Published 2004 Wiley-Liss, Inc.[†] Birth Defects Research (Part A) 70:609–676 (2004)

STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Updated May 2004

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). 2004. State Birth Defects Surveillance Program Directory. Birth Defects Research Part A . . .

DOI: 10.1002/bdra.20071

Alabama

Alabama Birth Defects Surveillance And Prevention Program (ABDSPP)

Purpose: surveillance, research, prevention
Partner: university, hospital, child program, advocacy
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1998
Organizational location: University
Population covered annually: 8,000/year for 1998-2000 data; 18,000 for 2001 data; 19,231 for 2002 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 data: add Barbour, Butler, Pike, and Russell counties to 2001 counties.
Current legislation or rule: none

Case Definition

Outcomes covered: major birth defects and genetic disorders
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations
Age: up to one year after delivery
Residence: 1998-2000 data: Mobile and Baldwin counties; 2001 data: Autauga, Baldwin, Bullock, Clarke, Coffee, Crenshaw, Dale, Elmore, Escambia, Geneva, Henry, Houston, Lowndes, Macon, Mobile, Monroe, Montgomery, and Washington counties; 2002 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: cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any birth certificate with a birth defect box checked, <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 apgar <7
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 2, 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, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

Data Collection Methods and Storage

Database storage/management: MS Access, Clipper

Data Analysis

Data analysis software: SPSS, MS Access, Hypercube; Excel pivot tables
Quality assurance: re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review, timeliness
Data use and analysis: baseline rates, rates by demographic and other variables, time trends, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

Funding

Funding source: CDC grant 80%, University 20%

Other

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

Contact(s)

Wladimir Wertelecki, MD
Director
Alabama Birth Defects Surveillance and Prevention Program
CCCB room 214, 307 University Boulevard
Mobile, AL 36688
Phone: 251-460-7505; Fax: 251-461-1591
E-mail: bdprevention@usouthal.edu

Peg Hilliard, BSN
Coordinator
Alabama Birth Defects Surveillance and Prevention
Program
CCCB 214, 307 University Boulevard
Mobile, AL 36688
Phone: 251-460-7692; Fax: 251-460-7684
E-mail: philliard@usouthal.edu

Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: surveillance

Partner: Department of Health, hospital, nursing, environment, child program

Program status: Currently collecting data

Start year: 1996

Earliest year of available data: 1996

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 10,000

Statewide: yes

Current legislation or rule: 7 AAC 27.012

Legislation year enacted: 1996

Case Definition

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

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

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

Residence: Alaska residents

Surveillance methods

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

Case finding/identification sources:

Vital records: birth certificates, fetal death certificates

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

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

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

Third party payers: Medicaid databases, Indian health services

Other specialty facilities: genetic counseling/clinical genetic facilities

Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, Any chart with an ICD-9 code of 760.71 or 742.1 and other birth defects as selected for review by the ABDR Program Manager.

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

Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

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

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

System Integration

System links: final birth file

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

Funding

Funding source: CDC grant 100%

Other

Web site: http://www.akepi.org/mchepi/ABDR/default.stm

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

Procedure manual available: yes

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

Contact(s)

Janine Schoellhorn, MS, MPH
MCH Epidemiologist
MCH EpidemiologyUnit ; Section of Epidemiology
3601 C Street, Suite 934
P.O. Box 240249
Anchorage, AK 99524-0249
Phone: 907-269-3442; Fax: 907-269-3493
E-mail: Janine_Schoelllhorn@health.state.ak.us

Sharilyn Mumaw, BBA, BED
ABDR Data Manager
MCH Epidemiology Unit; Section of Epidemiology
3601 C Street, Suite 540
PO Box 240249
Anchorage, AK 99524-0249
Phone 907-269-3443; Fax 907-269-3493
E-mail: Sharilyn_Mumaw@health.state.ak.us

Arizona
Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: surveillance, service, prevention
Partner: Department of Health, university, hospital, nursing, child program, advocacy
Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1986
Organizational location: Department of Health (Epidemiology/Environment), Bureau of Public Health Statistics/Office of Health Registries
Population covered annually: 90,783 in 2003
Statewide: yes
Current legislation or rule: statute: ARS sec. 36-133. *rule:* Title 9, Chapter 4, Articles 1 and 5, Adopted effective 1991.
Legislation year enacted: 1988

Case Definition

Outcomes covered: 44 composite categories covering the major birth defects and genetic diseases, as defined by the BPA/MACDP codes
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater; All gestational ages/birth weights included starting with 2002 data.), elective terminations (20 weeks gestation and greater)
Age: up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review (which occurs 2 -4 years after the child's birth or fetal death), then the more precise diagnosis is used.
Residence: in-state birth to state resident.

Surveillance methods

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

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle

Data Analysis

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

Funding

Funding source: general state funds 25%, MCH funds 3%, genetic screening revenues 22%, CDC grant 50%

Other

Web site: www.hs.state.az.us/phs/phstats/bdr/index.htm
Surveillance reports on file: Annual Reports, 1986 through 1997.
Procedure manual available: yes
Additional information on file: procedures manual, copy of legislation, case record form, case finding log, abstraction forms, quality assurance procedures.
Comments: Contact person 3: Bichtram Nguyen, Epidemiologist, Arizona Department of Health Services, 150 North 18th Avenue, Ste. 550, Phoenix, Arizona, 85007; Phone: 602-364-1302; FAX: 602-542-7447; E-mail: bnguyen@hs.state.az.us.

