

STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

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Prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

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

Suggested reference: National Birth Defects Prevention Network (NBDPN). 2006. State Birth Defects Surveillance Program Directory. Birth Defects Research Part A 76:837–893.

Alabama*Alabama Birth Defects Surveillance and Prevention Program (ABDSPP)*

Purpose: Surveillance, Research, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1998

Organizational location: University

Population covered annually: 8,000/year for 1998-2000 data; 18,009 for 2001 data; 19,261 for 2002 data; 19,322 for 2003 data
Statewide: No; 1998-2000 data: Mobile and Baldwin counties; 2001 data: Autauga, Baldwin, Bullock, Clarke, Coffee, Crenshaw, Dale, Elmore, Escambia, Geneva, Henry, Houston, Lowndes, Macon, Mobile, Monroe, Montgomery, and Washington counties; 2002 and 2003 data: add Barbour, Butler, Pike, and Russell counties to 2001 counties.

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 (All gestational ages)

Age: Up to one year after delivery

Residence: 1998-2000 data: Mobile and Baldwin counties; 2001 data: Autauga, Baldwin, Bullock, Clarke, Coffee, Crenshaw, Dale, Elmore, Escambia, Geneva, Henry, Houston, Lowndes, Macon, Mobile, Monroe, Montgomery, and Washington counties; 2002 and 2003 data: add Barbour, Butler, Pike, and Russell counties to 2001 counties.

Surveillance Methods

Case ascertainment: Active case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Fetal death certificates

Delivery hospitals: Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Congenital Anomaly reporting form

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

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Data sharing agreements with other states: Yes

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (<2500 Gms), All stillborn infants, All neonatal deaths, All elective abortions, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, 5 minute appgar <7

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections),

Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: California's coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, Access, Excel pivot tables

Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Baseline rates, Rates by demographic and other variables, Time trends, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding

Funding source: Other funding source 100%

Other

Web site: www.usouthal.edu/genetics/

Additional information on file: Birth Defects Syndromes fact sheets

Comments: Site linked to International Birth Defect Information Systems

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Alaska*Alaska Birth Defects Registry (ABDR)*

Purpose: Surveillance

Partner: Local Health Departments, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1996

Organizational location: Department of Health (Maternal and Child Health), Department of Health (Women's, Children's and Family Health)

Population covered annually: 10,000

Statewide: Yes

Current legislation or rule: 7 AAC 27.012

Legislation year enacted: 1996

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights)

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

Residence: Alaska residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based; Active case ascertainment for alcohol-related birth defects (including fetal alcohol syndrome)

Case finding/identification sources:

Vital Records: Birth certificates

Other state based registries: Programs for children with special needs, Newborn metabolic screening program, Infant learning programs, Genetics clinics, Specialty clinics (heart, cleft lip/palate, neurodevelopmental), MIMR (FIMR), Public health nursing

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

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

Third party payers: Medicaid databases, Indian Health Services

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9 code of 760.71 or 742.1 and other birth defects as selected for review by the ABDR Program Manager.

Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

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

Database storage/management: Access

Data Analysis

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

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking assigned codes, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Grant proposals, Education/public awareness

System Integration

System links: Link case finding data to final birth file

Funding

Funding source: 25% General state funds, 75% MCH funds

Other

Web site: <http://www.epi.hss.state.ak.us/mchebi/ABDR/default.stm>

Surveillance reports on file: Family Health Datalines, ABDR Surveillance Updates, MCH Fact Sheets (ex: Folic Acid Knowledge and Use in Alaska), Alaska Maternal and Child Health Data Book 2003, Alaska Maternal and Child Health Data Book 2005.

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

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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1986

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

Population covered annually: 95,798 in 2005

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 & genetic diseases, as defined by the BPA/CDC codes

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, < 20 weeks gestation included if infant \geq 500 gms), Elective Terminations (20 weeks gestation and greater, < 20 weeks gestation included if infant \geq 500 gms)

Age: Up to 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, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn metabolic screening program, Cases are identified through Children Rehabilitation Services Clinics and the Newborn Intensive Care Program, both of which are in the Office for Children with Special Health Care Needs.

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Mothers charts for stillborns

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Mothers' charts for stillborns

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic lab, Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Ocular conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal diagnostic information, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Access, Oracle

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding

Funding source: General state funds 19%, MCH funds 10%, Genetic screening revenues 18%, CDC grant 52%

Other

Web site: <http://www.azdhs.gov/phs/phstats/bdr/index.htm>

Surveillance reports on file: Annual Reports, 1986 through 1997.

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

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Arkansas*Arkansas Reproductive Health Monitoring System (ARHMS)*

Purpose: Surveillance, Research, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1980

Earliest year of available data: 1980

Organizational location: University, Arkansas Children's Hospital

Population covered annually: 37,000

Statewide: Yes

Current legislation or rule: Senate Bill Act 214

Legislation year enacted: 1985

Case Definition

Outcomes covered: Major structural birth defects

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (All gestational ages)

Age: two years after delivery

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Population-based, Active case ascertainment

Case finding/identification sources:

Vital Records: Birth certificates

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Specialty outpatient clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports

Data sharing agreements with other states: Yes

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with 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, Stillborns occurring in the hospital setting

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

Coding: Locally modified BPA/CDC and NBDPS coding system

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information

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

Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

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

Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access, STATA

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link case finding data to final birth file

Funding

Funding source: General state funds 100%

Other

Web site: www.ARbirthdefectsresearch.uams.edu

Surveillance reports on file: Annual reports

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California

California Birth Defects Monitoring Program (CBDMP)

Purpose: Surveillance, Research

Partner: Local Health Departments, Universities, Hospitals

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 conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.

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

Legislation year enacted: 1982

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (20 weeks gestation and greater)

Age: One year

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

Surveillance Methods

Case ascertainment: Active case ascertainment; Population-based

Case finding/identification sources:

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs,

Postmortem/pathology logs, Surgery logs

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases, apgar 0-0

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, GI condition (e.g. recurrent blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravity/parity, Illnesses/conditions, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

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

Database storage/management: FoxPro

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Validity checks are done on all abstracts.

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Grant proposals, Education/public awareness

System Integration

System links: Link case finding data to final birth file

Funding

Funding source: General state funds 35%, MCH funds 20%, CDC grant 20%, Other federal funding 25%,

Other

Web site: www.cbdmp.org

Surveillance reports on file: Current data on web site

Additional information on file: Publications Index, Summaries of research findings, Collaboration Protocol, Confidentiality Procedures, Cluster Investigation Protocol, Statutes, Video.

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

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/ Org, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1989

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 68,700 (2005)

Statewide: Yes

Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101 - 25-1.5-105

Legislation year enacted: 1985

Case Definition

Outcomes covered: Structural birth defects, Fetal alcohol syndrome, Selected genetic and metabolic disorders; Muscular dystrophy; Selected developmental disabilities; Very low birth weight (less than 1500 grams); Others with medical and maternal risk factors for developmental delay

Pregnancy outcome: Live Births, Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater, less than 20 week limited to selected post-mortem pathology sites)

Age: Up to the 3rd birthday, (up to the 10th birthday for FAS)

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

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based; Active for selected data sources and for special projects like fetal alcohol syndrome

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Fetal death certificates

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics, Selected postmortem pathology sites

Pediatric & tertiary care hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics, Selected postmortem pathology sites

Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, Selected sites for fetal alcohol syndrome and muscular dystrophy

Case Ascertainment

Conditions warranting chart review in newborn period: Selected chart reviews for prenatal to age 3: for statistical trends monitoring (20 conditions - categories); Selected death and fetal deaths; Fetal alcohol syndrome (to age 7); Active case ascertainment data sources (postmortem pathology and specialty clinics); Quality control (selected procedures); and others as needed.

Coding: ICD-9-CM, extended code utilized to describe syndromes, further detail of a condition, and to specify status

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), 99% of data are collected in electronic format

Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access, ArcView (GIS software), Mapitude, SaTScan

Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness, Ongoing quality control procedures for problematic conditions and situations; Records linkage and de-duplication.

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Environmental studies

System Integration

System links: Match to vital records files (birth, death, fetal death)

Funding

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

Other

Web site: <http://www.colorado.gov/> and search on CRCSN

Additional information on file: CRCSN Reference Guide; CRCSN Community Notification and Referral Program Site Manual; Information on the web site

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Connecticut*Connecticut Birth Defects Registry (CTBDR)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, reporting for MCH Block Grant

Partner: Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 2000

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

Population covered annually: 45,000

Statewide: Yes

Current legislation or rule: Sec. 19a-56a. (Formerly Sec. 10a-132b). Birth defects surveillance program.; Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children.

Legislation year enacted: Sec. 10a-132b: 1991; Sec. 19-21a: 1949 Sec. 19-21: 1949.

