

STATE BIRTH DEFECTS SURVEILLANCE PROGRAMS DIRECTORY

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

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

S60 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Alabama

Alabama Birth Defects Surveillance and Prevention Program (ABDSPP)

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1998

Organizational location: University

Population covered annually: 8,000 for 1998-2000 data; 18,500 for 2001 data

Statewide: No - Mobile and Baldwin counties for 1998-2000 data; Mobile, Baldwin, Escambia, Monroe, Houston, Coffee, Crenshaw, and Montgomery counties for 2001 data.

Current legislation or rule: none

Case Definition

Outcomes covered: major birth defects and genetic disorders

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

Age: up to one year after delivery

Residence: Mobile and Baldwin counties for 1998-2000 data; Mobile, Baldwin, Escambia, Monroe, Houston, Coffee, Crenshaw, and Montgomery counties for 2001 data.

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, 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

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff

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

Data Analysis

Data analysis software: Epi-Info, SPSS, Hypercube

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

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

Funding

Funding source: Other federal funding (non-CDC grant) 80%, University 20%

Other

Web site: www.usouthal.edu/genetics/

Procedure manual available: yes

Additional information on file: Birth Defects Syndromes fact sheets

Comments: Site linked to international birth defect information systems.

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Alaska

Alaska Birth Defects Registry (ABDR)

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 and greater)

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

Residence: Alaska residents

Surveillance methods

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

Case finding/identification sources:

Vital records: birth certificates, fetal death certificates

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

Delivery hospitals: chart review, obstetrics logs (i.e., labor & delivery), reportable ICD-9 code reports are received from the health information management department

Pediatric & tertiary care hospitals: chart review, 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

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

Coding: ICD-9-CM

Data Collected

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

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

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: MS Access

Data Analysis

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

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

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

Funding

Funding source: CDC grant 100%

Other

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

Surveillance reports on file: Family Health Dataline

Procedure manual available: yes

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

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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: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Bureau of Public Health Statistics/Office of Health Registries

Population covered annually: 80,505 in 1999

Statewide: yes

Current legislation or rule: statute: ARS sec. 36-133.rule: Title 9, Chapter 4, Articles 1 and 5, Adopted effective 1991.

Legislation year enacted: 1988

Case Definition

Outcomes covered: 44 composite categories covering the major birth defects and genetic diseases, as defined by the BPA/MACDP codes

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

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

Residence: in-state birth to state resident.

Surveillance methods

Case ascertainment: active case ascertainment, population based

Case finding/identification sources:

Vital records: birth certificates, 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, cytogenetic 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, ultrasound reports, cytogenetic reports, stillborn logs, mother's charts for still borns

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

Other sources: children receiving services from Children Rehabilitation Services (CRS) facilities, whose diagnosis falls within the ABDMP case-finding criteria.

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 birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all elective abortions

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

Coding: CDC coding system based on BPA

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

Database storage/management: Oracle

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, data/hospital audits

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

Funding

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

Other

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

Surveillance reports on file: Annual Reports, 1986 through 1996.

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. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)

Age: two years after delivery

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

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 index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, specialty outpatient clinics

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

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

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

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 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: MS Access

Data Analysis

Data analysis software: SAS, MS Access

Quality assurance: re-abstraction of cases, clinical review, timeliness

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

Funding

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

Other

Web site: www.ARbirthdefectsresearch.uams.edu

Surveillance reports on file: Annual reports

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S66 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

California

California Birth Defects Monitoring Program (CBDMP)

Program status: Currently collecting data

Start year: 1983

Earliest year of available data: 1983

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

Population covered annually: 60,000

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

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

Legislation year enacted: 1982

Case Definition

Outcomes covered: Serious structural birth defects, primarily encompassed within ICD codes 740-759.

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

Age: one year

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

Surveillance methods

Case ascertainment: Active case ascertainment, population based.

Case finding/identification sources:

Delivery hospitals: 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: electronic file/report filled out by staff at facility (laptop, web-based, etc.), 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, validity checks are done on all abstracts.

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

Funding

Funding source: general state funds 41%, MCH funds 5%, CDC grant 17%, other federal funding (non-CDC grant) 19%, DHS/UC Pass through 18%

Other

Web site: www.cbdmp.org

Surveillance reports on file: Current data on web site.

Procedure manual available: yes

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

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S68 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Colorado

Colorado Responds To Children With Special Needs: Colorado (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: Structural, genetic and selected metabolic birth defects; selected developmental disabilities; very low birth weight (less than 1500 grams); others with medical and maternal risk factors for developmental delay

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

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

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

Surveillance methods

Case ascertainment: Passive, population based, multiple sources; active for special projects including fetal alcohol syndrome

Case finding/identification sources:

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

Other state based registries: newborn 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, Cleft lip/cleft palate clinic, Spinal defects clinic, Developmental clinic

Third party payers: Medicaid databases

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: 13 selected conditions for CUSUM monitoring, fetal alcohol syndrome, or other designated reason. Review is performed for 12 additional conditions based on a data quality analysis.

Conditions warranting chart review beyond newborn period: as above

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: MS Access

Data Analysis

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

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

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

Funding

Funding source: general state funds 61%, CDC grant 33%, other federal funding (non-CDC grant) 6%

Other

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

Procedure manual available: yes

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

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Connecticut

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 Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

Case Ascertainment

Conditions warranting chart review in newborn period: 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.)

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

Other

Comments: Birth defects surveillance for CT will be contained within the Children with Special Health Care Needs Registry, which is under development. A description of this new Registry follows.

Name: Children with Special Health Care Needs Registry (CSHCN Registry); Status: not currently collecting data; anticipated Spring 2002; Start year: 2000; Organization: Department of Health (Other): Children with Special Health Care Needs Unit; Annual number of live births: approx 45,000; State-wide: yes; Legislation: Sec. 19a-56a. (Formerly Sec. 10a-132b). Birth defects surveillance program; Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children.