Contact(s)

Timothy J. Flood, MD
Medical Director, Arizona Department of Health Services
150 North 18th Ave., Ste. 550
Phoenix, AZ 85007
Phone: 602-542-7331; Fax: 602-364-0082
E-mail: tflood@hs.state.az.us

Allison K. Varga, RN
Program Manager, ABDMP
Arizona Department of Health Services
150 North 18th Ave., Ste. 550
Phoenix, AZ 85007
Phone: 602-542-7335; Fax: 602-542-7447
E-mail: avarga@hs.state.az.us

Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

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

Case Definition

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

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any birth certificate with a birth defect box checked, all stillborn infants, all elective abortions
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA, Modified CDC and NBDPS coding system

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

System Integration

System links: final birth file
System integration: no

Funding

Funding source: general state funds 100%

Other

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

Contact(s)

Bridget S. Mosley, MPH
Epidemiologist
Arkansas Center for Birth Defects Research and Prevention
11219 Financial Center Parkway,
Financial Park Place, Suite 250
Little Rock, AR 72211
Phone: 501-364-8951; Fax: 501-364-5107
E-mail: MosleyBridgetS@uams.edu

Charlotte A. Hobbs, MD, PhD
Associate Professor of Pediatrics
Section Chief, Birth Defects Research
UAMS College of Medicine
Arkansas Center for Birth Defects Research & Prevention
11219 Financial Centre Parkway, Suite 250
Little Rock, AR 72211
Phone: 501-364-5000; Fax: 501-364-5107
E-mail: hobbscharlotte@uams.edu

California

California Birth Defects Monitoring Program (CBDMP)

Purpose: surveillance, research
Partner: Department of Health, university
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: Occupational and Environmental Disease Control, March of Dimes under contract with 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 genetic facilities, maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases, Apgar 0-0
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: FoxPro

Data Analysis

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

System Integration

System links: final birth file

Funding

Funding source: general state funds 34%, MCH funds 20%, CDC grant 20%, other federal funding 16%, DHS/UC Pass through 10%

Other

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

Contact(s)

Mary Jo Campodonica
Data Director
California Birth Defects Monitoring Program
1917 Fifth Street
Berkeley, CA 94710-1916
Phone: 209-384-8388; Fax: 510-549-4175
E-mail: mca@cbdmp.org

Gary M. Shaw, DrPH, MPH
Research Director/Senior Epidemiologist
California Birth Defects Monitoring Program
1917 Fifth Street
Berkeley, CA 94710-1916
Phone: 510-549-4155; Fax: 510-549-4175
E-mail: gsh@cbdmp.org

Colorado

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

Purpose: surveillance, service, prevention
Partner: Department of Health, university, environment, child program, advocacy
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 68,420 (2002)
Statewide: yes
Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101 – 25-1.5-105
Legislation year enacted: 1985

Case Definition

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

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: prenatal to age 3: 18 selected conditions for CUSUM statistical trends monitoring, selected death and fetal deaths, and fetal alcohol syndrome; plus all active case ascertainment data sources (postmortem pathology and specialty clinics.
Coding: ICD-9-CM, Extended code utilized to describe syndromes and further specify condition

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

System Integration

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

Funding

Funding source: general state funds 15%, MCH funds 15%, CDC grant 60%, other federal funding 10%

Other

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

Contact(s)

Margaret Schonbeck, BS, MSPH(c)
Program Manager
CRCSN
4300 Cherry Creek Drive
Denver, CO 80246-1530
Phone: 303-692-2636; Fax: 303-782-0904
E-mail: margaret.schonbeck@state.co.us

Lisa Ann Miller, MD, MSPH
Medical Director
Colorado Responds to Children with Special Needs
4300 Cherry Creek Dr
Denver, CO 80246-1530
Phone: 303-692-2663; Fax: 303-782-0904
E-mail: lisa.miller@state.co.us

Connecticut

Connecticut Birth Defects Registry (CTBDR)

Purpose: surveillance, service, prevention, Reporting for MCH Block Grant
Partner: hospital, child program, advocacy
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: to be determined
Organizational location: Department of Public Health (Maternal and Child Health)
Population covered annually: 45,000
Statewide: yes
Current legislation or rule: Sec. 19a-56a. (Formerly Sec. 10a-132b). Birth defects surveillance program.; Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children.
Legislation year enacted: Sec. 10a-132b: 1991; Sec. 19-21a: 1949 Sec. 19-21: 1949.

Case Definition

Outcomes covered: All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71
Pregnancy outcome: live births (all gestational ages and birth weights, PDA GE to 2500 gms birth weight)
Age: up to one year after delivery for birth defects
Residence: in and out of state births to state residents

Surveillance methods

Case ascertainment: Passive, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, inpatient hospitalizations, ambulatory surgery and emergency room visits
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease 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: Yes
Other sources: physician reports, mandatory reporting by health care providers and facilities; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle

Data Analysis

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

System Integration

System links: final birth file

Funding

Funding source: MCH funds 100%

Other

Web site: none
Surveillance reports on file: none
Procedure manual available: yes
Additional information on file: none

Contact(s)

Martha Okafor
Division Director
Family Health Division
410 Capitol Ave. MS #11FHD
Hartford, CT 06134
Phone: 860-509-8066; Fax: 860-509-7720
E-mail: martha.okafor@po.state.ct.us

Chunfu Liu, MSc, MPH
Epidemiologist III
Connecticut Department of Public Health, Family Health Division
410 Capitol Avenue, MS #11MAT
Hartford, CT 06134
Phone: 860-509-7765; Fax: 860-509-7720
E-mail: chun-fu.liu@po.state.ct.us

Delaware

Delaware Birth Defects Surveillance Project

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

Case Definition

Outcomes covered: Birth Defects Registry - All birth defects for passive surveillance, selected birth defects for active surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (greater than 20 weeks)
Age: Birth to 5 years
Residence: In-state and out-of-state birth to state resident, and in-state birth to state non-resident.

