:
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 145,000
Statewide: yes

Case Definition
Outcomes covered: 740-759 ICD-9
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc.
Age: one year of age
Residence: in-state birth to state resident
Surveillance methods
Case ascertainment: population based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, HC4 data
Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, newborn biochemical screening program will be added.
Pediatric & tertiary care hospitals:
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetic facilities
Case Ascertainment
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, prenatal care, prenatal diagnostic information, exposures
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Data Collection Methods and Storage
Database storage/management: Mainframe
Data Analysis
Data analysis software: MS Access
Quality assurance: comparison/verification between multiple data sources
Data use and analysis: baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, needs assessment, service delivery, referral
Funding
Funding source: MCH funds 100%
Other
Comments: Pennsylvania is in the process of collecting data from birth certificates and data from children enrolled in programs in the Bureau of Family Health. This includes the genetics program, metabolic program, newborn hearing screening program, and special health care needs programs. We are also reviewing data available through the Health Care Cost Containment Council for possible usage.

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Puerto Rico

Puerto Rico Birth Defects Surveillance System (PRBDSS)

Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: DOH (Maternal and Child Health), Folic Acid Campaign, Division of Children with Special Health Care Needs
Population covered annually: 60,000
Statewide: yes
Current legislation or rule: Not mandatory

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
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20weeks gestation), elective terminations (<20week gestation, ≥20weeks gestation)
Age: 1 year old
Residence: in state birth to state residents

Surveillance methods

Case ascertainment: Active case ascertainment and population based
Case finding/identification sources:
Other state based registries: programs for children with special needs
Delivery hospitals: chart review, 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
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 ICD9-CM codes in addition to 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, all elective abortions, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the new period: any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SPSS, MS Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
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: MCH funds 39%, CDC grant 41%, CDC Visiting Fellowship Program 20%

Other

Web site: http://www.defectoscongenito.spr.org
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

Under development. We have received a cooperative agreement from CDC.

Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 1999
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 12,500
Statewide: yes

Case Definition
Outcomes covered: major birth defects and genetic diseases
Pregnancy outcome: live births (all gestational ages and birth weights)
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, fetal death certificates
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 8 programs including: Universal Newborn Developmental Risk Screening, Universal Newborn Hearing, Newborn Metabolic Screening, Early Intervention, Immunization, Lead Poisoning, WIC, and Home Visiting.
Delivery hospitals: discharge summaries
Case Ascertainment
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, prenatal care, pregnancy/delivery complications
Father:
Data Collection Methods and Storage
Data collection: birth and death data were entered into ACCESS database
Database storage/management: MS Access
Data Analysis
Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, needs assessment, grant proposals, education/public awareness
Funding
Funding source: MCH funds 30%, CDC grant 70%

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South Carolina

South Carolina Birth Defects Surveillance and Prevention Program

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

<u>Case Definition</u>

Outcomes covered: neural tube defects

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

Age: up to one year after delivery

Residence: in and out of state births to residents of South Carolina

<u>Surveillance methods</u>

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: chart review, disease index or discharge index, discharge summaries, postmortem/pathology logs, ICD-9 Codes

Pediatric & tertiary care hospitals: chart review, 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

<u>Case Ascertainment</u>

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a ICD9-CM codes in addition to 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, all prenatal diagnosed or suspected cases

Coding: ICD-9-CM

<u>Data Collected</u>

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

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

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

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

Data collection: printed abstract/report filled out by staff

Database storage/management: MS Access, SAS

<u>Data Analysis</u>

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, identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, education/public awareness, prevention projects

<u>Funding</u>

Funding source: general state funds 60%, CDC grant 10%, other federal funding 30%

<u>Other</u>

Web site: http://www.ggc.org

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South Dakota

Program status: No surveillance program

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Tennessee

Tennessee Birth Defects Registry (TN BDR)

Program status: Currently collecting data
Start year: 2000
Earliest year of available data:
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 6000
Statewide: no
Legislation year enacted: 2000

Case Definition
Outcomes covered: major birth defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥500 grams, or in the absence of weight, of 22 completed weeks of gestation or more. Induced abortions are not included.)
Age: diagnosed up to age 5
Residence: in-state birth to state resident
Surveillance methods
Case ascertainment: hospital based matched to vital records
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
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Other sources: Regional Perinatal Centers (hospitals that oversee other hospitals)
Case Ascertainment
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Data Collection Methods and Storage
Data collection: electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: MS Access, SAS, Mainframe
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, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), service delivery, referral, grant proposals, education/public awareness, prevention projects
Funding
Funding source: general state funds 100%
Other
Surveillance reports on file: Reports from the 1991-1993 registry are available. Pilot project reports are not yet available.
Comments: Tennessee's Birth Defects Registry lasted from 1991 to 1993 and covered the entire state. For the year 2000, we have a new registry pilot project that covers one region of the state.