Case Definition

Outcomes covered: All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.); Pregnancy outcome: Live births of all gestational ages and birth weight with exclusion criteria for certain disorders (i.e. PDA); Age: for birth defects <1 year; for special health care needs <18 years; Residence: in and out of state births to Connecticut residents.

Surveillance methods

Case ascertainment: Passive population based system; Case finding/identification sources: mandatory reporting by health care providers and facilities; CSHCN Programs; birth and death certificates, matched birth and death file; Newborn Screening System (for genetic disorders and hearing impairment);disease/discharge indexes- inpatient, ambulatory surgery and emergency room visits (delivery, pediatric and tertiary care hospitals); Case finding/data collection outside of the state: planned.

Case Ascertainment

Chart review: any birth certificate with a birth defect box checked and no case report, cases from birth admissions where the reporting form is the sole source of case ascertainment (lack of confirmation by disease/discharge indexes); cases of multiple anomalies without a specified syndrome; cases where diagnoses are qualified as 'preliminary' or 'rule-out'; all cases of chromosomal anomalies lacking confirmation by karyotype, and a 10% random sample, stratified on birth hospital, of all obvious birth defects that were not reported from birth admission but documented in the CHIME database; Coding: ICD-9-CM

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Data Collected

Infant/fetus: identification, demographic and birth defect diagnostic information; **Mother:** identification, demographic, gravidity/parity, illnesses/conditions, prenatal care and diagnostic information, pregnancy/delivery complications and exposures; **Mother:** identification, demographic, gravidity/parity, illnesses/conditions, prenatal care and diagnostic information, pregnancy/delivery complications and exposures; **Father:** identification and demographic.

Data Collection Methods And Storage

Electronic file/report added onto the existing electronic Newborn Screening System filled out by staff at facility, with printed reports as backup. Electronic file/report submitted by other agencies. Linkage to electronic Newborn Screening System for cases of biochemical, genetic and hearing impairment; Database Storage/Management: Oracle; Data Analysis: SAS; Quality Assurance: validity checks, verification between multiple data sources, data/hospital audits, selected clinical review, timeliness, completeness of screening/reporting for birth cohort, confirmation of referral and enrollment in CSHCN Centers; Data Use and Analysis: routine statistical monitoring, baseline rates for birth defects and other special needs conditions, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, epidemiologic studies, needs assessment, service delivery, referral, grant proposals, prevention projects and provider education.

Budget

Source: 100% CDC Grant

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Delaware

Delaware Birth Defects Surveillance Project

Program status: Currently collecting data

Organizational location: Department of Health (Maternal and Child Health), Community Health Care Access Section, Women's & Reproductive 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

Case Definition

Outcomes covered: Birth Defects Registry - All birth defects for passive surveillance, selected birth defects for active surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections that cause birth defects, neural tube defects.

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

Age: Birth to 5 years

Residence: In-state and out-of-state birth to state resident, and in-state birth to state non-resident.

Surveillance methods

Case ascertainment: Active and passive surveillance, population-based.

Case finding/identification sources:

Vital records: birth certificates, death certificates

Case Ascertainment

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

Data Collected

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

Mother: 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: electronic birth certificate

Data Analysis

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

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S72 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

District of Columbia

District of Columbia Birth Defects Surveillance System

Program status: Program has not started collecting data

Start year: 2002

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

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

Statewide: yes

Case Definition

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

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

Residence: State resident at the time of diagnosis

Surveillance methods

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

Case finding/identification sources:

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

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

Third party payers: Medicaid databases

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

Other sources: physician reports

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

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 stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, ICD9-CM 740-741.9, 742.3, 749-749.25, 758-758.2, 760.71, 389, 243, 270.1, 270.3, 271.1, 282.2, 282.4-63, 282.69, 282.7

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, developmental delay, all infant deaths (excluding prematurity), auditory/hearing conditions, any infant with a codable defect

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

Data Collected

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

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

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, 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, printed abstract/report submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Oracle

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS

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

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

Funding

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

Other

Procedure manual available: yes

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

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S74 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

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: 204,125 in 2000

Statewide: yes

Current legislation or rule: Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added to the list in July 1999.

Case Definition

Outcomes covered: Major structural malformations and selected genetic disorders

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

Age: until age 1

Residence: Florida

Surveillance methods

Case ascertainment: Population based passive case ascertainment

Case finding/identification sources:

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

Other state based registries: programs for children with special needs

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: MS Access, SAS, Excell

Data Analysis

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

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

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

Funding

Funding source: general state funds 100%

Other

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

Surveillance reports on file: 1996 Annual Report, Neural Tube Defects Report, Data Quality Assurance Report, Active Surveillance Report, Website

Procedure manual available: yes

Additional information on file: Grants, progress reports, educational and health promotion materials, and video tapes

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Georgia

Metropolitan Atlanta Congenital Defects Program (MACDP)

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: 50019

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

Current legislation or rule: 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 and greater), elective terminations (20 weeks gestation and greater)

Age: Before 6 years of age

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

Surveillance methods

Case ascertainment: Active case ascertainment; population-based

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, infants with low birth weight or low gestation (< 2500 grams or < 37 weeks), 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 gestation

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, fever of unknown origin, 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

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, monitoring outbreaks and cluster investigations, time trends, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, prevention projects

Funding

Funding source: other federal funding 100%

Other

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

Surveillance reports on file: numerous reports and bibliography

Procedure manual available: yes

Additional information on file: rate tables by defect by year

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

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Hawaii

Hawaii Birth Defects Program (HBDP)

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1986

Organizational location: University

Population covered annually: ~20,036 average over 15 years

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 ~1,154+ recommended by CDC in their May 1987 Birth Defects Branch Six Digit Code for Reportable Congenital Anomalies, based on B.P.A. Classification of Diseases (1979) and W.H.O. I'C'D'9 CM (1977).