Case Definition

Outcomes covered: All major structural birth defects; Biochemical, genetic and hearing impairment through linkage with Newborn Screening System; Any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71

Pregnancy outcome: Live Births (All gestational ages and birth weights, PDA GE to 2500 gms birth weight)

Age: Up to one year after delivery for birth defects

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Inpatient hospitalizations, Ambulatory surgery and emergency room visits

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry

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

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

Midwifery facilities: Midwifery facilities

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

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease). Any birth certificate with a birth defect box checked, Cases from birth admissions where the reporting form is the sole source of case ascertainment; Cases of multiple

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

Coding: ICD-9-CM

Data Collected

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

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Pregnancy/delivery complications, Maternal risk factors

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

Data Collection Methods and Storage

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

Database storage/management: Access, Oracle

Data Analysis

Data analysis software: SAS, Access, STATA, Arc GIS

Quality assurance: Validity checks, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, provider education

System Integration

System links: Link case finding data to final birth file

Funding

Funding source: MCH funds 100%

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Delaware*Delaware Birth Defects Surveillance Project*

Purpose: Surveillance, Referral to Prevention/Intervention

Partner: Hospitals, Early Childhood Prevention Programs

Program status: Program has not started collecting data yet

Start year: 2006

Earliest year of available data: 2006

Organizational location: Department of Health and Social Services, Division of Public Health, Family Health Services

Population covered annually: 11,046

Statewide: Yes

Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects

Legislation year enacted: 1997

Case Definition

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

Pregnancy outcome: Live Births (any gestation for live birth), Fetal deaths - stillbirths, spontaneous abortions, etc. (greater than 20 weeks for fetal death)

Age: Birth to 5 years

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

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Hospital discharge records/data

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry

Delivery hospitals: Disease index or discharge index

Pediatric & tertiary care hospitals: Disease index or discharge index

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths

Conditions warranting chart review beyond the newborn period: All infant deaths (excluding prematurity), Childhood deaths between 1 and 6

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

Data Collected

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

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Pregnancy/delivery complications, Maternal risk factors

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Electronic birth certificate

Data Analysis

Data use and analysis: Routine statistical monitoring

System Integration

System links: Link to Newborn Metabolic and Hearing Screening

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

Funding

Funding source: 100% genetic screening revenues

Other

Web site: <http://www.dhss.delaware.gov/dhss/dph/chca/dphbdr/html>

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

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2003

Earliest year of available data: 2003

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

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

Statewide: Yes

Case Definition

Outcomes covered: Major birth defects and genetic disorders.

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, >500gm)

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

Residence: State resident at the time of diagnosis

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs

Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

Third party payers: Medicaid databases

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports

Data sharing agreements with other states: Yes

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, ICD9-CM 740-741.9, 742.3, 743.1, 744-748.5, 749-749.25, 750-751.6, 758-758.2, 760.71, 389, 243, 270.1, 270.3, 271.1, 282.2, 282.4-63, 282.69, 282.7

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Development delay, All infant deaths (excluding prematurity), Auditory/hearing conditions, Any infant with a codable defect

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

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

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

Database storage/management: Oracle

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS

Quality assurance: Validity checks, Re-abstracting of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

Funding

Funding source: MCH funds 100%

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Florida*Florida Birth Defects Registry (FBDR)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Educate health care professionals

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Federal and state agencies

Program status: Currently collecting data

Start year: 1998

Earliest year of available data: 1996

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

Population covered annually: 218,045 in 2004

Statewide: Yes

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

Case Definition

Outcomes covered: Major structural malformations and selected genetic disorders

Pregnancy outcome: Live Births, Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Until age 1

Residence: Florida

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts

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

Third party payers: Medicaid databases, HMOs

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

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

Conditions warranting chart review beyond the newborn period:

Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), Auditory/hearing conditions, Any infant with a codable defect

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

Data Collected

Infant/fetus: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Birth measurements

(weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic info, Preg/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

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

Database storage/management: Access, Excel

Data Analysis

Data analysis software: SPSS, SAS, Access, Excel

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies, Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

Funding

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

Other

Web site: www.fbdr.org

Surveillance reports on file: '96 Annual Report, NTD Report, Data Quality Assurance Report, Active Surveillance Report, & Website

Additional information on file: Grants, Progress reports, educational and health promotion materials, & CD and video tapes

Comments: The FBDR received funding via CDC's Environmental Public Health Tracking Program to expand active surveillance of selected malformations through 2011.

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Georgia

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

Purpose: Surveillance, Research

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups

Program status: Currently collecting data

Start year: 1967

Earliest year of available data: 1968

Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities

Population covered annually: 51,676

Statewide: No. Births to mothers residing within one of five central counties in the metropolitan Atlanta area of the state of Georgia

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

Case Definition

Outcomes covered: Major structural or genetic birth defects

Pregnancy outcome: Live Births, (≥ 20 weeks), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (All gestational ages)

Age: Before 6 years of age

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

Surveillance Methods

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

Case finding/identification sources:

Vital Records: Birth certificates, Fetal death certificates

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, induction logs and miscarriage logs

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (birth weight < 2500 grams or <36 weeks gestation), All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database storage/management: Epi-Info, Mainframe

Data Analysis

Data analysis software: SPSS, SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Prevention projects, survival analysis

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, National Death Index

Funding

Funding source: Other federal funding 100%

Other

Web site: <http://www.cdc.gov/ncbddd/bd/macdp.htm>

Surveillance reports on file: Numerous reports and bibliography

Additional information on file: Rate tables by defect by year

Comments: For surveillance reports and other information regarding the MACDP, e-mail MACDP@cdc.gov.

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Georgia

Georgia Birth Defects Reporting And Information System (GBDRIS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 2003

Earliest year of available data: 2004

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 138,000

Statewide: Yes

Current legislation or rule: Birth defects are reportable under State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2 which mandate the reporting of notifiable diseases and newborn hearing screening, and Chapters 290-5-3-.02 and 290-5-24 of the Rules of Department of Human Resources, which regulate the reporting of notifiable diseases and metabolic disorders.

Legislation year enacted: Updated in 2003

Case Definition

Outcomes covered: Major birth defects, genetic diseases, FAS and CP

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater)

Age: Up to 6 years of age

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance

Delivery hospitals: Disease index or discharge index, Discharge summaries

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

Third party payers: Medicaid databases

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease)

Coding: ICD-9-CM

Data Collected

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

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Epidemiologic studies (using only program data), Service delivery, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

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

Funding

Funding source: General state funds 30%, Other federal funding 70%

Other

Web site:

<http://health.state.ga.us/epi/mch/birthdefects/gbdris/index.asp>

Comments: 3rd Contact Person: Nicole Alexander, MPH GA Division of Public Health, MCH Epidemiology Section 2 Peachtree St, NW Suite 14-414 Atlanta, GA 30303 Phone: 404-651-5196 Fax: 404-657-7517 E-mail: ntucker@dhr.state.ga.us

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Hawaii*Hawaii Birth Defects Program (HBDP)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1988

Earliest year of available data: 1986

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

Population covered annually: ~19,754 average over the last 18 yrs

Statewide: Yes

Current legislation or rule: 8/15/1988 to 6/30/2002 - Hawaii Revised Statutes (HRS), Sections 321-31 and 338-2 in conjunction, per Executive Chamber ruling by Governor on 6/16/1989. HRS Sections 324-1 and 324-2, for additional legislative authority (1990 Amendments). 7/1/02 to Present - Act 252 (2002) - Relating to Birth Defects (SB 2763, SD 2, HD 2, CD 1).

Legislation year enacted: 1989, 1990 and 2002

Case Definition

Outcomes covered: All ~1,154+ outcomes recommended by CDC in their May 1987 Birth Defects Branch Six Digit Code for Reportable Congenital Anomalies, based on B.P.A. Classification of Diseases (1979) and W.H.O. ICD-9 CM (1977).

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

Age: Up to one year after delivery, except for Fetal Alcohol Syndrome which can be diagnosed at any age.

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

Surveillance Methods

Case ascertainment: Active case ascertainment, Population-based

Case finding/identification sources:

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

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

Delivery hospitals: Disease index or discharge index, Discharge summaries, Information from specific logs, laboratories, clinics, etc. are usually found in the medical record when doing chart review.

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

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic lab, Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of

ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases, Medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect, and parents elected not to bring baby to term, or mother spontaneously aborted.

Conditions warranting chart review beyond the newborn period:

All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Any infant with a codable defect

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

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database storage/management: Access, SQL Server 2000

Data Analysis

Data analysis software: Access, SQL Server 2000

Quality assurance: Validity checks, Re-abstractation of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness, Prevention projects, Publication of 49 articles (as of 2/23/06) in peer-review professional journals.