Surveillance methods

Case ascertainment: Active and passive surveillance, population-based, Hospital discharge records/data
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 biochemical screening program, cancer registry, AIDS/HIV registry
Delivery hospitals: disease index or discharge index
Pediatric & tertiary care hospitals: disease index or discharge index

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: electronic birth certificate

Data Analysis

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

System Integration

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

Other

Web site: None at present time

Contact(s)

JoAnn Baker, MSN, FNP
Director, Family Planning Program
DE Division of Public Health
P. O. Box 637
Dover, DE 19903
Phone: (302) 744-4554; Fax: (302) 739-6653
E-mail: JoAnnM.Baker@state.de.us

Betsy Voss
Coordinator, Birth Defects and Newborn Screening
DE Division of Public Health
P.O. Box 637
Dover, DE 19903
Phone: (302) 744-4909; Fax: (302) 739-6653
E-mail: Betsy.Voss@state.de.us

District of Columbia

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

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, child program, advocacy
Program status: Currently collecting data
Start year: 603
Earliest year of available data: 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, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (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 genetic facilities, maternal serum screening facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all 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 a chart review beyond the newborn period: facial dysmorphism or abnormal facies, developmental delay, all infant deaths (excluding prematurity), auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

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

System Integration

System links: state registry, final birth file

Funding

Funding source: MCH funds 15%, CDC grant 80%

Contact(s)

Deneen Long-White
Chief, Data Collection and Analysis Division
DC Department of Health, Maternal and Family Health Administration
825 N. Capitol Street, NE, Room 3181
Washington, DC 20002
Phone: (202) 442-9343; Fax: (202) 442-4828
E-mail: dlong-white@dchealth.com

Joyce Brooks, MSW, LICSW
Chief, Children With Special Health Care Needs Division
DC Department of Health, Maternal and Family Health Administration
825 North Capitol Street, NE Room 3106
Washington, DC 20002
Phone: (202)727-7540; Fax: (202)727-7789
E-mail: jbrooks@dchealth.com

Florida
Florida Birth Defects Registry (FBDR)

Purpose: surveillance, research, service, prevention, Educate health care professionals
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator, federal and state agencies
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment), Florida Department of Health, Bureau of Community Environmental Health, University
Population covered annually: 205,580 in 2002
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: Population-based, passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: 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 or charts, pediatric logs
Third party payers: Medicaid databases, health maintenance organizations (HMOs)
Other sources: physician reports

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

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

Data Collection Methods and Storage
Database storage/management: MS Access, Excel

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

System Integration
System links: state registry

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

Other
Web site: http://flbdr.hsc.usf.edu
Surveillance reports on file: 1996 Annual Report, Neural Tube Defects Report, Data Quality Assurance Report, Active Surveillance Report, Website
Procedure manual available: yes
Additional information on file: Grants, progress reports, educational and health promotion materials, and video tapes

Contact(s)
Jane A. Correia, BS
Environmental Specialist III
Florida Department of Health
4052 Bald Cypress Way, Bin A08
Tallahassee, FL 32399-1712
Phone: 850-245-4444, ext. 2198; Fax: 850-922-8473
E-mail: Jane_Correia@doh.state.fl.us

Eric Grimm, MPA
Burea Chief
Florida Department of Health
4052 Bald Cypress Way, Bin A08
Tallahassee, FL 32399-1712
Phone: 850-245-4115; Fax: 850-922-8473
E-mail: Eric_Grimm@doh.state.fl.us

Geogia

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

Purpose: surveillance, research, service
Partner: university, hospital
Program status: Currently collecting data
Start year: 1967
Earliest year of available data: 1968
Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities
Population covered annually: 50746
Statewide: No: Births to mothers residing within one of five counties in the metropolitan Atlanta area of the state of Georgia
Current legislation or rule: State Laws Official Georgia Code Annotated (OCGA) 31-12-2

Case Definition

Outcomes covered: Major structural or genetic birth defects
Pregnancy outcome: live births (>=20 weeks), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (less than 20 week gestation, 20 weeks gestation and greater)
Age: Before 6 years of age
Residence: Births to mothers residing in one of five metropolitan Atlanta counties

Surveillance methods

Case ascertainment: Active case ascertainment; population-based; Combination of active and passive case ascertainment for cases ascertained only at perinatal offices.
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, postmortem/ pathology logs, Induction logs and miscarriage logs
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, birth weight < 2500 grams or <36 weeks gestation, all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (ie seizure), GI condition (ie intestinal blockage), cardiovascular condition, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Epi-Info, Mainframe

Data Analysis

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

System Integration

System links: state registry, final birth file

Funding

Funding source: other federal funding 100%

Other

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

Contact(s)