Pregnancy outcome: live births, fetal deaths (less than 20 week gestation, 20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater), medical terminations that were carried out because some screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect and the parents elected not to bring the baby to term

Age: Up to one year after delivery

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

Surveillance methods

Case ascertainment: Active case ascertainment, population-based.

Case finding/identification sources:

Vital records: Vital records are used to supplement information collected from other data sources but are not used to primarily identify potential cases. Vital records data are also used as denominators for determining birth defects rates per 10,000 births.

Other state based registries: The HBDP supplies aggregate, de-identified data to the entities listed; they do not supply data to the HBDP.

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

Pediatric & tertiary care hospitals: chart review, disease index or discharge index, discharge summaries, Note: Information from specific logs, laboratories, clinics, etc. are usually found in the medical record when doing chart review.

Other specialty facilities: prenatal fetal 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 prenatally diagnosed or suspected cases, medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect and parents elected not to bring baby to term or mother spontaneously aborted.

Conditions warranting a chart review beyond the newborn period: all infant deaths (excluding prematurity), childhood deaths between 1 and 6, any infant with a codable defect

Coding: CDC coding system based on BPA

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

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, electronic file/report filled out by staff at facility (laptop, web-based, etc.), lap top computers are the first choice, followed by hard copy if electronic is not possible.

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 65.5%, CDC grant 24.1%, other federal funding (non-CDC grant) 5.6%, private foundations 4.8%

Other

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

S78 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Surveillance reports on file: (8) Hawaii Birth Defects Program Statewide Surveillance Data Reports - 1) = 1989-1991, 2) = 1988-1993, 3) = 1988-1994, 4) = 1988-1995, 5) = 1987-1996, 6) = 1986-1997, 7) = 1986-1998, 8) = 1986-1999, 9) = 1986-2000, and 10) = 1986-2001, to be published in late 2002.

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 (5); peer-reviewed journal articles (14).

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Idaho

Program status: No surveillance program

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S80 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

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: 182,027

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

Age: End of newborn hospitalization

Residence: In-state births mandatory

Surveillance methods

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

Case finding/identification sources:

Vital records: fetal death certificates

Delivery hospitals: chart review, disease index or discharge index, discharge summaries, Hospitals are mandated to identify newborn cases and report to IDPH.

Case Ascertainment

Conditions warranting chart review in newborn period:

Newborn infant charts are reviewed for clarification of hospital reporting; about 5% of newborn cases are reviewed. Maternal charts are reviewed to collect maternal data.

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.), 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, FoxPro, Mainframe

Data Analysis

Data analysis software: SAS, MS Access

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

Data use and analysis: routine statistical monitoring, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, referral

Funding

Funding source: general state funds 77%, CDC grant 20%, other federal funding (non-CDC grant) 3%

Other

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

Surveillance reports on file: See Web Site

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

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Indiana

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

Program status: Interested in developing a program

Start year: 2002

Earliest year of available data: 2003

Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health)

Population covered annually: 83,000

Statewide: yes

Current legislation or rule: IC 16-38-4-7Rule 410 IAC 21-3

Legislation year enacted: 2001

Case Definition

Outcomes covered: ICD-9-CM Codes 740-759.9, low birth weight, fetal deaths, metabolic and hearing disorders from Newborn Screening, selected neoplasms, and congenital blood disorders, and certain eye disorders.

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

Age: Less than 3 years of age

Residence: In and out of state births to state residents

Surveillance methods

Case ascertainment: Passive, population based.

Case finding/identification sources:

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

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

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

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

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period:

Randomly selected charts of targeted medical conditions.

Coding: ICD-9-CM

Data Collected

Infant/fetus: identification 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: electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Oracle, SAS

Data Analysis

Data analysis software: SAS

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

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

Funding

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

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S82 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

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; Revised 2001

Case Definition

Outcomes covered: Major Birth Defects and Metabolic Disorders

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

Age: 1 year

Residence: Maternal residence in Iowa at time of delivery

Surveillance methods

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

Case finding/identification sources:

Vital records: birth 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, specialty outpatient clinics

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, specialty outpatient clinics

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

Other sources: physician reports, Outpatient Surgery Facilities

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

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 a CDC/BPA code, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases

Conditions warranting a chart review beyond the newborn

period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect

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

Data Collected

Infant/fetus: identification 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

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, Oracle, SAS, Mainframe

Data Analysis

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

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

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

Funding

Funding source: general state funds 5%, CDC grant 38%, other federal funding (non-CDC grant) 32%, IA Department of Health -1 year commitment 25%

Other

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

Surveillance reports on file: Iowa Birth Defects Registry Annual Report 2000Iowa Birth Defects Registry Annual Report 2001

Procedure manual available: yes

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Kansas

Birth Defects Reporting System

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 1985

Organizational location: Department of Health (Vital Statistics, Maternal and Child Health)

Population covered annually: 39,654 (Year 2000)

Statewide: yes

Current legislation or rule: KSA 65-102

Legislation year enacted: 1979

Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics, but are not used as part of a birth defects surveillance system. 24 anomalies are listed on the birth certificate and are reported, however, these are not linked to ICD codes.

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

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

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

Surveillance methods

Case ascertainment: Passive, population-based.

Case finding/identification sources:

Vital records: birth certificates

Pediatric & tertiary care hospitals: Congenital Malformations reporting form - sent by hospitals for infants up to one year of age.

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

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

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

Data Analysis

Data analysis software: SAS, Ad-hoc summary reports developed as needed from Crystal Reports.