System Integration

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

Funding

Funding Source: General state funds 50%, CDC grant 29%, Other federal funding (non-CDC grants) 5%, Private foundation 4%, Birth Defects Special Fund (state non-general fund funding) 12%. Please note that all the figures above represent average funding amounts for years 1988 to 2006.

Other

Surveillance reports on file: Twelve (12) 135+ page 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, 11) 1986-2002, and 12) 1986-2003, with 13) 1986-2004 data currently being completed.

Additional information on file: HBDP informational brochure; copies of legislation; abstraction forms; abstraction manual; annual reports; HBDP data; quality assurance reports (completeness, accuracy, timeliness); presentation slides; special study reports; and HBDP articles published in peer-review Journals.

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Program status: No surveillance program

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Illinois*Adverse Pregnancy Outcomes Reporting System (APORS)*

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1989

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 182,000

Statewide: Yes

Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)

Legislation year enacted: 1985

Case Definition

Outcomes covered: ICD-9-CM Codes 740.0 through 759.9; Infants positive for controlled substances; Serious congenital infections; Congenital endocrine, metabolic or immune disorders; Congenital blood disorders; Other conditions such as retinopathy of prematurity, FAS

Pregnancy outcome: Live Births, Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: End of newborn hospitalization

Residence: In-state birth to state residents

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based; Birth defect diagnoses are confirmed in a review of medical records by APORS staff.

Case finding/identification sources:

Vital Records: Birth certificates, Fetal death certificates

Delivery hospitals: Disease index or discharge index, Discharge summaries, Hospitals mandated to identify newborn cases and report to IDPH

Pediatric & tertiary care hospitals: Disease index or discharge index, Hospitals mandated to report newborns discharged from any to the NICU or specialty units

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with 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 (e.g. abnormal facies, congenital heart disease), Infants with low birth weight or low gestation, <1500 grams, All neonatal deaths

Coding: CDC coding system based on BPA

Data Collected

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

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity

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

Data Collection Methods and Storage

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

Database storage/management: Access, Mainframe

Data Analysis

Data analysis software: SAS, Access, Arch Map, JoinPoint & SaTScan

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Public Use Data Set

System Integration

System links: Link case finding data to final birth file

System integration: No

Funding

Funding source: General state funds 68%, CDC grant 29%, Other federal funds (non-CDC) 3%

Other

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

Surveillance reports on file: Available on website

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Indiana*Indiana Birth Defects And Birth Problems Registry (IBDPR)*

Purpose: Surveillance, Research, Referral to Services

Partner: Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 2003 birth data is available in 2006

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

Population covered annually: 88,000

Statewide: Yes

Current legislation or rule: IC 16-38-4-7

Rule 410 IAC 21-3

Legislation year enacted: 2001

Case Definition

Outcomes covered: ICD-9-CM Codes 740-759.9, Fetal Alcohol Spectrum Disorder (760.71), Pervasive Developmental Disorder (299.0), Fetal deaths, Metabolic and hearing disorders from Newborn Screening, Selected neoplasms, and congenital blood disorders, and certain eye disorders.

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: Up to 5 years

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based, Combined with selected active confirmation

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, chart audits of 45 targeted birth defects

Pediatric & tertiary care hospitals: Disease index or discharge index, Chart audits of 45 targeted birth defects

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports, Audiologist reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD9-CM codes with a selected list within 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759

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

Coding: ICD-9-CM, and BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

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

Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

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

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, Oracle and ArcView GIS

Quality assurance: Validity checks, Re-abstracting of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: This is the first data reported (Annual Report to the Indiana General Assembly). No other analysis has been done.

System Integration

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

System integration: The database is linked with births, deaths, newborn hearing screening, newborn metabolic screening data, and hospital discharge data.

Funding

Funding source: General state funds 3%, MCH funds 72%, Other federal funds (non-CDC) 25%

Other

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

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Iowa

Iowa Registry For Congenital And Inherited Disorders (IRCID)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Prevention education programs

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Legislators

Program status: Currently collecting data

Start year: 1983

Earliest year of available data: 1983

Organizational location: University

Population covered annually: 37,831 avg. 10 yr

Statewide: Yes

Current legislation or rule: Iowa Code 136A, IAC 641-4.7

Legislation year enacted: 1986; Revised 2001, 2003, 2004

Case Definition

Outcomes covered: Major birth defects, Duchenne/Becker muscular dystrophy, Fetal deaths with and without birth defects

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (All gestational ages)

Age: 1 year

Residence: Maternal residence in Iowa at time of delivery

Surveillance Methods

Case ascertainment: Active case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth and death certificates, Fetal death certificates

Other state based registries: State perinatal program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Specialty outpatient clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports, outpatient surgery facilities

Data sharing agreements with other states: Yes

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 (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases, Muscular dystrophy

Conditions warranting chart review beyond the newborn period:

Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

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

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

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

Database storage/management: Access, Oracle, PC server

Data Analysis

Data analysis software: SPSS, SAS, Access, Oracle

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link case finding data to final birth file. For specific studies, data may be linked with environmental databases or other state databases.

System integration: No

Funding

Funding source: General state funds 44%, CDC grant 56%

Other

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

Surveillance reports on file: Registry reports for 2000, 2002, 2005, 2006

Comments: Former name: Iowa Birth Defects Registry

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Kansas*Birth Defects Reporting System***Purpose:** Registry**Partner:** Hospitals**Program status:** Currently collecting data**Start year:** 1985**Earliest year of available data:** 1985**Organizational location:** Department of Health (Vital Statistics),
Department of Health (Maternal and Child Health)**Population covered annually:** 39,353 (Year 2003)**Statewide:** Yes**Current legislation or rule:** KSA 65-102; KSA 75-3715a (Senate
Bill No. 418)**Legislation year enacted:** 1979; 2004**Case Definition****Outcomes covered:** The outcome data below are available from Office of Vital Statistics, but are not used as part of a birth defects surveillance system. Twenty-four anomalies are listed on the birth certificate and are reported, however, these are not linked to ICD codes.**Pregnancy outcome:** Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (All gestational ages)**Age:** Passive reporting on congenital malformation reports continues through the first year of life**Residence:** In and out of state births to Kansas residents and in-state births to out of state residents**Surveillance Methods****Case ascertainment:** Passive, Hospital-based**Case finding/identification sources:****Vital Records:** Birth certificates, Fetal death certificates**Other state based registries:** Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics**Midwifery facilities:** Midwifery facilities**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities**Other sources:** Physician reports**Data sharing agreements with other states:** Yes**Data Collected****Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and

procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors**Father:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)**Data Collection Methods and Storage****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.). After the birth certificate record has been registered in vital statistics, Any additional reports of birth anomalies from hospitals are entered manually into vital certificates data storage system.**Database storage/management:** Mainframe**Data Analysis****Data analysis software:** SAS, ad-hoc summary reports developed as needed from Crystal Reports.**Quality assurance:** Comparison/verification between multiple data sources, Office of Vital Statistics conducts verification on birth certificate data.**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Grant proposals, Ad-hoc upon request**System Integration****System links:** Link to other state registries/databases**System integration:** Our program has a link with vital statistics records.**Funding****Funding source:** MCH funds 100%**Contacts****Jamie S. Kim, MPH****Epidemiologist****Kansas Department of Health & Environment****1000 SW Jackson, Suite 220****Topeka, KS 66612-1274****Phone: 785-296-6467 Fax: 785-296-6553****E-mail: jkim@kdhe.state.ks.us****Greg G. Crawford, BA****Chief, Vital Statistics Data Analysis****Kansas Department of Health & Environment****1000 SW Jackson Suite 130****Topeka, KS 66612-1354****Phone: 785-296-1531 Fax: 785-368-7118****E-mail: gcrawfor@kdhe.state.ks.us**

Kentucky*Kentucky Birth Surveillance Registry (KBSR)*

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention, Prevention of birth defects

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1998

Organizational location: Department for Public Health, Division of Adult and Child Health Improvement, Early Childhood Development Branch

Population covered annually: 54,500

Statewide: Yes

Current legislation or rule: KRS 211.651-211.670

Legislation year enacted: 1992

Case Definition

Outcomes covered: Major birth defects, Genetic diseases, Fetal mortality

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 20 weeks or 350 gms), Elective Terminations (20 weeks gestation and greater), elective terminations prior to 20 weeks are identified in pilot active surveillance project at 8 hospitals in KY, represents 36% of births

Age: Up to fifth birthday

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

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, medical laboratory reporting mandated; Outpatient reporting voluntary

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Specialty outpatient clinics, Laboratory records

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Lab records

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic lab, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, Local health departments

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), Cardiovascular condition, Any infant with a codable defect

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

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic 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.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, Mainframe

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, IRB-approved research projects

System Integration

System links: Link case finding data to final birth file

System integration: True positives identified by newborn screening are integrated into the KBSR database.