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Texas

Texas Birth Defects Monitoring Division (TBDMD)

Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1995
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 350,000
Statewide: yes, Statewide as of 1999 deliveries
Current legislation or rule: Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87.
Legislation year enacted: 1993

<u>Case Definition</u>
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. (≥20weeks gestation, or birth weight of at least 500 grams.), elective terminations (<20week gestation, ≥20weeks gestation, or birth weight of at least 500 grams)
Age: up to one year after delivery (FAS up to 6 years)
Residence: in-state & out-of-state births to Texas residents.
<u>Surveillance methods</u>
Case ascertainment: active, population-based.
Case finding/identification sources:
Delivery hospitals: chart review, 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, Genetics logs, stillbirth logs, radiology logs
Pediatric & tertiary care hospitals: chart review, 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
<u>Case Ascertainment</u>
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a ICD9-CM codes in addition to 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, gestational age < 34 weeks, all stillborn infants, all neonatal deaths
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, any infant with a codable defect
Coding: CDC coding system based on BPA
<u>Data Collected</u>
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal diagnostic information, pregnancy/delivery complications, exposures, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
<u>Data Collection Methods and Storage</u>
Data collection: printed abstract/report filled out by staff
Database storage/management: FoxPro
<u>Data Analysis</u>
Data analysis software: Epi-Info, SAS, MS Access
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, data/hospital audits, clinical review, timeliness, Re-casefinding, re-review of medical records
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, education/public awareness, prevention projects
<u>Funding</u>
Funding source: general state funds 38%, MCH funds 38%, CDC grant 24%
<u>Other</u>
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.

Procedure manual available: yes
Additional information on file: copy of legislation; brochure on the Texas Birth Defects Monitoring Division (English and Spanish); brochure on Fetal Alcohol Syndrome (English and Spanish); Recent Trends in Neural Tube Defects in Texas; Leading Causes of Infant Mortality in Texas, 1993 by Ethnicity; summary report on birth defect cluster investigations conducted, 1994-1997; newsletters
Comments: 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. It was working closely with the Texas Birth Defects Monitoring Division for effective coverage of the whole state, with concentrated effort in specific geographic areas.

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Utah

Utah Birth Defect Network (BDN)

Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1994
Organizational location: Department of Health (Maternal and Child Health), University
Population covered annually: 47,000
Statewide: yes
Current legislation or rule: Birth Defect Rule
Legislation year enacted: 1999

<u>Case Definition</u>
Outcomes covered: 742.000 - 759.000
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (<20week gestation, ≥20weeks gestation), elective terminations (<20week gestation, ≥20weeks gestation)
Age: 2
Residence: maternal residence in Utah at time of delivery
<u>Surveillance methods</u>
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
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
<u>Case Ascertainment</u>
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 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 prenatal diagnosed or suspected cases, all stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all fetal death certificates, NICU reports
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, all infant deaths (excluding prematurity) GI condition, cardiovascular condition, any infant with a codable defect
Coding: CDC coding system based on BPA, also use codes for pregnancy terminator (600s)
<u>Data Collected</u>
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history
<u>Data Collection Methods and Storage</u>
Data collection: printed abstract/report filled out by staff
All cases reviewed clinically by M. Feldkamp/J. Carey, MD.
Database storage/management: Epi-Info
<u>Data Analysis</u>
Data analysis software: Epi-Info, SPSS
Quality assurance: double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness, reabstraction of cases
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, prevention projects, referral, education/public awareness
<u>Funding</u>
Funding source: MCH funds 33%, CDC grant 66%
<u>Other</u>
Surveillance reports on file: 1994 NTD Surveillance, 1994-1996 registry report
Procedure manual available: yes
Additional information on file: draft form of Data Sharing Protocol

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Vermont

Program status: Interested in developing a surveillance program

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Virginia

Virginia Congenital Anomalies Reporting and Education System (VaCARES)

Program status: Currently collecting data
Start year: 1989
Earliest year of available data: 1989
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 94000
Statewide: yes
Current legislation or rule: Health Law 32.1.69.1, Article 8 1985
Legislation year enacted: 1986

Case Definition

Outcomes covered: major birth defects and genetic diseases
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: 2
Residence: in-state birth to state resident

Surveillance methods

Case ascertainment: passive, hospital report & birth certificate based information
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
Other state based registries: newborn genetic screening program, newborn biochemical screening program
Delivery hospitals: VaCARES forms submitted by hospitals
Pediatric & tertiary care hospitals: VaCARES forms submitted by hospitals

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Data collection: printed abstract/report submitted by other agencies (hospitals, etc.)
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, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

Funding

Funding source: MCH funds 100%

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Washington

Washington State Birth Defects Registry

Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1987
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 80,000
Statewide: yes
Current legislation or rule: Notifiable Conditions: WAC 246-101
Legislation year enacted: 2000

Case Definition

Outcomes covered: From 1987 to the current time, we receive Casefinding logs listing ICD-9CM codes 740-759; specific primary cancers; specific metabolic conditions; FAS/FAE. Over the next year the Registry will receive cases of anencephaly, spina bifida, limb reductions, cleft lip/palate; hypospadias; gastroschisis; omphalocele; and Down syndrome. We plan to explore ascertainment of Autism, Cerebral Palsy, and FAS/FAE.
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 (transitioning to 1 year of age)
Residence: resident births; child born or diagnosed in state