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

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

Funding

Funding source: MCH funds 100%

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Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1998

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

Population covered annually: 54,500

Statewide: yes

Current legislation or rule: KRS 211.651-211.670

Legislation year enacted: 1992

Case Definition

Outcomes covered: Major Birth Defects, Genetic Diseases, Fetal Mortality

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

Age: up to fifth birthday

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

Surveillance methods

Case ascertainment: Combination of active and passive, 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, newborn biochemical screening program

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

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

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: Local health departments

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a 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, prenatally diagnosed or suspected cases

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

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

Data Collected

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

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

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures, 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 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, grant proposals, education/public awareness, prevention projects

Funding

Funding source: general state funds 40%, CDC grant 60%

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

Start year: 2002

Earliest year of available data: 2003-2005

Organizational location: Children's Special Health Services

Population covered annually: 65,000 +

Statewide: yes

Current legislation or rule: R.S. 40:31.41 - 40:31.48, Act No. 194

Legislation year enacted: 2001

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Case Definition

Outcomes covered: major structural, functional, or genetic birth defect

Pregnancy outcome: in progress, in progress, in progress

Age: in progress

Residence: in and out of state births to state residents (tentative criteria)

Surveillance methods

Case ascertainment: active case ascertainment

Case finding/identification sources:

Vital records: in progress

Other state based registries: in progress

Delivery hospitals: in progress

Pediatric & tertiary care hospitals: in progress

Third party payers: in progress

Other sources: in progress

Case Ascertainment

Conditions warranting chart review in newborn period: in progress

Coding: in progress

Data Collection Methods and Storage

Data collection: in progress

Database storage/management: in progress

Data Analysis

Data analysis software: in progress

Quality assurance: in progress

Data use and analysis: in progress

Funding

Funding source: in progress

Other

Web site: in progress

Comments: pending

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Maine

Maine Birth Defects Program (MBDP)

Program status: Program has not started collecting data

Start year: 1999

Earliest year of available data: not available 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 and Omphalocele, Major heart defects, Trisomy 13,18 and 21

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

Age: Through age one

Residence: All in-state births to Maine residents

Surveillance methods

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

Case finding/identification sources:

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

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases

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

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

Data Collected

Infant/fetus: identification 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.)

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, Citrix

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, data/hospital audits, clinical review, timeliness

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

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: Family Health Administration, Office for Genetics & Children with Special Health Care Needs

Population covered annually: 68,000

Statewide: yes

Current legislation or rule: Health-General Article, Section 18-206; Annotated Code of Maryland

Legislation year enacted: 1982

Case Definition

Outcomes covered: Selected Birth Defects - Anencephaly, Spina Bifida, Hydrocephaly, Cleft Lip, Cleft 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. and terminations (20 weeks gestation and greater, or ≥ 500 grams weight). We do accept reports on fetal deaths and terminations < 500 grams or < 20 weeks if sent to us

Age: Newborn

Residence: All in-state births

Surveillance methods

Case ascertainment: Passive surveillance, multiple source, population based

Case finding/identification sources:

Vital records: birth certificates, fetal death certificates

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

Delivery hospitals: obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts. Sentinel Birth Defects hospital report form is our primary source.

Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts. Sentinel Birth Defects hospital report form is our primary source.

Midwifery facilities:

Other specialty facilities: genetic counseling/clinical genetic facilities, maternal serum screening facilities

Case Ascertainment

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

Coding: ICD-9-CM

Data Collected

Infant/fetus: identification 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/genetics> (then select Birth Defects Reporting Information System)

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

Procedure manual available: yes

Additional information on file: Copies of publications, legislation, miscellaneous booklets and other information related to birth defects surveillance in Maryland.

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Massachusetts

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

Program status: Currently collecting data

Start year: 1997

Earliest year of available data: 1999 for statewide data

Organizational location: Bureau of Health Statistics, Research and Evaluation

Population covered annually: 80,866 for 1999

Statewide: yes

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

Case Definition

Outcomes covered: major birth defects and chromosomal anomalies

Pregnancy outcome: live births (all gestational ages and birth weights, exclude less than 20 weeks gestation or less than or equal to 350 grams), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, or \geq 350 gms)

Age: up to one year

Residence: in and out of state births to state residents

Surveillance methods

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

Case finding/identification sources:

Vital records: birth certificates, death certificates, 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

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

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

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, developmental delay, auditory/hearing conditions, any infant with a codable defect

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

Data Collected

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

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures, 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, Data from printed hospital reporting form is entered into electronic surveillance data base.

Database storage/management: MS Access, SAS, Mainframe, Microsoft Excel

Data Analysis

Data analysis software: SAS, MS Access, Microsoft Excel

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

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, Selected cases from surveillance are eligible for CDC 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 November 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 Community Health, Bureau of Epidemiology

Population covered annually: 135,400

Statewide: yes

Current legislation or rule: Public Act 236 of 1988

Legislation year enacted: 1988

Case Definition

Outcomes covered: Congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems

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

Age: up to two years after delivery

Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

Surveillance methods

Case ascertainment: passive, population-based.

Case finding/identification sources:

Vital records: birth certificates, death certificates, matched birth/death file, cytogenetic laboratories

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, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked

Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, ocular conditions, auditory/hearing conditions, any infant with a codable defect

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

Database storage/management: FoxPro

Data Analysis

Data analysis software: SPSS, 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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S94 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Minnesota

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 2002

Organizational location: Environmental Health

Population covered annually: 66,000

Statewide: yes

Current legislation or rule: MS 144.2215

Legislation year enacted: 1996

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Case Definition

Outcomes covered: Initial system will analyze neural tube defects and oro-facial clefts; additional conditions may be added in the future.

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

Age: Initial proposal of up to 1 year after delivery; will be examined collaboratively and adjusted as needed.

Residence: Initial proposal of only using in-state data; will be examined collaboratively and adjusted as needed.

Surveillance methods

Case ascertainment: Initial system will be passive combined with selected active confirmation; will be examined collaboratively and adjusted as needed.