Funding

Funding source: General state funds 100%

Other

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

Surveillance reports on file: Legislation and regulation; Hospital Reporting Administrative Manual; Draft confidentiality guidelines; Conditions definitions, KBSR fact sheet, KBSR brochure

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Louisiana*Louisiana Birth Defects Monitoring Network (LBDMN)*

Purpose: Surveillance, Referral to Services

Partner: Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2005

Earliest year of available data: 2005

Organizational location: Department of Health (Children's Special Health Services)

Population covered annually: Approx. 23,750 for 2006

Statewide: No, for 2006, covering the following parishes: Ascension, Bossier, Caddo, Calcasieu, Cameron, East Baton Rouge, East Feliciana, Iberville, Orleans, Pointe Coupee, West Baton Rouge, and West Feliciana.

Current legislation or rule: LA R.S. 40:31.41 - 40:31.48. Rule: LAC 48:V.Chapters 161 and 163

Legislation year enacted: 2001

Case Definition

Outcomes covered: Major structural birth defects; Selected genetic diseases; Selected blood, endocrine and metabolic disorders

Pregnancy outcome: Live Births

Age: Up to third birthday

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

Surveillance Methods

Case ascertainment: active case ascertainment, Limited population-based

Case finding/identification sources:

Vital Records: In progress

Other state based registries: In progress

Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Third party payers: In progress

Other sources: In progress

Case Ascertainment

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

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

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and

procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications, Maternal risk factors, Family history

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, SAS

Quality assurance: Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review

Data use and analysis: Routine statistical monitoring

System Integration

System links: in progress

Funding

Funding source: General 100% CSHCN funds

Other

Comments: * Information listed below for primary contact is temporary; offices were flooded due to Hurricane Katrina and still have not been permanently relocated.

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Maine*Maine Birth Defects Program (MBDP)*

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, March of Dimes

Program status: Currently collecting data

Start year: 1999

Earliest year of available data: Reporting began May 1, 2003

Organizational location: Department of Health (Children with Special Health Needs, Department of Health and Human Services)

Population covered annually: 13,500

Statewide: Yes

Current legislation or rule: 22 MRSA c. 1687

Legislation year enacted: 1999

Case Definition

Outcomes covered: Selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21 and major heart defects

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, prenatally diagnosed at any gestation), Elective Terminations (prenatally diagnosed at any gestation)

Age: Through age one

Residence: All in-state births to Maine residents

Surveillance Methods

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

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics

Midwifery facilities: Midwifery facilities

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: MD reports, Children with Special Health Needs

Case Ascertainment

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

Conditions warranting chart review beyond the newborn period: Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codable defect

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

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

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

Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

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

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

Data Analysis

Data analysis software: SAS, Stat-exact

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

System integration: Newborn Hearing/ Newborn Bloodspot Screening Programs

Funding

Funding source: 100% MCH funds

Other

Web site: <http://www.maine.gov/dhhs/boh/cshn/home.html>

Additional information on file: Program manual in draft form

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Maryland*Maryland Birth Defects Reporting and Information System (BDRIS)*

Purpose: Surveillance, Research, Referral to Services
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1984
Organizational location: Department of Health (Family Health Administration, Office for Genetics & Children with Special Health Care Needs)
Population covered annually: 70,000
Statewide: Yes
Current legislation or rule: Health-General Article, Section 18-206; Annotated Code of Maryland
Legislation year enacted: 1982

Case Definition

Outcomes covered: Selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome
Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, or ≥ 500 grams weight, reports accepted on fetal deaths < 500 grams or < 20 weeks gestation if sent to us), Elective terminations (20 weeks gestation and greater, or ≥ 500 grams weight; reports accepted on terminations < 500 grams or < 20 weeks gestation if sent to us)
Age: Newborn
Residence: All in-state births

Surveillance Methods

Case ascertainment: Passive case ascertainment, multiple sources, 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 metabolic screening program, Sickle Cell Disease
Delivery hospitals: Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Primary source: sentinel birth defects hospital report form
Midwifery facilities: Midwifery facilities
Other specialty facilities: Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Case Ascertainment

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

Data Collected

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

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

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: In the process of linkage with other state registries/databases

Funding

Funding source: General state funds 100%

Other

Web site: <http://www.fha.state.md.us/genetics> (then select Birth Defects Reporting Information)
Surveillance reports on file: Provisional surveillance reports 1984-1992; 1995-2003
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*Birth Defect Monitoring Program, Massachusetts Center For Birth Defects Research And Prevention (MBDMP)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups

Program status: Currently collecting data

Start year: 1997

Earliest year of available data: 1999 for statewide data

Organizational location: Department of Health (Bureau of Family and Community Health)

Population covered annually: 81,000

Statewide: Yes

Current legislation or rule: Massachusetts General Laws, Chapter 111, Section 67E. In 2002 the Massachusetts Legislature amended this statute, expanding the birth defects monitoring program.

Legislation year enacted: 1963

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (>=20 weeks gestation or >=350 grams)

Age: Up to one year, up to three years when new legislation implemented (regulations pending)

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

Surveillance Methods

Case ascertainment: Population based, State-wide, Combination of active case ascertainment and administrative review

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Fetal death certificates

Delivery hospitals: Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs

Pediatric & tertiary care hospitals: Disease index or discharge index, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics

Other sources: Physician reports

Data sharing agreements with other states: Yes

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, All infant deaths (excluding prematurity), Auditory/hearing conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal

diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Data from printed hospital reporting form is entered into electronic surveillance database.

Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access, Excel

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, 1) selected cases from surveillance are eligible for CDC's National Birth Defects Prevention Study 2) craniofacial defects used for grant to determine cost of these defects

System Integration

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

Funding

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

Other

Web site: <http://www.mass.gov/birthdefectscenter>

Surveillance reports on file: Latest surveillance report available online at http://www.mass.gov/dph/fch/birthdefects/surveillance_report.htm#2000_2001; Prevention and Resource Booklet at <http://www.mass.gov/dph/fch/birthdefects/bdefects.htm>

Comments: statewide coverage started October 1998

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Michigan*Michigan Birth Defects Registry (MBDR)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, incidence and mortality statistics

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1992

Earliest year of available data: 1992

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

Population covered annually: 127,000

Statewide: Yes

Current legislation or rule: Public Act 236 of 1988

Legislation year enacted: 1988

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Other gestational age and/or birth weight criterion, 20 weeks or >400 grams)

Age: Up to two years after delivery

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

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry

Delivery hospitals: Disease index or discharge index, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Specialty outpatient clinics

Third party payers: Medicaid databases

Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: ICD-9-CM

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors

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

Data Collection Methods and Storage

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

Database storage/management: FoxPro

Data Analysis

Data analysis software: SPSS, Access, Fox-pro

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies, Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

System integration: No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

Funding

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

Other

Web site: http://www.michigan.gov/mdch/0,1607,7-132-2944_4670---,00.html

Surveillance reports on file: Birth defects incidence and mortality annual reports

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Minnesota*Minnesota Birth Defects Information System (BDIS)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 2005

Earliest year of available data: 2006

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 71,000

Statewide: No, the surveillance system will be phased in over a number of years. Implementation will begin in the two largest counties in Minnesota Hennepin and Ramsey counties. These two counties account for approximately 50 percent of the births.

Current legislation or rule: MS 144.2215-2219

Legislation year enacted: 2004

Case Definition

Outcomes covered: Major "reported birth defects" as defined by CDC and ICD-9 codes up to 1 year of age; age 6 for FAS

Pregnancy outcome: Live Births (up to one year); FAS cases will include children up to 6 years of age

Age: Up to 1 year after delivery

Residence: In-state data

Surveillance Methods

Case ascertainment: Active surveillance will be phased in based on resources; Passive sources will also be used after validation

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Infant death records

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

Third party payers: Medicaid databases, Health maintenance organization (HMOs)

Other specialty facilities: Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All infants in NICU or special care nursery

Conditions warranting chart review beyond the newborn period:

Facial dysmorphism or abnormal facies

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

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care

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.), laptops encrypted and data downloaded regularly

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

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness, Physician review as needed

Data use and analysis: Public health program evaluation, Baseline rates, Referral, Grant proposals, Education/public awareness, Prevention projects, Full system implementation in 2005; many of these listed above will be used when full data sets are available

System Integration

System links: Link case finding data to final birth file

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

Funding

Funding source: 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/divs/eh/birthdefects

Surveillance reports on file: Data summaries and services/prevention updates are available on website.

Comments: System will use an opt-out format that will be monitored regularly to ensure that data trends remain valid.