Leslie A. O'Leary, PhD
Managing Director, MACDP
Centers for Disease Control and Prevention
1600 Clifton Rd., MS E-86
Atlanta, GA 30333
Phone: 404-498-3808; Fax: 404-498-3040
E-mail: LOLeary@cdc.gov

Janet D. Cragan, MD
Medical Director, MACDP
Centers for Disease Control and Prevention
1600 Clifton Rd., MS E-86
Atlanta, GA 30333
Phone: 404-498-3807; Fax: 404-498-3040
E-mail: JCragan@cdc.gov

Georgia

Georgia Birth Defects Reporting And Information System (GBDRIS)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, advocacy
Program status: Currently collecting data
Start year: 2003
Earliest year of available data: 2003
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 133,000
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
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), elective terminations
Age: Up to 6 years of age
Residence: In and out of state births to state residents

Surveillance methods

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

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

System Integration

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

Funding

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

Other

Web site: http://health.state.ga.us/epi/mch/publications.shtml
Procedure manual available: yes

Contact(s)

Debra L. Hersh, MPH
GBDRIS Coordinator
GA Division of Public Health, MCH Epidemiology Section
2 Peachtree St., NW Suite 14-404
Atlanta, GA 30303
Phone: 404-651-5131; Fax: 404-657-7517
E-mail: dlhersh@dhr.state.ga.us

Hema Joshi, M Med Sci
Assistant Coordinator
GA Division of Publit Health, MCH Epidemiology Section
2 Peachtree St, NW Suite 14-405
Atlanta, GA 30303
Phone: 404-463-0906; Fax: 404-657-7517
E-mail: hjoshi@dhr.state.ga.us

Hawaii
Hawaii Birth Defects Program (HBDP)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, nursing, environment, child program, advocacy, legislator
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: DOH/Children With Special Health Needs Branch, Research Corporation of the University of Hawaii
Population covered annually: ~19,906 average over 16 years
Statewide: yes
Current legislation or rule: 8/15/1988 to 6/30/2002 - Hawaii Revised Statutes (HRS), Sections 321-31 and 338-2 in conjunction per Executive Chamber ruling by Governor on 6/16/1989. HRS Sections 324-1 and 324-2 for additional legislative authority (1990 Amendments). 7/1/02 to Present - Act 252 (2002) - Relating to Birth Defects (SB 2763, SD 2, HD 2, CD 1)
Legislation year enacted: 1989, 1990 and 2002

<u>Case Definition</u>

Outcomes covered: All ~1,154+ recommended by CDC in their May 1987 Birth Defects Branch Six Digit Code for Reportable Congenital Anomalies, based on B.P.A. Classification of Diseases (1979) and WHO 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 (Data collected on all elective medical terminations that were carried out because a screening test or diagnositc procedure documented that the fetus was severely impaired with a birth defect and the parents elected not to bring the baby to term.)
Age: Up to one year after delivery
Residence: All in-state Hawaii births (resident and non-resident)

<u>Surveillance methods</u>

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

<u>Case Ascertainment</u>

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, all stillborn infants, all neonatal deaths, all prenatal diagnosed or suspected cases. Medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect and parents elected not to bring baby to term or mother spontaneously aborted.
Conditions warranting a chart review beyond the newborn period: all infant deaths (excluding prematurity), childhood deaths between 1 and 6, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

<u>Data Collected</u>

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

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

Database storage/management: MS Access

<u>Data Analysis</u>

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

<u>System Integration</u>

System links: Although not initiated yet, the HBDP is in the planing stages of embarking on a GIS statistical mapping project.

Funding

Funding source: general state funds 63%, CDC grant 28%, other federal funding 5%, private foundations 4%

Other

Web site: http://members.aol.com/entropynot/hbdp.html
Surveillance reports on file: Eleven (11) 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, and 11) 1986-2002
Procedure manual available: yes
Additional information on file: HBDP informational brochure; copies of legislation; original and revised abstraction forms; abstraction manual; annual reports; HBDP data; quality assurance reports (completeness, accuracy, timeliness); special study reports (6).

Contact(s)

Ruth D. Merz, MS, Administrator
Hawaii Birth Defects Program
76 North King Street, #208
Honolulu, HI 96817-5157
Phone: 808-587-4120; Fax: 808-587-4130
E-mail: hbdp@crch.hawaii.edu

Idaho

Program status: No surveillance program

Contact(s)

Russell A. Duke
Chief, Bureau of Clincal and Preventive Services
Idaho Dept of Health and Welfare
450 W. State Street
Boise, ID 83720
Phone: 208-334-0670; Fax: 208-332-7307
E-mail: duke@idhw.state.id.us

Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: surveillance, service, prevention
Partner: Department of Health, university, hospital, environment, advocacy, legislator
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 184,000
Statewide: yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)
Legislation year enacted: 1985

Case Definition

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

Surveillance methods

Case ascertainment: Population based, passive ascertainment of newborn cases. Active ascertainment of major birth defects diagnosed up to 2 years of age began 7/01.
Case finding/identification sources:
Vital records: birth certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, Hospitals are mandated to identiy newborn cases and report to IDPH.
Pediatric & tertiary care hospitals: disease index or discharge index, Hospitals are mandated to report newborns discharged from any to the NICU or speciality 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 ie abnormal facies, congenital heart disease, <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.)
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Database storage/management: MS Access, FoxPro, Mainframe

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: 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, rates by demographic and other variables, time trends, epidemiologic studies (using only program data), needs assessment, service delivery, referral, grant proposals, education/public awareness

System Integration

System integration: No

Funding

Funding source: general state funds 69%, CDC grant 31%

Other

Web site: idph.state.il.us/about/epi/aporsrpt.htm
Surveillance reports on file: See Web Site
Comments: APORS is transition to more active case ascertainment and expand case age to 2 years.