Case finding/identification sources:

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

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

Case Ascertainment

Conditions warranting chart review in newborn period: any birth certificate with a birth defect box checked

Coding: ICD-9-CM, only for selected data retrieval; functioning system not yet in place.

Funding

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

Other

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

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

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Mississippi

Mississippi Birth Defects Registry (MBDR)

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: Department of Health (Maternal and Child Health), Department of Health (Division of Genetics), Mississippi State Department of Health

Population covered annually: 44,000

Statewide: yes

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

Legislation year enacted: 1997

Case Definition

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

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

Age: 0 to 21

Residence: In and out of state births to state residents

Surveillance methods

Case ascertainment: combination of active and passive case ascertainment

Case finding/identification sources:

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

Other state based registries: newborn 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

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 prenatal diagnosed or suspected cases

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

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

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

Data Collected

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

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

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

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 file/report submitted by other agencies (hospitals, etc.)

Database storage/management: MS Access

Data Analysis

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 10%, genetic screening revenues 80%

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S96 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Missouri

Missouri Birth Defects 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

Case Definition

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

Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, fetal death certificates are only source of data), elective terminations (less than 20 week gestation, 20 weeks gestation and greater), Surveillance of terminations currently limited to NTDs, expansion in progress

Age: up to one year after delivery

Residence: in and out of state births to state residents

Surveillance methods

Case ascertainment: passive, multi-source

Case finding/identification sources:

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

Other state based registries: programs for children with special needs

Delivery hospitals: discharge summaries

Pediatric & tertiary care hospitals: discharge summaries, specialty outpatient clinics

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

Other sources: enrollment data, Missouri Dept. of Mental Health

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, 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: SAS

Data Analysis

Data analysis software: SAS

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

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

Funding

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

Other

Surveillance reports on file: Missouri Birth Defects 1995-1999

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

Program status: Currently collecting data

Start year: 1999

Earliest year of available data: 2000

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

Population covered annually: 11,000

Statewide: yes

Current legislation or rule: none

Case Definition

Outcomes covered: Neural Tube Defects, Cleft lip/palate, Congenital heart defects, Congenital hypothyroidism

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

Age: Birth to age 3

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

Surveillance methods

Case ascertainment: combination of active and passive case ascertainment

Case finding/identification sources:

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

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

Delivery hospitals: specialty outpatient clinics

Third party payers: Medicaid databases

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

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any birth certificate with a birth defect box checked

Conditions warranting a chart review beyond the newborn period: cardiovascular condition, all infant deaths (excluding prematurity), auditory/hearing conditions

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

Data Collected

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

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

Data Analysis

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

Quality assurance: 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, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, referral, education/public awareness, prevention projects

Funding

Funding source: CDC grant 100%

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S98 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Nebraska

Nebraska Birth Defects Registry

Program status: Currently collecting data

Start year: 1973

Earliest year of available data: 1973

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

Population covered annually: 24,000+ births annually

Statewide: yes

Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §71-646, §71-647, §71-648, §71-649)

Legislation year enacted: 1972

Case Definition

Outcomes covered: All birth defects, exclusions according to CDC exclusion list

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

Age: Birth to 1 year

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

Surveillance methods

Case ascertainment: Combination of active and passive case ascertainment.

Case finding/identification sources:

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

Delivery hospitals: 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 reg.

Funding

Funding source: MCH funds 100%

Other

Surveillance reports on file: 2000 report in Vital Statistics Report. 2001 report will be available in published form in August 2002.

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: 2000

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

Population covered annually: 30,000

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

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

Legislation year enacted: 1999

Case Definition

Outcomes covered: major birth defects and genetic diseases

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

Age: Cover from 0-7 years of age

Residence: In-state births

Surveillance methods

Case ascertainment: Combination of active and passive ascertainment

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 hearing screening program, 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

Pediatric & tertiary care hospitals: chart review, disease index or discharge index

Third party payers: Medicaid databases

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: physician reports, State sponsored specialty clinics

Case Ascertainment

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

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

Coding: ICD-9-CM

Data Collected

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

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

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

Data Collection Methods and Storage

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

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

Data Analysis

Data analysis software: SPSS, SAS

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

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

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S100 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

New Hampshire

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

Program status: Program has not started collecting data

Start year: 2002

Earliest year of available data: 2003

Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health), Bureau of WIC Nutrition Services, University

Population covered annually: 13,560

Statewide: yes

Current legislation or rule: None

Case Definition

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

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

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

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

Surveillance methods

Case ascertainment: active case ascertainment and population based

Case finding/identification sources:

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

Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, cancer registry, AIDS/HIV registry

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

Pediatric & tertiary care hospitals: chart review, discharge summaries, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics, cytogenetics laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files

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

Case Ascertainment

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

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

Data Collected

Infant/fetus: identification 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, exposures, family history

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

Data Collection Methods and Storage

Data collection: electronic file/report filled out by staff at facility (laptop, web-based, etc.)

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

Data Analysis

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

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

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

Funding

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

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S102 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

New Jersey

Special Child Health Services 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: mandated reporting of birth defects diagnosed age 1, voluntary reporting of birth defects diagnosed > age 1 and all children diagnosed with Special Needs conditions who are ≤ 21 yrs. of age

Residence: in/out NJ births to NJ res; because of our link to the SCHS Case Management system, we also enroll anyone becoming NJ res

Surveillance methods

Case ascertainment: Passive, population based reporting system with annual quality assurance visits by BDR staff to birthing hospitals, birthing centers and, pediatric care facilities. Medical chart review is conducted on all children registered with any of the defects used by Centers of Excellence Interviews.