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Mississippi*Mississippi Birth Defects Registry (MBDR)*

Purpose: Surveillance

Partner: Local Health Departments, Hospitals

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: Department of Health (Maternal and Child Health), Department of Health (Division of Genetic Services)

Population covered annually: 42,000

Statewide: Yes

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

Legislation year enacted: 1997

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 350 grams or more)

Age: 0 to 21

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: passive case ascertainment

Case finding/identification sources:

Vital Records: Birth certificates, Fetal death certificates

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Cancer registry

Delivery hospitals: Disease index or discharge index, Discharge summaries

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

Other sources: Physician reports

Case Ascertainment

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

Conditions warranting chart review beyond the newborn period: CNS condition (e.g. seizure), GI condition (e.g. recurrent

blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: Access

Quality assurance: Validity checks

Data use and analysis: Routine statistical monitoring, Education/public awareness

Funding

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

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Missouri*Missouri Birth Defects Registry*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 1980

Organizational location: Department of Health (Vital Statistics)

Population covered annually: 77,000

Statewide: Yes

Current legislation or rule: None

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)

Age: Up to one year after delivery

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive, Multi-source

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics

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

Case Ascertainment

Coding: ICD-9-CM, ICD-10

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

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

Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications

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

Data Collection Methods and Storage

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

Database storage/management: SAS (Unix)

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link case finding data to final birth file

Other

Web site: <http://www.dhss.mo.gov/BirthDefectsRegistry/>

Surveillance reports on file: Missouri Birth Defects 1996-2000

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Montana*Montana Birth Outcomes Monitoring System (MBOMS)*

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Hospitals, Advocacy Groups, private practice physicians

Program status: Currently collecting data

Start year: 1999

Earliest year of available data: 2000

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

Population covered annually: 11,500

Statewide: Yes

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights, >20 weeks gestation & 500 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective Terminations (All gestational ages)

Age: Birth through age 3

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

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, 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 metabolic screening program

Delivery hospitals: Disease index or discharge index

Third party payers: Medicaid databases, SSI referrals

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports, fetal pathology

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any birth certificate with a birth defect box checked

Conditions warranting chart review beyond the newborn period: Cardiovascular condition

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal diagnostic information, Maternal risk factors

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

Data Collection Methods and Storage

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.)

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, ClusterSeer 2

Quality assurance: Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals

System Integration

System links: Link to other state registries/databases

System integration: Integrated with Children with Special Health Care Needs database

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Nebraska
Nebraska Birth Defects Registry

Purpose: Surveillance, Research, We are in the process of developing a program of referral to services and prevention programs.

Partner: Hospitals, Department of Health and Human Services and MCH

Program status: Currently collecting data

Start year: 1973

Earliest year of available data: 1973

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

Population covered annually: Statewide, 24,000+ births annually
Statewide: Yes

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

Legislation year enacted: 1972

Case Definition

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

Pregnancy outcome: Live Births, (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 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

Delivery hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Nebraska Birth Defects Prevention Program Congenital Defects Case Record

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics, Nebraska Birth Defects Prevention Program Congenital Defects Case Record

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

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

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collected

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

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Defects taken from paper copies of birth certificates submitted to the Vital Statistics Office.

Database storage/management: Key-entry 3 and QS technologies

Data Analysis

Data analysis software: SAS and reports from QS technologies

Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Case finding, data coding and entry

Data use and analysis: Baseline rates, Monitoring outbreaks and cluster investigation, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Incidence rates, Trend analysis, Birth defect registry

Funding

Funding source: MCH funds 100%

Other

Surveillance reports on file: 2004 report in Vital Statistics Report. 2005 report will be available in published form in summer of 2007.

Additional information on file: Copy of legislation, congenital defects case record form

Comments: State legislation introduced to allow release of patient-identifying information to approved researcher for the purpose of research; development of a system so that hospitals may use the electronic birth certificate to initially alert the surveillance program of the birth of a child with an anomaly.

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Nevada
Nevada Birth Defects Registry

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Hospitals, Early Childhood Prevention Programs, Bureau of Health Planning and Statistics

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 2000

Organizational location: State Division of Health, Bureau of Family Health Services (MCH)

Population covered annually: 36,485 in 2005

Statewide: Year 2000 data is for Las Vegas only. Year 2001 - statewide data completed, Statewide active case review and abstraction from hospitals and birthing centers started from 2005. Collection of data for the year 2005 is complete and the process of analysis is in progress.

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

Legislation year enacted: 1999

Case Definition

Outcomes covered: Major birth defects and genetic diseases

Pregnancy outcome: Live Births (20 weeks of gestation and greater with all birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 20 weeks gestation and greater)

Age: Cover from 0-7 years of age

Residence: In-state births

Surveillance Methods

Case ascertainment: Combination of active and passive ascertainment initially; restarted Combination case ascertainment in July 2005, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Hospital medical records, Diagnostic/laboratory reports

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

Third party payers: Medicaid databases

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

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

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Development delay, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Any infant with a codable defect

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, SAS, Access

Quality assurance: Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

Funding

Funding source: Service fees 100%

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New Hampshire*New Hampshire Birth Conditions Program (NHBCP)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 2003

Earliest year of available data: 2003

Organizational location: Department of Health (Maternal and Child Health), Department of Health (Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, Department of Environmental Services Bureau of Env. Health), University

Population covered annually: 14,000

Statewide: Collecting 2005 data for all birth hospitals in the state.

Current legislation or rule: Working with the NH Chapter of the March of Dimes and the NH DHHS to begin the process of proposed legislation for birth conditions reporting in NH.

Case Definition

Outcomes covered: All major birth defects and genetic diseases recommended by the CDC/NBDPN

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (All gestational ages)

Age: Fetuses >20 weeks gestation and newborns/infants up to 1 year of age

Residence: All New Hampshire residents, In-state & out-of-state

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based, Combination of active and passive case ascertainment

Case finding/identification sources:

Vital Records: Birth certificates, Fetal death certificates, hospital ICD-9 codes for admissions, discharges and transports, fetal pathology reviews at Dartmouth Hitchcock Medical Center

Other state based registries: Programs for children with special needs, Newborn hearing screening program

Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Specialty outpatient clinics, medical records abstraction of charts of selected ICD 9 Codes

Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, 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 genetics facilities, Maternal serum screening facilities

Case Ascertainment

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

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

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

Data Collected

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

Mother: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic info, Maternal risk factors, Family history

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility

Database storage/management: Oracle, AURIS, a web-based reporting system currently utilized by the NH DHHS Newborn Hearing Screening Program, has added a module to the currently operating system to meet the birth defects tracking requirements.

Data Analysis

Data analysis software: SPSS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Public health program evaluation, Baseline rates, Observed vs expected analyses, Statewide data collection began January 2005 for calendar years 2003 and 2004. Limited data use and analysis has been completed to date, however we are in the process of developing a survey to evaluate access to care for infants born with a reportable birth condition.

System Integration

System integration: Integrated into the NH DHHS Newborn Hearing Screening Program registry, a state-wide universal hearing program for all NH infants.

Funding

Funding source: CDC grant 100%

Other

Web site: In production to be completed 5/2006

Additional information on file: Abstract for a pilot study on the comparison between birth certificate data and ICD-9 code data alone and with the use of medical chart abstraction for NH birth defects surveillance.

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New Jersey

Special Child Health Services Registry (SCHS REGISTRY)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1928

Earliest year of available data: 1985

Organizational location: Department of Health & Senior Services - Special Child, Adult, and Early Intervention Services

Population covered annually: 115,000

Statewide: Yes

Current legislation or rule: NJSA 26:8 et seq., NJAC 8:20 - Enacted 08-04-1983, with effective date of 03-04-1985. Changes to legislation 1990, 1991, 1992, 2005. Readopted 05/2005.

Legislation year enacted: 1983

Case Definition

Outcomes covered: All birth defects, including structural, genetic, and biochemical are required to be reported. While not mandated, all special needs and any condition which places a child at risk, e.g. prematurity, asthma, cancer, developmental delay, are also reported. Due to an amendment to the legislation (08/05/2005), severe hyperbilirubinemia is now required to be reported to the Registry.

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: Mandated reporting of birth defects diagnosed \leq age 2, voluntary reporting of birth defects diagnosed $>$ age 2 and all children diagnosed with Special Needs conditions who are \leq 22 yrs. of age. As part of the amendment on 08/05/2005, children with mandated conditions are required to be reported through age five.

Residence: In/out NJ births to NJ residents; Because of our link to the SCHS Case Management system, we also enroll anyone becoming NJ resident.

Surveillance Methods

Case ascertainment: Passive, Population-based reporting system with annual quality assurance visits by BDR staff to birthing hospitals, Birthing centers and, pediatric care facilities; Medical providers are contacted to confirm questionable diagnoses. Medical chart review is conducted on all children registered with any of the defects eligible for participation in the National Birth Defects Prevention Study.