Contact(s)

Trish Egler, MPA
Manager
Illinois Department of Public Health
605 W. Jefferston Street
Springfield, IL 62761
Phone: 217-785-7133; Fax: 217-557-5152
E-mail: tegler@idph.state.il.us

Tiefu Shen, MD, MPH, PhD
Division Chief
Illinois Department of Public Health
605 W. Jefferson Street
Springfield, IL 62761
Phone: 217-785-7118; Fax: 217-524-1770
E-mail: tshen@idph.state.il.us

Indiana

Indiana Birth Defects and Problems Registry (IBDPR)

Purpose: surveillance, research, service
Partner: university, hospital, child programs, advocacy groups, legislators
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 2005 (for births occurring in 2003)
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 85,000
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 deaths, metabolic and hearing disorders from Newborn Screening, selected neoplasms, congenital blood disorders, certain eye disorders, Fetal Alcohol Spectrum Disorder (760.71), and Pervasive Developmental Disorder (299.0)
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations
Age: Less than 3 years of age; age up to 5 years for Fetal Alcohol Spectrum Disorder and Pervasive Developmental Disorder
Residence: In and out of state births to state residents

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: charts of 45 targeted medical conditions.
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Oracle

Data Analysis

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

System Integration

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

Funding

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

Other

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

Contact(s)

Nancy B. Meade, RD, MPH
Program Manager, Genomics in Public Health/
Newborn Screening
Indiana State Department of Health
2 North Meridian Street
Indianapolis, IN 46204
Phone: 317-233-7827; Fax: 317-233-1300
E-mail: Nmeade@isdh.state.in.us

Iowa
Iowa Birth Defects Registry (IBDR)

Purpose: surveillance, research, service, prevention, Prevention Education Programs
Partner: Department of Health, university, hospital, environment, legislator
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: University
Population covered annually: 37,831 avg 10 yr
Statewide: yes
Current legislation or rule: Administrative Code of Iowa, Volume I, Chapter 135.37, Section 40, Division III
Legislation year enacted: 1986; Revised 2001, 2003

Case Definition

Outcomes covered: Major Birth Defects and Metabolic Disorders
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations
Age: 1 year
Residence: Maternal residence in Iowa at time of delivery

Surveillance methods

Case ascertainment: Population-based (state-wide), active case ascertainment
Case finding/identification sources:
Vital records: birth 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, pediatric logs, postmortem/pathology logs, surgery logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, specialty outpatient clinics
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports, Outpatient Surgery Facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants, all neonatal deaths, all elective abortions, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle, Mainframe

Data Analysis

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

System Integration

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

Funding

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

Other

Web site: http://www.public-health.uiowa.edu/birthdefects
Surveillance reports on file: Iowa Birth Defects Registry Annual Report 2000, 2002
Procedure manual available: yes

Contact(s)

Paul A. Romitti, PhD
Director
Iowa Birth Defects Registry
University of Iowa, C21-E GH, 200 Hawkins Dr
Iowa City, IA 52242
Phone: 319-384-5012; Fax: 319-353-8711
E-mail: paul-romitti@uiowa.edu

Bradley D. McDowell, PhD
Deputy Director
Iowa Birth Defects Registry
W117 Oakdale Hall
Iowa City, IA 52242
Phone: 319-335-4107; Fax: 319-335-4030
E-mail: bradley-mcdowell@uiowa.edu

Kansas
Birth Defects Reporting System

Purpose: Registry
Partner: hospital
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 39,338 (Year 2002)
Statewide: yes
Current legislation or rule: KSA 65-102
Legislation year enacted: 1979

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

Surveillance methods
Case ascertainment: Passive, population-based., passive, hospital
Case finding/identification sources:
Vital records: birth certificates
Pediatric & tertiary care hospitals: Congenital Malformations reporting form - sent by hospitals for infants up to one year of age.

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

Data Collection Methods and Storage
Database storage/management: Mainframe

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

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

Funding
Funding source: MCH funds 100%

Contact(s)
Jane H. Stueve, RN, BSN
Birth Defects Registry Coordinator
Kansas Department of Health & Environment
1000 SW Jackson, Suite 220
Topeka, KS 66612-1274
Phone: 785-291-3363; Fax: 785-291-3493
E-mail: jstueve@kdhe.state.ks.us

Carloyn S. Nelson, BSE
Director, Children's Develomental Services
Kansas Dept of Health and Environment
1000 SW Jackson Suite 220
Topeka, KS 66612-1274
Phone: 785-296-6136; Fax: 785-296-8626
E-mail: cnelson@kdhe.state.ks.us

Kentucky
Kentucky Birth Surveillance Registry (KBSR)

Purpose: surveillance, service, prevention of birth defects
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator
Program status: Currently collecting data
Start year: 1996
Earliest year of available data: 1998
Organizational location: Department for Public Health, Division of Adult and Child Health Improvement, Maternal and Child Health 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 eight hospitals in Kentucky which represent 36% of births.
Age: up to fifth birthday
Residence: All in-state births; out of state births to state residents