Surveillance methods

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

Case Ascertainment

Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Data collection: printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.), Reports are used to generate case lists and we are in the process of linking data to vital records for additional demographic and pregnancy risk information.
Database storage/management: MS Access, D-base

Data Analysis

Data analysis software: MS Access, SAS
Quality assurance: validity checks, comparison/verification between multiple data sources, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, observed vs expected analyses, grant proposals, education/public awareness, service delivery, monitor outbreaks and cluster investigations

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
Comments: From 1986 through 1991, the Washington state birth defects registry was an active case ascertainment system; when funds were cut, the system became passive. Information concerning the active surveillance program profile is stated below. Outcomes covered: all birth defects, specific genetic diseases, FAS/E, fetal deaths with birth defects. Birth status: live births and stillbirths. Age, gestation, weight, and residence are same as passive surveillance. Case ascertainment: medical facility-generated log (medical records department personnel). Data sources: medical facility (birth and pediatric hospitals and out-patient clinics, including genetics) records. Vital Statistics Certificates (Birth, Death and Fetal Death) database. Coding: British Pediatric Association (BPA). Data collected: name, date of birth, demographic data, name of hospital, names of physicians, measurements at birth, diagnoses, syndromes, medical history, pertinent family history, cytogenetic analysis, discharge disposition, medical record number. Quality assurance: reabstraction of predetermined percentages of cases of each field worker. Data analysis: incidence rates. Data use same as passive system. Monitoring: yes Funding source: CDC

Grant. Staff: Program director, quality assurance coordinator, 5 field state data abstractors, epidemiologist, secretarial support staff, data manager. Procedure manual: yes.

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West Virginia

West Virginia Birth Defects Surveillance System

Program status: Currently collecting data
Start year: 1989
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 21,000
Statewide: yes
Current legislation or rule: State Statute Section 16-5-12a
Legislation year enacted: 1991

Case Definition
Outcomes covered: congenital anomalies of ICD-9 codes 740-759
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Residence: in and out of state births to state residents
Surveillance methods
Case ascertainment: active case ascertainment
Case finding/identification sources:
Vital records: birth certificates
Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, cancer registry, AIDS/HIV registry
Other sources: physician reports
Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759
Coding: ICD-9-CM, ICD-10-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), birth measurements (weight, gestation, Apgars, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), family history

Data Collection Methods and Storage
Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.)
Database storage/management: 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, rates by demographic and other variables, epidemiologic studies (using only program data)
Funding
Funding source: MCH funds 100%

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Wisconsin

Wisconsin Birth Defects Prevention and Surveillance Program (WBDPSP)

Program status: Program has not started collecting data yet
Start year: 2001
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 67,000
Statewide: yes
Current legislation or rule: 1999 Wisconsin Act 114
Legislation year enacted: 2000

Case Definition
Outcomes covered: structural, genetic, biochemical defects; specific defects TBD
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths-stillbirths, spontaneous abortions, etc. (≥20weeks gestation)
Age: birth to 2 years
Residence: Wisconsin
Surveillance methods
Case ascertainment: population based, passive
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death reports
Other state based registries: newborn hearing screening program, newborn biochemical screening program, cancer registry, AIDS/HIV registry
Third party payers: Medicaid databases
Other sources: physician reports
Case Ascertainment
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)
Data Collection Methods and Storage
Data collection: TBD
Database storage/management: TBD
Data Analysis
Data analysis software: TBD
Quality assurance: TBD
Data use and analysis: 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, Items checked above are the ones likely to be used.
Funding
Funding source: general state funds 35%, MCH funds 23%, CDC grant 42%
Other
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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Department of Defense

United States Department of Defense (DoD) Birth Defects Registry

Program status: Currently collecting data
Start year: 1997
Earliest year of available data:
Organizational location: Department of Defense Center for Deployment Health Research, Naval Health Research Center, San Diego, CA
Population covered annually: 90,000
Statewide: no, nation/world
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum
Legislation year enacted: 1998

Case Definition
Outcomes covered: CDC-recommended severe birth defects
Pregnancy outcome: live births (≥20weeks gestation and any birth weight)
Age: birth to 1 year
Residence: worldwide; any birth to a DoD beneficiary
Surveillance methods
Case ascertainment: electronic diagnostic codes from all inpatient and outpatient encounters of DoD beneficiaries
Case finding/identification sources:
Delivery hospitals: All inpatient and outpatient encounters are captured in standardized DoD data.
Pediatric & tertiary care hospitals: 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 data performed by case review 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
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM
Data Collected
Infant/fetus: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), tests and procedures, infant complications, birth defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, pregnancy/delivery complications, exposures
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, exposures
Data Collection Methods and Storage
Data collection: electronic file/report filled out by staff at facility (laptop, web-based, etc.), electronic file/report submitted by other agencies (hospitals, etc.), All DoD inpatient and outpatient encounters require e-report with diagnostic coding
Database storage/management: 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, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals
Funding
Funding source: other federal funding (non-CDC) 100%
Other
Web site: www.nhrc.navy.mil
Surveillance reports on file: DoD/HA policy memorandum; technical reports

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