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 metabolic screening program, AIDS/HIV registry

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics. Quality assurance visit consisting of chart review of 3 month period

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period

Midwifery facilities: Midwifery facilities

Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, Special Child Health Services county based Case Management units, Parents, 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 selected list of ICD9-CM codes outside 740-759, All neonatal deaths, all death certificates for $<$ 1 year of age

Conditions warranting chart review beyond the newborn period: GI condition (e.g. recurrent blockage), GU condition (e.g. 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 info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic info

Mother: Identification info (name, address, date-of-birth, etc.)

Father: Identification info (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.), Plan to implement web-based reporting within next year

Database storage/management: SAS

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness, merge registry with birth certificate registry and the death certificate registry

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time-space cluster analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to hearing screening registry

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

Funding

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

Other

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

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

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

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

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, legislature

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1995

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

Population covered annually: 28,500

Statewide: Yes

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

Legislation year enacted: January 1, 2000

Case Definition

Outcomes covered: 740-760.71

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, and terminations included in NTD counts), Elective Terminations (All gestational ages)

Age: Birth through age 4 years--This was just changed April 2006.

Residence: Births to New Mexico residents. Due to a change in Vital Records procedures, we only receive birth records for NM residents with births occurring in-state.

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based, Combination of active and passive 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, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Medical chart review

Pediatric & tertiary care hospitals: Disease index or discharge index, Specialty outpatient clinics, including neurosurgery and plastic surgery

Midwifery facilities: Midwifery facilities

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

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

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 (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All prenatal

diagnosed or suspected cases, 760.71, any charts with a list of other ICD9-CM codes selected by CMS

Conditions warranting chart review beyond the newborn period:

All infant deaths (excluding prematurity), Any infant with a codable defect

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

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

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, Excel

Data Analysis

Data analysis software: SAS, Stata

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

System integration: BDPASS is integrated with the Children's Chronic Conditions Registry

Other

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

Surveillance reports on file: Birth Defects in New Mexico 1997-1998; Birth Defects in New Mexico 1995-1999

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New York*New York State Congenital Malformations Registry (CMR)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Community outreach and education

Partner: Universities, Hospitals, Early Childhood Prevention Programs, March Of Dimes

Program status: Currently collecting data

Start year: 1982

Earliest year of available data: 1983

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 250,000 - 300,000

Statewide: Yes

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

Legislation year enacted: 1982

Case Definition

Outcomes covered: Major malformations - a detailed list is available upon request

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: 2 years

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

Surveillance Methods

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

Case finding/identification sources:

Other state based registries: NYS Dept. of Health statewide hospital discharge database

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Other specialty facilities: Cytogenetic laboratories

Other sources: Physician reports, Hospital discharge data

Case Ascertainment

Conditions warranting chart review in newborn period: Charts with major malformations - a detailed list is available upon request

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

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information

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

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

Data Collection Methods and Storage

Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, FoxPro, Sybase

Data Analysis

Data analysis software: SAS, Access, Visual FoxPro

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

Funding

Funding source: General state funds 13.5%, MCH funds 16.2%, CDC grant 51.8%, Other federal funding 18.5%

Other

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

Surveillance reports on file: Reports for 1983-2003.

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North Carolina*North Carolina Birth Defects Monitoring Program (NCBDMP)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Education, Advocacy

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 1987

Earliest year of available data: 1989

Organizational location: State Center for Health 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 (All gestational ages)

Age: Up to one year after delivery

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

Surveillance Methods

Case ascertainment: Population-based, Active ascertainment

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Case finding/identification sources:

Other state based registries: Programs for children with special needs

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics

Third party payers: Medicaid databases

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities

Data sharing agreements with other states: Yes

Case Ascertainment

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

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

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

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

Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

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

Database storage/management: Access, Mainframe, SAS

Data Analysis

Data analysis software: SPSS, SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Advocacy

System Integration

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

Funding

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

Other

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

Surveillance reports on file: Annual reports, Special studies

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North Dakota*North Dakota Birth Defects Monitoring System (NDBDMS)*

Purpose: Surveillance

Partner: Universities, March of Dimes

Program status: Currently collecting data

Start year: 2002

Earliest year of available data: 1994

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

Population covered annually: 7719

Statewide: Yes

Current legislation or rule: North Dakota Century code 50-10

Legislation year enacted: 1941

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights, numbers collected and reported via Vital Records), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, numbers collected and reported via Vital Records), Elective Terminations (less than 20 week gestation, 20 weeks gestation and greater, numbers collected and reported via Vital Records)

Age: newborn period

Residence: in-state resident births and out of state birth receiving services in ND

Surveillance Methods

Case ascertainment: Passive case ascertainment

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry, FAS

Delivery hospitals: Birth certificate completion

Pediatric & tertiary care hospitals: Specialty outpatient clinics

Third party payers: Medicaid databases, Health maintenance organization (HMOs), Private insurers

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Data sharing agreements with other states: Yes

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 (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked

Coding: ICD-9-CM, ICD 10

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records

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

Data Analysis

Data analysis software: SPSS

Quality assurance: Validity checks, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding

Funding source: SSDI Grant

Other

Web site: [www.http://ndhealth.gov/vital/](http://ndhealth.gov/vital/)

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Ohio*Ohio Connections For Children With Special Needs (OCCSN)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Program has not started collecting data yet
Start year: 2004

Earliest year of available data: N/A

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

Population covered annually: System in development

Statewide: No, state will begin collecting data from hospitals in 4 counties of the state in May, 2006.

Current legislation or rule: Ohio Revised Code (ORC) 3705.30 - 3705.36, signed into law in July, 2000. "The Director of Health shall establish and, if funds for this purpose are available, implement a statewide birth defects information system for the collection of information concerning congenital anomalies, stillbirths, and abnormal conditions of newborns." Administrative rules became effective June 3, 2005.

Legislation year enacted: 2000

Case Definition

Outcomes covered: 45 disorders recommended by NBDPN

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: Up to 5 years of age

Residence: All children 0-5 years of age seen for medical care at a hospital in one of the 4 counties

Surveillance Methods

Case ascertainment: Passive case ascertainment, Hospital-based

Case finding/identification sources:

Vital Records: Birth certificates

Other state based registries: Programs for children with special needs

Delivery hospitals: Hospital electronic data systems for medical records and billing

Pediatric & tertiary care hospitals: Hospital electronic data systems for medical records and billing

Case Ascertainment

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

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

Data Collection Methods and Storage

Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.), Reporting hospitals upload information to ODH via secure internet transmission. Low volume reporters will have option of web-based manual data entry screens in October, 2006.

Database storage/management: SQL server

Data Analysis

Data analysis software: SAS

Quality assurance: Comparison/verification between multiple data sources, Timeliness, Other QA procedures to be implemented in Summer, 2006

System Integration

System integration: Shared demographic database with Ohio's early intervention program, but the systems will not be integrated.

Funding

Funding source: CDC grant 100%

Other

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Oklahoma*Oklahoma Birth Defects Registry (OBDR)*

Purpose: Surveillance, Referral to Prevention/Intervention
Partner: Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Cytogenetics/ & Medical Genetics
Program status: Currently collecting data
Start year: 1992; statewide 1994
Earliest year of available data: 1992
Organizational location: Department of Health (Family Health Services)
Population covered annually: 50,000
Statewide: Yes
Current legislation or rule: 63 O.S. Section 1-550.2
Legislation year enacted: 1992

Case Definition

Outcomes covered: Modified 6-digit ICD-9-CM codes for birth defects and genetic diseases (CDC/BPA)
Pregnancy outcome: Live Births (\geq 20 weeks gestation), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (20 weeks gestation and greater)
Age: 2 years
Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Active case ascertainment, Population-based
Case finding/identification sources:
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Delivery hospitals: Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics
Midwifery facilities: Midwifery facilities
Third party payers: Indian health services, Military hospitals delivering babies
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Data sharing agreements with other states: Yes

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

Data Collected

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

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Maternal risk factors, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

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

Data Analysis

Data analysis software: SAS, Access, ArcView GIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Timeliness, editing of all completed abstracts
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, program quality assurance

System Integration

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

Funding

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

Other

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

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Oregon

Program status: No surveillance program

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

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Community Nursing Services, Advocacy Groups

Program status: Currently collecting data

Start year: 2003

Earliest year of available data: 2001

Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 143,404 total live births in 2001; 142,388 total live births in 2002; 145,952 total live births in 2003; 144,500 total live births in 2004 (preliminary).

Statewide: Yes

Case Definition

Outcomes covered: 740-759.9 and 760.71 ICD-9

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (16 weeks gestation and greater)

Age: Birth to 24 months of age

Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Matched birth/death file, Fetal death certificates, Hospital discharge data collected by the Pennsylvania Health Care Cost Containment Council (PHC4--a separate independent state agency).

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry

Delivery hospitals: PHC4 data is based on hospital discharge summaries

Pediatric & tertiary care hospitals: PHC4 data is based on hospital discharge summaries

Case Ascertainment

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

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Hospitals submit patient discharge data to the Pennsylvania Health Care Cost Containment Council (PHC4--a state agency). PA Department of Health receives data from PHC4.