Surveillance methods

Case ascertainment: Combination of active and passive, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, Medical laboratory reporting is mandated, voluntary outpatient reporting
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, specialty outpatient clinics, Laboratory records
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, Laboratory records
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities
Other sources: physician reports, Local health departments

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, CNS condition (ie seizure), cardiovascular condition, any infant with a codable defect
Coding: ICD-9-CM, ICD-10 for Vital Statistics death data

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Mainframe

Data Analysis

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

System Integration

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

Funding

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

Other

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

Contact(s)

Joyce M. Robl, MS, CGC
KBSR Program Administrator
Kentucky Department for Public Health
275 East Main Street, HS 2GW-A
Frankfort, KY 40621
Phone: 502-564-2154 x3768; Fax: 502-564-8389
E-mail: joyce.robl@ky.gov

Sandy G Fawbush, RN
Nurse Consultant/Inspector
Kentucky Department for Public Health
275 East Main Street, HS 2GW-A
Frankfort, KY 40621
Phone: 502-564-2154 x3761; Fax: 502-564-8389
E-mail: sandy.fawbush@ky.gov

Louisiana

Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: surveillance, service
Partner: university, hospital, child program, advocacy
Program status: Program has not started collecting data yet
Start year: 2004
Earliest year of available data: 2005
Organizational location: Children's Special Health Services
Population covered annually: 65,000 +
Statewide: yes
Current legislation or rule: R.S. 40:31.41 - 40:31.48, Act No. 194
Legislation year enacted: 2001

Case Definition
Outcomes covered: major structural, functional, or genetic birth defect
Age: up to third birthday
Residence: in- and out-of-state births to state residents (tentative criteria)

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

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

Data Collection Methods and Storage
Database storage/management: MS Access, in progress

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

System Integration
System links: in progress

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

Contact(s)
Linda B. Pippins, MCD
Administrator, Children's Special Health Services
DHH/Office of Public Health
325 Loyola Ave., Ste. 607
New Orleans, LA 70112
Phone: 504-568-5055; Fax: 504-568-7529
E-mail: lpippins@dhh.la.gov

Maine

Maine Birth Defects Program (MBDP)

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

Case Definition

Outcomes covered: Selected major birth defects: NTD, Clefts, Gastroschisis and Omphalocele, 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
Age: Through age one
Residence: All in-state births to Maine residents

Surveillance methods

Case ascertainment: Combination of active and passive case ascertainment, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts, pediatric logs, specialty outpatient clinics
Other specialty facilities: genetic counseling/clinical genetic facilities, maternal serum screening facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, 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, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), illnesses/conditions, family history

Data Collection Methods and Storage

Database storage/management: MS Access, Citrix

Data Analysis

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

System Integration

System links: state registry, final birth file

Funding

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

Other

Web site: pending
Additional information on file: Program manual in draft form.

Contact(s)

Ellie Mulcahy, RNC
Director, Genetics Program
Maine Bureau of Health
11 State House Station, 286 Water St.-7th floor
Augusta, ME 04333
Phone: 207-287-4623; Fax: 207-287-4743
E-mail: eleanor.a.mulcahy@maine.gov

Patricia Y. Day, RN
Program Coordinator, MBDP
Maine Bureau of Health
11 State House Station, 286 Water St. 7th floor
Augusta, ME 04333
Phone: 207-287-8424; Fax: 207-287-4743
E-mail: patricia.y.day@maine.gov

Maryland

Maryland Birth Defects Reporting And Information System (BDRIS)

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

Case Definition

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

Surveillance methods

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

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

System links: In the process of linkage with other state registries/databases
System integration: No

Funding

Funding source: general state funds 100%

Other

Web site: http://fha.state.md.us/genetics (then select Birth Defects Reporting and Information System)
Surveillance reports on file: Provisional surveillance reports 1984-1992; 1995-2000, 2001
Procedure manual available: yes
Additional information on file: Copies of publications, legislation, miscellaneous booklets and other information related to birth defects surveillance in Maryland.

Contact(s)

Susan R. Panny, MD
Director, Office for Genetics and CSHCN
Maryland Dept. of Health & Mental Hygiene
201 W. Preston Street, Room 421A
Baltimore, MD 21201
Phone: 410-767-6730; Fax: 410-333-5047
E-mail: PannyS@dhmh.state.md.us

Rosemary A. Baumgardner, BA
Data Manager, Birth Defects Program
Maryland Dept. of Health & Mental Hygiene
201 W. Preston Street, Room 423A
Baltimore, MD 21201
Phone: 410-767-6801; Fax: 410-333-5047
E-mail: BaumgardnerR@dhmh.state.md.us

Massachusetts

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

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

Case Definition

Outcomes covered: Major structural birth defects and chromosomal anomalies of medical, surgical or cosmetic significance.
Pregnancy outcome: live births, reportable fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater 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
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions i.e. abnormal facies, congenital heart disease, all stillborn infants
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Microsoft Access

Data Analysis

Data analysis software: SAS, Microsfot Access, Microsoft Excel
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, grant proposals, Selected cases from surveillance are eligible for CDC's National Birth Defects Prevention Study