Case finding/identification sources:

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

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

Delivery hospitals: 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

Midwifery facilities:

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

Other sources: physician reports, Special Child Health Services county based Case Management units, parents, schools, medical examiners

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with 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, all neonatal deaths, all death certificates for < 1 year of age

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

Coding: ICD-9-CM

Data Collected

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

Mother: identification information (name, address, 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, MS Access

Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness, merge registry with birth certificate registry and the death certificate registry

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, 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 85%, CDC grant 10%, dedicated state funds 5%

Other

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

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

Procedure manual available: yes

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

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S104 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

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: In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regs.

Legislation year enacted: January 1, 2000

Case Definition

Outcomes covered: 740-760.71

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

Age: age 14

Residence: In and out of state births to state residents, 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, Children's Chronic Conditions 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, Abstractors contact neurosurgeons quarterly to identify all NTD cases. Also contact plastic surgeons to identify children with OFCs.

Third party payers: Medicaid databases, health maintenance organizations (HMOs), Indian health services, Children's Medical Services

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

Other sources: physician reports, Children's Chronic Condition's Registry

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 birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases, Charts with ICD code 760.71

Conditions warranting a chart review beyond the newborn

period: any infant with a codable defect

Coding: ICD-9-CM

Data Collected

Infant/fetus: identification 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, exposures, 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, timeliness

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, time trends, needs assessment, grant proposals, education/public awareness, prevention projects, Beginning to develop linkage with early intervention services (IDEA Part C) and exploring ways to work with Medicaid to link children to medical home and case-management.

Funding

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

Other

Surveillance reports on file: 1995-1996 Report of birth defects 1997-1998 Report of birth defects 1995-1999 Report of birth defects (in press)

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S106 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

New York

New York State Congenital Malformations Registry (CMR)

Program status: Currently collecting data

Start year: 1982

Earliest year of available data: 1983

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 260,000

Statewide: yes

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

Legislation year enacted: 1982

Case Definition

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

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

Age: 2 years

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

Surveillance methods

Case ascertainment: combination of active and passive case ascertainment

Case finding/identification sources:

Vital records:

Delivery hospitals: disease index or discharge index, ICU/NICU logs or charts

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

Other sources: physician reports, hospital discharge data

Case Ascertainment

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

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

Data Collected

Infant/fetus: identification 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: MS Access, FoxPro, SAS, Sybase

Data Analysis

Data analysis software: SAS, MS Access, Visual FoxPro

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 41%, CDC grant 49%, other federal funding (non-CDC grant) 10%

Other

Web site:

<http://www.health.state.ny.us/nysdoh/cmrcmhome.htm>

Surveillance reports on file: Reports for 1983-1997.

Procedure manual available: yes

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North Carolina

North Carolina Birth Defects Monitoring Program (NCBDMP)

Program status: Currently collecting data

Start year: 1987

Earliest year of available data: 1989

Organizational location: Department of Health (Vital Statistics)

Population covered annually: 120,000

Statewide: yes

Current legislation or rule: NCGS 130A-131

Legislation year enacted: 1995

Case Definition

Outcomes covered: Major birth defects

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

Age: Up to one year after delivery

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

Surveillance methods

Case ascertainment: Population-based, combined active and passive ascertainment

Case finding/identification sources:

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

Other state based registries: programs for children with special needs

Delivery hospitals: chart review, disease index or discharge index, discharge summaries

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

Third party payers: Medicaid databases

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

Other sources: Hospital-based newborn discharge planners

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 (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, 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, timeliness

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

Funding

Funding source: general state funds 76%, CDC grant 24%

Other

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

Surveillance reports on file: Annual reports, Special studies

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S108 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

North Dakota

Program status: In process of developing a system

Earliest year of available data: N/A

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

Population covered annually: 7676

Statewide: yes

Current legislation or rule: N/A

Legislation year enacted: N/A

Case Definition

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

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

Age: Newborn period

Residence: In-state resident births

Surveillance methods

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

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

Case Ascertainment

Coding: ICD-9-CM, ICD 10

Data Collected

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

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, exposures, 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 submitted by other agencies (hospitals, etc.), electronic file/report submitted by other agencies (hospitals, etc.)

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

Data Analysis

Data analysis software: SPSS

Quality assurance: comparison/verification between multiple data sources

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

Funding

Funding source: No funding specifically directed to birth defects

Other

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 a developing a system

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S110 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

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: 48,000

Statewide: yes

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

Legislation year enacted: 1992

Case Definition

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

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

Age: 2 years

Residence: In-state births to state residents

Surveillance methods

Case ascertainment: population based, active case ascertainment

Case finding/identification sources:

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

Delivery hospitals: 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

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

Case Ascertainment

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

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

Coding: CDC coding system based on BPA

Data Collected

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

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

gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, 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

Database storage/management: MS Access

Data Analysis

Data analysis software: SAS, MS Access, ArcView GIS

Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, timeliness, Editing of all completed abstracts

Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time-space cluster analyses, needs assessment, referral, grant proposals, education/public awareness, prevention projects, Program quality assurance

Funding

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

Other

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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S112 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Pennsylvania

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

Program status: Interested in developing a program

Start year: 2002

Organizational location: Division of Newborn Disease Prevention and Identification

Population covered annually: ~145,000

Statewide: yes

Case Definition

Outcomes covered: 740-759.9 and 760.71 ICD-9

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

Age: birth to two years of age

Residence: in-state births to state residents

Surveillance methods

Case ascertainment: population-based

Case finding/identification sources:

Vital records: birth certificates, death certificates, matched birth/death file, Health Care Cost Containment Council data

Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, newborn biochemical screening program, These will eventually be linked in the future.

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: MS Access, 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, time trends, needs assessment, service delivery, referral, education/public awareness, prevention projects

Funding

Funding source: MCH funds 100%

Other

Comments: Pennsylvania is in the process of developing a plan for a demonstration project to identify children within the

above-specified IC9 code range and link them with early intervention and other appropriate services. The project will collect data from birth certificates and data pertaining to children enrolled in programs administered by the Bureau of Family Health. These include the genetics program, metabolic program, newborn hearing screening program, and special healthcare needs programs. The project will also review hospital discharge and outpatient data available through the Health Care Cost Containment Council.