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, SAS, Access

Quality assurance: Validity checks, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding

Funding source: MCH funds 100%

Other

Web site: <http://www.dsf.health.state.pa.us/health/cwp/view.asp?a=179&q=242196&PM=1>

Additional information on file: See website URL for written explanation of birth defects monitoring system data matching and file building process

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

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

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1995

Organizational location: Department of Health (Maternal and Child Health), Department of Health (Division of Children with Special Health Care Needs)

Population covered annually: 56,000

Statewide: Yes

Current legislation or rule: Yes, Law 351

Legislation year enacted: September 16th, 2004

Case Definition

Outcomes covered: neural tube defects (anencephaly, encephalocele, myelomeningocele and meningocele), cleft lip and/or cleft palate, gastroschisis, club foot, limb reduction defects, Down syndrome, omphalocele, ambiguous genitalia, trisomy 13, trisomy 18, conjoined twins, albinism, and congenital heart defects

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (All gestational ages)

Age: Up to 6 years after delivery

Residence: In state birth to state residents

Surveillance Methods

Case ascertainment: Active case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Programs for children with special needs

Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Laboratory logs

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, Any infant with a codable defect

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, 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.)

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, Access, Excel

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, 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 59%, CDC grant 41%

Other

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

Surveillance reports on file: Description of registry development, case report form, manual for case report form

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Rhode Island*Rhode Island Birth Defects Surveillance Program*

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention

Partner: Hospitals, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 1997

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

Population covered annually: 12,500

Statewide: Yes

Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws requires the development of a birth defects surveillance, reporting and information system that will: a) describe the occurrence of birth defects in children up to age five; b) detect trends of morbidity and mortality; and c) identify newborns and children with birth defects to intervene on a timely basis for treatment.

Legislation year enacted: 2003

Case Definition

Outcomes covered: Major birth defects and genetic diseases

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: Currently at birth

Residence: RI residents

Surveillance Methods

Case ascertainment: Currently, passive case ascertainment

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file

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

Delivery hospitals: Discharge summaries, ICU/NICU logs or charts

Pediatric & tertiary care hospitals: Specialty outpatient clinics

Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Chart reviews are conducted for every newborn identified with a birth defect

Coding: ICD-9-CM

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

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

Data Collection Methods and Storage

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

Database storage/management: Access, Oracle

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System Integration

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

Funding

Funding Source: MCH funds 60%, CDC grant 40%, Note: CDC Grant = no cost extension \$ from birth defects surveillance grant

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South Carolina*South Carolina Birth Defects Program (SCBDP)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Legislators, Greenwood Genetic Center

Program status: Currently collecting data

Start year: 2006

Earliest year of available data: 1993

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

Population covered annually: 57,134

Statewide: Yes

Current legislation or rule: A281,R308,H4115

Legislation year enacted: 2004

Case Definition

Outcomes covered: Neural Tube Defects, cardiac malformations, limb reduction defects, orofacial clefts program was transitioned this year from Greenwood Genetic Center to SCDHEC. Additional defects will be added over time.

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 age 2.

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

Surveillance Methods

Case ascertainment: Active case ascertainment

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Elective termination certificates

Other state based registries: Programs for children with special needs, autopsy

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Postmortem/pathology logs, Specialty outpatient clinics, ICD-9 codes

Pediatric & tertiary care hospitals: 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 genetics facilities, Maternal serum screening facilities

Other sources: Physician reports

Data sharing agreements with other states: yes

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects

or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Cardiovascular condition
Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness, Prevention projects

Funding

Funding source: General state funds 100%

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South Dakota

Program status: No surveillance program

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Tennessee*Tennessee Birth Defects Registry (TBDR)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 1999

Organizational location: Department of Health (Other, please specify):, Research

Population covered annually: 80,000

Statewide: Yes

Current legislation or rule: TCA 68-5-506

Legislation year enacted: 2000

Case Definition

Outcomes covered: Major structural birth defects

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (500 grams or more, or in the absence of weight, of 22 completed weeks of gestation or more.)

Age: Diagnosed up to one year after delivery

Residence: in and out state births to state resident

Surveillance Methods

Case ascertainment: Passive case ascertainment supplemented with active case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Third party payers: Medicaid databases

Data sharing agreements with other states:

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Infants with low birth weight or low gestation (active review sample infants with no known diagnosis and oversample for low birth weight), ICD9-CM code 760.71

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

Coding: ICD-9-CM

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors

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

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by registry staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, SQL Server

Data Analysis

Data analysis software: SAS, Access, SQL Server, Arc-GIS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Needs assessment, Education/public awareness, Prevention projects

System Integration

System links: Link case finding data to final birth file

Funding

Funding source: General state funds 100%

Other

Surveillance reports on file: Tennessee Birth Defects 2000-2002

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Texas

Texas Birth Defects Epidemiology And Surveillance Branch (TBDES)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Advocacy Groups

Program status: Currently collecting data

Start year: 1994

Earliest year of available data: 1996

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 377,374 in 2003

Statewide: Yes

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

Legislation year enacted: 1993

Case Definition

Outcomes covered: All major structural birth defects and FAS

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Elective Terminations (All gestational ages)

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

Residence: In-state births to state residents.

Surveillance Methods

Case ascertainment: Active case ascertainment, Population-based

Case finding/identification sources:

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization lab, Specialty outpatient clinics, genetics logs, stillbirth logs, radiology logs

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, genetics logs, radiology logs

Midwifery facilities: Midwifery facilities

Other sources: Licensed birthing centers

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Infants with low birth weight or low gestation, please specify: (<34 weeks GA), All stillborn infants

Conditions warranting chart review beyond the newborn period:

CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Any infant with a codable defect

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification info (name, address, date-of-birth, etc.), Demographic info (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic info, Pregnancy/delivery complications, Maternal risk factors, Family history

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff

Database storage/management: SQL Server

Data Analysis

Data analysis software: SPSS, SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness, Re-case finding, Re-review of medical records

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies, Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness

System Integration

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

Funding

Funding source: General state funds 58%, MCH funds 42%, Preventive Health block grant 16% *Note: does not include CDC-funded Texas Birth Defects Research Center funds

Other

Web site: <http://www.dshs.state.tx.us/birthdefects/default.shtm>

Surveillance reports on file: Report of Birth Defects Among 1995 Deliveries. 1996 Birth Defects in the Lower Rio Grande Valley. Report of Birth Defects Among 1996 and 1997 Deliveries. Report of Birth Defects Among 1998 and 1999 Deliveries, Among 1999 and 2001 Deliveries. Queriable web based data base: <http://soupfin.tdh.state.tx.us/bdefdoc.htm>

Additional information on file: Legislation; TX Birth Defects Monitoring Division fact sheet; TX Center for Birth Defects Research and Prevention fact sheet; FAS brochure (English and Spanish); Pregnancy Outcome Patterns for Various Defects; Impact of Including Induced Pregnancy Terminations Before 20 Weeks Gestation on Birth Defect Rates; Cluster Investigation Reports; Birth Defects Glossary; Recent Trends in Neural Tube Defects in TX Birth Defects Risk Factor Series.

Comments: Statewide as of 1999 deliveries. Until 2000, the TX DOH also had the TX Neural Tube Defect Surveillance and Intervention Project along the Texas border with Mexico (active surveillance and research on neural tube defects for 14 counties).

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Utah*Utah Birth Defect Network (UBDN)*

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, education

Partner: Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups

Program status: Currently collecting data

Start year: 1994

Earliest year of available data: 1994

Organizational location: University, Department of Health

Population covered annually: 50,000

Statewide: Yes

Current legislation or rule: Birth Defect Rule (R398-5)

Legislation year enacted: 1999

Case Definition

Outcomes covered: 742.000 - 759.000

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Elective Terminations (All gestational ages)

Age: 2

Residence: Maternal residence in Utah at time of delivery

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based; All medical records are reviewed for all reported potential cases

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Fetal death certificates

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, Champions report live births delivered at their respective hospitals

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Other sources: Physician reports, lay midwives

Data sharing agreements with other states:

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, all fetal deaths certificates, NICU reports, infant deaths are reviewed

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

Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and

procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.),

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

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, SAS, Access, Epi2000, Stata 8

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, Logical checks, Duplicate check in tracking and surveillance module, Case record form checked for completeness, Timeliness through system, Manual review of subset of surveillance module case data compared to case record form.

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention

System Integration

System links: Link to birth records

Funding

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

Other

Web site: www.health.utah.gov/birthdefect

Surveillance reports on file: 1994 NTD Surveillance report, 1994-1996 registry report, Scientific Collaboration Protocol - Data Sharing Agreement

Additional information on file: Newsletters, brochure

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Vermont*Birth Information Network (BIN)*

Purpose: Surveillance, Referral to Services

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, VT Department of Banking, Insurance, Securities & Healthcare Administration; VT Association of Hospitals and Health Systems.