System Integration

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

Funding

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

Other

Web site: website in development
Surveillance reports on file: First surveillance report published in November 2001; available online at http://www.state.ma.us/dph/bhsre/birthdefects/bdefects.htm or by calling contacts; MCBDRP Prevention and Resource Booklet at http://www.state.ma.us/dph/bhsre/birthdefects/bdefects.htm
Procedure manual available: yes
Comments: Statewide coverage started October 1998

Contact(s)

Linda Casey, MS, MPH
Administration Director of Research and Operation
Massachusetts Department of Public Health
5th Floor, 250 Washington Street
Boston, MA 02108-4619
Phone: 617-624-5507; Fax: 617-624-5574
E-mail: linda.casey@state.ma.us

Cathy Higgins, BA
Surveillance Coordinator
Massachusetts Department of Public Health
5th Floor, 250 Washington Street
Boston, MA 02108-4619
Phone: 617-624-5510; Fax: 617-624-5574
E-mail: cathleen.higgins@state.ma.us

Michigan
Michigan Birth Defects Registry (MBDR)

Purpose: surveillance, research, service, prevention, incidence and mortality statistics
Partner: Department of Health, university, hospital, environment, legislator
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics)
Population covered annually: 135,400
Statewide: yes
Current legislation or rule: Public Act 236 of 1988
Legislation year enacted: 1988

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

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

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

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

Data Collection Methods and Storage
Database storage/management: FoxPro

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

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

Funding
Funding source: general state funds 50%, CDC grant 25%, other federal funding 12%, EHDI 12.5%

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

Contact(s)
Glenn Copeland, MBA
Director
Michigan Birth Defects Registry
3423 N. Logan
Lansing, MI 48909
Phone: 517-335-8677; Fax: 517-335-9513
E-mail: CopelandG@state.mi.us

Lorrie Simmons, RHIT
Field Representative
Michigan Dept. of Community Health
3423 N. Logan St.
Lansing, MI 48909
Phone: 517-335-9197; Fax: 517-335-8711
E-mail: Simmonsl@state.mi.us

Minnesota

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, early childhood prevention programs, advocacy, legislator
Program status: Currently collecting data
Start year: 2005
Earliest year of available data: 2005
Organizational location: Department of Health, Environmental Health
Population covered annually: 68,000
Statewide: yes
Current legislation or rule: MS 144.2215
Legislation year enacted: 2004

Case Definition

Outcomes covered: major "reported birth defects" as defined by CDC and ICD-9 codes.
Pregnancy outcome: live births, fetal deaths—stillbirths, spontaneous abortions, etc.
Age: up to 1 year after delivery
Residence: only will abstract in-state data

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, infant death records
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (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, HMOs

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), any birth certificate with a birth defect box checked
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
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Analysis

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

System Integration

System links: final birth file

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
Surveillance reports on file: data summaries and services/prevention updates are availabe on website
Comments: System will use an opt-out format that will be monitored regularly to ensure that data trends remain valid.

Contact(s)

Myron Falken, PhD, MPH
Principal Epidemiologist
Minnesota Department of Health
121 East 7th Place, Suite 220
St. Paul, MN 55164
Phone: 651-215-0877; Fax: 651-215-0975
E-mail: myron.falken@health.state.mn.us

Daniel Symonik, PhD
Unti Supervisor
Minnesota Department of Health
121 East 7th Place, Suite 220
St. Paul, MN 55164
Phone: 651-215-0776; Fax: 651-215-0975
E-mail: daniel.symonik@health.state.mn.us

Mississippi
Mississippi Birth Defects Registry (MBDR)

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

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

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

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

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

Data Collection Methods and Storage
Database storage/management: MS Access

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

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

Contact(s)
Jerry McClure, BS
Director, Genetics Program
Mississippi State Dept. of Health
P.O. Box 1700
Jackson, MS 39215-1700
Phone: 601-576-7619; Fax: 601-576-7498
E-mail: jmcclure@msdh.state.ms.us

Pat Terry, LSW
Branch Director
Mississippi State Dept. of Health
P.O. Box 1700
Jackson, MS 39215-1700
Phone: 601-576-7619; Fax: 601-576-7498
E-mail: pterry@msdh.state.ms.us

Missouri
Missouri Birth Defects Registry

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

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

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

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

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

Data Collection Methods and Storage
Database storage/management: SAS (Unix)

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

System Integration
System links: final birth file

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

Other
Surveillance reports on file: Missouri Birth Defects 1995-99

Contact(s)
Janice M Bakewell, BA
Research Analyst
Missouri Dept of Health, Health Data Analysis
PO Box 570, 920 Wildwood
Jefferson City, MO 65102
Phone: 573-751-6278; Fax: 573-526-4102
E-mail: bakewj@dhss.state.mo.us

Montana
Montana Birth Outcomes Monitoring System (MBOMS)

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

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

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

<u>Case Ascertainment</u>
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 a chart review beyond the newborn period: cardiovascular condition
Coding: ICD-9-CM

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

<u>Data Collection Methods and Storage</u>
Database storage/management: Oracle

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

<u>System Integration</u>
System links: state registry
System integration: Integrated with Children with Special Health Care Needs database

<u>Funding</u>
Funding source: CDC grant 100%

<u>Contact(s)</u>
Sib Clack
Supervisor
FCHB/ DPHHS
P.O. Box 202951
Helena, MT 59620-2951
Phone: 406-444-4119; Fax: 406-444-2606
E-mail: sclack@state.mt.us