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Puerto Rico

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

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1995

Organizational location: Department of Health (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: No 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. (20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)

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:

Vital records: birth certificates, fetal death certificates

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 newborn period: any infant with a codable defect

Coding: ICD-9-CM

Data Collected

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

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

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

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: general state funds 3%, MCH funds 38%, CDC grant 52%, other federal funding (non-CDC grant) 10%, CDC Visiting Fellowship Program

Other

Web site: http://lineainteractiva.etbyte.net/divisiones/servicios-habilitativos/acido_folico/index.html

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

Procedure manual available: yes

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S114 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Rhode Island

Rhode Island Birth Defects Surveillance Program- Under Development

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

Current legislation or rule: None

Case Definition

Outcomes covered: major birth defects and genetic diseases

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

Age: Currently at birth

Residence: RI residents

Surveillance methods

Case ascertainment: Currently, passive case ascertainment

Case finding/identification sources:

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

Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, RI has an integrated database called KIDS NET, which links data from 9 programs including: Universal Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting and Vital Records.

Delivery hospitals: discharge summaries

Case Ascertainment

Conditions warranting chart review in newborn period: At this time we have not conducted chart reviews. We will be working with our Advisory Committee to identify ICD-9 codes for chart review.

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, 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: electronic file/report submitted by other agencies (hospitals, etc.), Birth and death data were entered into ACCESS database

Database storage/management: MS Access, Oracle, SAS

Data Analysis

Data analysis software: SAS, MS Access

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

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

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

Case Definition

Outcomes covered: Neural Tube Defects

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

Age: Up to one year after delivery

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

Surveillance methods

Case ascertainment: Combination of active and passive case ascertainment

Case finding/identification sources:

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

Other state based registries: programs for children with special needs, Autopsy

Delivery hospitals: 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

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

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 prenatal diagnosed or suspected cases

Coding: ICD-9-CM

Data Collected

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

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

gravidity/parity, illnesses/conditions, prenatal care, prenatal diagnostic information, pregnancy/delivery complications, 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: MS Access, SAS

Data Analysis

Data analysis software: SAS, MS Access

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

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

Funding

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

Other

Web site: [Http://www.ggc.org](http://www.ggc.org)

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S116 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

South Dakota

Program status: No surveillance program

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Tennessee

Tennessee Birth Defects Surveillance Project (TBDSP)

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: Research

Population covered annually: 6000

Statewide: no, We have a hospital-based pilot project that covers the Northeast Region. We have statewide Vital Records and Hospital Discharge data.

Current legislation or rule: TCA 68-5-506

Legislation year enacted: 2000

Case Definition

Outcomes covered: Major Birth Defects

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

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: printed abstract/report filled out by staff, electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: MS Access, SAS

Data Analysis

Data analysis software: SAS, MS Access

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

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 hospital-based registry pilot project that covers one region of the state. The regional pilot project is supplemented by statewide Vital Statistics and Hospital Discharge Data System extracts.

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S118 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

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)

Population covered annually: 350,000

Statewide: yes, as of 1999 deliveries

Current legislation or rule: Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87.

Legislation year enacted: 1993

Case Definition

Outcomes covered: All major structural birth defects and fetal alcohol syndrome

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

Age: Up to one year after delivery - FAS up to 6 years

Residence: In-state births to state residents.

Surveillance methods

Case ascertainment: Active, population-based.

Case finding/identification sources:

Vital records:

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

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, infant with low birth weight or low gestation (<34 weeks GA), all stillborn infants

Conditions warranting a chart review beyond the 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, infant with low birth weight or low gestation (<34 weeks GA), all stillborn infants. Note: TX only collects diagnoses made up to the 1st year of age.

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, phone number.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff

Database storage/management: FoxPro, SQL Server

Data Analysis

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

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

Data use and analysis: 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

Funding

Funding source: general state funds 52%, MCH funds 35%, Preventive Health block grant 13%

Other

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

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

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; annual summary reports on birth defect cluster investigations conducted; 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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S120 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

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: 48,000

Statewide: yes

Current legislation or rule: Birth Defect Rule

Legislation year enacted: 1999

Case Definition

Outcomes covered: 742,000 - 759,000

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

Age: 2

Residence: Maternal residence in Utah at time of delivery

Surveillance methods

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

Case finding/identification sources:

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

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

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

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

Other sources: physician reports, lay midwives

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-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 stillborn infants, all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, All fetal deaths certificates, NICU reports, infant deaths are reviewed

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

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

Data Collected

Infant/fetus: identification 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

Data Collection Methods and Storage

Data collection: printed abstract/report filled out by staff, All cases reviewed clinically by M. Feldkamp/J. Carey, MD

Database storage/management: MS Access, Epi-Info

Data Analysis

Data analysis software: Epi-Info, SPSS, Statview

Quality assurance: re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness, Just starting to reabstract cases from each data abstractor's list

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

Funding

Funding source: MCH funds 33%, CDC grant 66%

Other

Web site: health.utah.gov/birthdefect

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

Procedure manual available: yes

Additional information on file: draft form of Data Sharing Protocol

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S122 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Vermont

Program status: Interested in developing a program

Case Definition

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

Other

Comments: Vermont is interested in developing a program appropriate for a rural state with a small number of births. The legislature is expected to pass a bill that would establish a birth information council to advise on the need for and implementation of such a system.