Program status: Program has not started collecting data yet

Start year: 2006

Organizational location: Department of Health (Statistics)

Population covered annually: 6,500

Statewide: Yes

Current legislation or rule: Act 32 (TITLE 18 VSA §5087)

Legislation year enacted: 2003

Case Definition

Outcomes covered: Major birth defects and genetic diseases, very low birthweight (less than 1500 grams)

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Up to one year after delivery

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Case finding/identification sources:

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries

Third party payers: Medicaid databases

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected procedure codes

Coding: ICD-9-CM

Data Collected

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

Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Prenatal diagnostic information, Maternal risk factors

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

Data Collection Methods and Storage

Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access

Data Analysis

Data analysis software: SPSS, Access, Excel

Quality assurance: Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness

Funding

Funding source: CDC grant 100%

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Virginia*Virginia Congenital Anomalies Reporting And Education System (VACARES)*

Purpose: Surveillance

Partner: Universities, Hospitals, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 1987

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

Population covered annually: >100,000

Statewide: Yes

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

Legislation year enacted: 1985, amended 1986, 1988, 2006

Case Definition

Outcomes covered: Major birth defects and genetic diseases

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: below 24 months of age

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

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file

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

Delivery hospitals: Discharge summaries, Medical records abstracts codes from charts

Pediatric & tertiary care hospitals: Discharge summaries, Medical records abstracts codes from charts

Other specialty facilities: Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All neonatal deaths, chart review done by the coders in Health Information Management

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

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

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

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

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

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Needs assessment, Service delivery, Referral, Grant proposals, Prevention projects

System Integration

System links: Link to other state registries/databases

System integration: The current system, Virginia Infant Screening and Infant Tracking System (VISITS), is an integrated database for VaCARES and the Virginia Newborn Hearing Screening Program.

Funding

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

Other

Web site: www.vahealth.org/genetics

Additional information on file: Oracle database

Comments: As of January 2005, hospitals are entering data directly into the Virginia Infant Screening and Infant Tracking Program (VISITS), a web-based tracking and data management system. Additional case ascertainment is currently underway in the three contracted genetic centers.

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Washington*Washington State Birth Defects Surveillance System (BDSS)*

Purpose: Surveillance, Referral to Services

Partner: Universities, Hospitals, Environmental Agencies/Organizations

Program status: Currently collecting data

Start year: 1986- Active and 1991- Passive

Earliest year of available data: 1987

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

Population covered annually: 80,000

Statewide: Yes

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

Legislation year enacted: 2000

Case Definition

Outcomes covered: From 1987 to 1991 (active surveillance), and from 1991 to the 2000 (passive surveillance), the cases reportable to the Birth Defects Registry included those with ICD-9-CM codes 740-759, selected primary cancers, selected metabolic conditions, and FAS/FAE. Since the adoption of the Notifiable Conditions law in 2000, conditions subject to mandatory reporting are neural tube defects, orofacial clefts, limb deficiencies, abdominal wall defects, hypospadias/epispadias and Down Syndrome. FAS/FAE, Cerebral Palsy and Autism are designated as reportable with systems being established to ascertain cases outside the hospital setting.

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: To age 4 years historically, We are transitioning to ascertainment through 1 year of age for structural defects and to age ten for FAS/FAE, Cerebral Palsy and Autism.

Residence: Resident births; Children born, diagnosed or treated in-state

Surveillance Methods

Case ascertainment: Passive case ascertainment

Case finding/identification sources:

Other state based registries: Programs for children with special needs

Delivery hospitals: Disease index or discharge index

Pediatric & tertiary care hospitals: Disease index or discharge index

Other sources: University-based FAS/FAE and Autism specialty centers

Case Ascertainment

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

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.)

Father: Identification info (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.), Case finding Log listing of all data elements required for each case are completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff. Several facilities submit print-outs from data query of internal system of discharge data. Minimal use of diskette or other forms of electronic data transfer. A web-based reporting system is currently in development.

Database storage/management: Web-based SQL server

Data Analysis

Data analysis software: SAS, Access, Stata

Quality assurance: Validity checks, Re-abstraction of cases, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Monitoring outbreaks and cluster investigation, Time trends, Observed vs expected analyses, Service delivery, Education/public awareness, Prevention projects

System Integration

System links: Link case finding data to final birth file, Link to environmental databases, CSHCN program participant file

System integration: Member of the Environmental Health Tracking Grant project.

Funding

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

Other

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

Available by June 2006 Washington State Birth Defects Surveillance System: Status Report 1995 -- 2004

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West Virginia

Congenital Abnormalities Registry, Education And Surveillance System (CARESS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention

Partner: Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 1989

Earliest year of available data: 1989

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

Population covered annually: 21,000

Statewide: Yes

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

Legislation year enacted: 1991

Legislation updated: 2002

Case Definition

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

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (20 weeks gestation and greater)

Age: 0-6 years

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Monthly reports sent from all state birthing facilities

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Elective termination certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry, SIDS

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts

Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics, physicians complete birth defect reporting forms for those diagnosed after delivery

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports, pediatric referrals of children diagnosed after delivery and discharge

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (less than 2500 grams or less than 37 weeks), All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g. seizure), GI condition (e.g. recurrent blockage), GU condition (e.g. recurrent infections),

Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: ICD-9-CM, ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic info

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

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

Database storage/management: Access, Mainframe

Data Analysis

Data analysis software: Access

Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Plans are underway to link several programs housed in the Office of Maternal, Child and Family Health.

Funding

Funding source: Title V Block Grant funds 100%

Other

Web site: www.wvdhhr.org

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Wisconsin*Wisconsin Birth Defects Registry (WBDR)*

Purpose: Surveillance, Research, Referral to Services

Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups

Program status: Currently collecting data

Start year: 2004

Earliest year of available data: 2004

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

Population covered annually: ~70,000

Statewide: Yes

Current legislation or rule: Statute 253.12

Rules: HFS 116--Took effect April 1, 2003

Legislation year enacted: 2000

Case Definition

Outcomes covered: Structural malformations, deformations, disruptions, or dysplasias; genetic, inherited, or biochemical diseases.

Pregnancy outcome: Live Births (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: birth to 2 years

Residence: Statute mandates reporting of birth defects diagnosed or treated in Wisconsin regardless of residence status

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population-based

Case finding/identification sources:

Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Case reports from nursery managers

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

Midwifery facilities: Midwifery facilities

Third party payers: Medicaid databases

Other specialty facilities: Genetic counseling/clinical genetics facilities

Other sources: Physician reports, Hospital discharge data through 2 yrs of age

Case Ascertainment

Coding: ICD-9-CM

Data Collected

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

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

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

Data Collection Methods and Storage

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

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Comparison/verification between multiple data sources

Data use and analysis: Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Capture-recapture analyses, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, NOTE: Items checked above are the ones likely to be used.

System Integration

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

Funding

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

Other

Web site: <https://wbdr.han.wisc.edu>

Surveillance reports on file: Birth and Developmental Outcome Monitoring Program 1990-91, Birth and Developmental Outcome Monitoring Program 1990-94

Comments: The new program requires complete specification through an Advisory Council and Administrative Rule. The Council meets quarterly. Administrative rules took effect April 1, 2003.

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Wyoming

Program status: Interested in developing a surveillance program

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

Purpose: Surveillance, Research

Partner: Universities, Hospitals, CDC

Program status: Currently collecting data

Start year: 1998

Earliest year of available data: 1998

Organizational location: DoD Center for Deployment Health Research, Naval Health Research Center, San Diego, CA

Population covered annually: Approx 95,000 per year

Statewide: No, National/Worldwide; DoD beneficiaries, includes all uniformed services personnel who are eligible for health care benefits

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

Legislation year enacted: 1998

Case Definition

Outcomes covered: Birth defects included in the case definition of the National Birth Defects Prevention Network

Pregnancy outcome: Live Births (All gestational ages and birth weights)

Age: Birth to 1 year

Residence: Worldwide; any birth to a US military beneficiary

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population-based; electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries

Case finding/identification sources:

Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, all inpatient and outpatient encounters are captured in standardized DoD data

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

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

Other sources: Validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from both military and civilian facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from both military and civilian healthcare facilities

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

Coding: ICD-9-CM

Data Collected

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

Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal diagnostic information, Pregnancy/delivery complications

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions

Data Collection Methods and Storage

Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.)

Database storage/management: Access, SAS

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Observed vs expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Prevention projects

System Integration

System links: DoD databases

System integration: DoD databases

Funding

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

Other

Web site:

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

Surveillance reports on file: DoD/Health Affairs policy memorandum; annual reports

Contacts

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