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Virginia

Virginia Congenital Anomalies Reporting And Education System (VACARES)

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 1987

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

Population covered annually: 95,207

Statewide: yes

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

Legislation year enacted: 1985, ammended 1986, 1988

Case Definition

Outcomes covered: Major Birth defects and genetic diseases

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

Age: below 24 months

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

Surveillance methods

Case ascertainment: Passive, population based

Case finding/identification sources:

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

Other state based registries: newborn genetic screening program, newborn biochemical screening program

Delivery hospitals: Medical records abstracts codes from charts

Pediatric & tertiary care hospitals: Medical Records abstracts codes from charts

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a 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, all neonatal deaths, Chart review is done by the coders in Health Information Management

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

Data Collected

Infant/fetus: identification 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 filled out by staff, printed abstract/report submitted by other agencies (hospitals, etc.), Some hospitals send computer print-outs

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%

Other

Web site: www.vahealth.org/genetics

Surveillance reports on file: Annual report

Procedure manual available: yes

Additional information on file: Oracle database

Comments: Plan for data to be entered directly into database from the hospital contacts via Virginia Infant Screening and Infant Tracking Program (VISITS), a web-based tracking and data management system.

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S124 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Washington

Washington State Birth Defects Registry

Program status: Currently collecting data

Start year: 1986- Active and 1991- Passive

Earliest year of available data: 1987

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

Population covered annually: 80,000

Statewide: yes

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

Legislation year enacted: 2000

Case Definition

Outcomes covered: From 1987 to 1991 (active surveillance), and since 1991 to the current time (passive surveillance), the Department of Health receive casefinding logs listing ICD-9-CM codes 740-759; specific primary cancers; specific metabolic conditions; FAS/FAE. Over 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 historically, We are transitioning to ascertainment through 1 year of age currently.

Residence: resident births; child born or diagnosed in state

Surveillance methods

Case ascertainment: Passive case ascertainment

Case finding/identification sources:

Delivery hospitals: discharge summaries, Casefinding Log completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff

Pediatric & tertiary care hospitals: discharge summaries, Casefinding Logs completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff

Case Finding/Case Data Collection Outside of the State: Yes, program has data sharing agreement(s) with other state(s) or conduct case finding or data collection in another state.

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. We are currently in the process of a web based

reporting, linking data to vital records for additional demographic and pregnancy risk (exposure) information
Database storage/management: D-base

Data Analysis

Data analysis software: SAS, MS Access

Quality assurance: validity checks, re-abstraction of cases, comparison/verification between multiple data sources, timeliness, We are in the process of developing our validation component.

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

Funding

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

Other

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

Procedure manual available: yes

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West Virginia

West Virginia Birth Defects Surveillance System

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), elective terminations (20 weeks gestation and greater)

Age: 0-6

Residence: In and out of state births to state residents

Surveillance methods

Case ascertainment: passive case ascertainment

Case finding/identification sources:

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

Other state based registries: programs for children with special needs, newborn genetic screening program, newborn hearing screening program, newborn biochemical screening program, cancer registry, AIDS/HIV registry, SIDS

Delivery hospitals: Hospital personnel complete Birth Defect Reporting forms, reports also sent from Genetics Program.

Pediatric & tertiary care hospitals: Hospital personnel complete Birth Defect Reporting forms, reports also sent from Genetics Program.

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: physician reports

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), education/public awareness

Funding

Funding source: MCH funds 100%

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S126 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

Wisconsin

Wisconsin Birth Defects Prevention And Surveillance Program (WBDPSP)

Program status: Program has not started collecting data

Start year: 2001

Earliest year of available data: 2003

Organizational location: Department of Health and Family Services (CSHCN)

Population covered annually: ~67,000

Statewide: yes

Current legislation or rule: 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)

Age: birth to 2 years

Residence: TBD, statute mandates reporting of birth defects diagnosed or treated in WI.

Surveillance methods

Case ascertainment: population based, passive

Case finding/identification sources:

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

Other state based registries: newborn hearing screening program, newborn biochemical screening program

Pediatric & tertiary care hospitals: Case reports from pediatric specialty clinics

Third party payers: Medicaid databases

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: physician reports, hospital discharge data through 2 yrs of age

Case Ascertainment

Coding: ICD-9-CM, TBD, considering verbatim diagnosis from case reports

Data Collected

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

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, 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: 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, capture-recapture analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, Items checked above are the ones likely to be used.

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 program

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S128 STATE-BASED BIRTH DEFECTS SURVEILLANCE PROGRAMS

US Department of Defense

United States Department Of Defense (DOD) Birth And Infant Health Registry

Program status: Currently collecting data

Start year: 1998

Earliest year of available data: 1998

Organizational location: Department of Defense Center for Deployment Health Research, Naval Health Research Center, San Diego, CA

Population covered annually: approx 90,000

Statewide: No - Nation/World; Department of Defense (DoD) beneficiaries, including active duty, reserve, and retired military personnel, and dependents of the US uniformed services who are eligible for health care benefits

Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum

Legislation year enacted: 1998

Case Definition

Outcomes covered: CDC-recommended major birth defects

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

Age: Birth to 1 year

Residence: Worldwide; any birth to a US military beneficiary

Surveillance methods

Case ascertainment: Electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries

Case finding/identification sources:

Vital records:

Delivery hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, All inpatient and outpatient encounters are captured in standardized DoD data

Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, specialty outpatient clinics, All inpatient and outpatient encounters are captured in standardized DoD data

Third party payers: All inpatient and outpatient encounters are captured in standardized DoD data

Other sources: Validation of standardized electronic data is performed by active case ascertainment and chart review of all births at one of the largest DoD hospitals (Naval Medical Center, San Diego)

Case Ascertainment

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

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

Coding: ICD-9-CM

Data Collected

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

Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, prenatal diagnostic information, pregnancy/delivery complications, 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-reporting 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, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, prevention projects

Funding

Funding source: other federal funding (non-CDC grant) 100%

Other

Web site:

<http://www.nhrc.navy.mil/rsch/code25/projects/birthdefects.htm>

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

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