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

Case Definition

Outcomes covered: All birth defects, exclusions according to CDC exclusion list
Pregnancy outcome: live births (greater than 20 weeks and greater than 500 grams), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Birth to 1 year
Residence: In-state and out-of-state birth to state resident

Surveillance methods

Case ascertainment: Combination of active and passive case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, Nebraska Birth Defects Prevention Program Congenital Defects Case Record
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics, Nebraska Birth Defects Prevention Program Congenital Defects Case Record
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Key-entry 3

Data Analysis

Data analysis software: SAS
Quality assurance: re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, case finding, data coding and entry
Data use and analysis: baseline rates, monitoring outbreaks and cluster investigations, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, grant proposals, incidence rates, trend analysis, birth defect registry

Funding

Funding source: MCH funds 100%

Other

Surveillance reports on file: 2002 report in Vital Statistics Report. 2003 report will be available in published form in August of 2004.
Procedure manual available: Yes
Additional information on file: Copy of legislation, congenital defects case record form
Comments: State legislation introduced to allow release of patient-identifying information to approved researcher for the purpose of research; development of a system so that hospitals may use the electronic birth certificate to initially alert the surveillance program of the birth of a child with an anomaly.

Contact(s)

Carla M. Becker, RHIA
Health Data Manager
Nebraska Health and Human Services System
301 Centennial Mall South P.O. Box 95007
Lincoln, NE 68509-5007
Phone: 402-471-3575; Fax: 402-471-9728
E-mail: carla.becker@hhss.state.ne.us

Nevada
Nevada Birth Defects Registry

Purpose: surveillance, service, prevention
Partner: university
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Division of Health, Bureau of Family Health Services (MCH)
Population covered annually: 33,000
Statewide: No: Year 2000 data is for Las Vegas only. Year 2001 - Statewide data complete.
Current legislation or rule: NRS 442.300 - 442.330 - Birth Defects Registry Legislation *** Regulation = NAC 442
Legislation year enacted: 1999

Case Definition
Outcomes covered: major birth defects and genetic diseases
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths (20 weeks gestation and greater), elective terminations (20 weeks gestation and greater)
Age: Cover from 0-7 years of age
Residence: In-state births

Surveillance methods
Case ascertainment: Combination of active and passive ascertainment initially. Currently - system is a "passive" system., active ascertainment to re-commence 7/1/04
Case finding/identification sources:
Vital records: birth certificates, matched birth/death file, Hospital medical records - for year 2000
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry
Delivery hospitals: disease index or discharge index
Pediatric & tertiary care hospitals: disease index or discharge index
Third party payers: Medicaid databases
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, any infant with a codable defect
Coding: ICD-9-CM

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

Data Collection Methods and Storage
Database storage/management: MS Access, Oracle, Mainframe

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

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

Funding
Funding source: service fees 100%

Contact(s)
Judith Wright
Bureau Chief
Bureau of Family Health Services - State Health Division
3427 Goni Road, Suite 108
Carson City, NV 89706
Phone: (775) 684-4285; Fax: (775) 684-4245
E-mail: jwright@nvhd.state.nv.us

Gloria M. Deyhle, RN, BA
Health Program Sepcialist
Nevada State Health Division
3427 Goni Road, Suite 108
Carson City, NV 89706
Phone: (775) 684-4243; Fax: (775) 684-4245
E-mail: gdeyhle@nvhd.state.nv.us

New Hampshire

New Hampshire Birth Conditions Program (NHBCP)

Purpose: surveillance, research, service, prevention
Partner: university, hospital, child program, advocacy, legislator
Program status: Currently collecting data
Start year: 2003
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health), Bureau of Vital Records: Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, University
Population covered annually: 13,560
Statewide: No: Currently collecting data at Dartmouth Hitchcock Medical Center, New Hampshire's primary tertiary center for obstetrical and neonatal care. Work is underway to begin data collection in all birth hospitals.
Current legislation or rule: Currently working toward a legislative rules revision that would include birth defects.

Case Definition

Outcomes covered: Major birth defects and genetic diseases
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations
Age: Fetuses >20 weeks gestation and newborns/infants up to 1 year of age.
Residence: All New Hampshire residents, those born in-state as well as out of state.

Surveillance methods

Case ascertainment: active case ascertainment and population- based
Case finding/identification sources:
Delivery hospitals: discharge summaries, Medical records abstraction of charts of selected ICD 9 Codes
Pediatric & tertiary care hospitals: discharge summaries, ICU/NICU logs or charts, specialty outpatient clinics, cytogenetics laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, all stillborn infants, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, cardiovascular condition, 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 defect diagnostic information
Mother: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.), gravidity/parity, prenatal diagnostic information

Data Collection Methods and Storage

Database storage/management: Oracle, The AURIS web-based reporting system, currently utilized by NH newborn hearing screening program, is being expanded to meet the birth defects tracking requirements.

Data Analysis

Data analysis software: SPSS, SAS, MS Access, STATA
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, comparison/verification between multiple data sources, clinical review
Data use and analysis: Data collection began at one hospital in 2003 and so no data use or analysis occurred in the past 12 months.

System Integration

System links: Not at this time
System integration: Not at this time

Funding

Funding source: CDC grant 100%

Other

Web site: Not as of 1/2004
Surveillance reports on file: Not at this time

Contact(s)

John B. Moeschler, MD
Project Director
Division of Genetics and Child Development,
Dept. of Pediatrics
Dartmouth Hitchcock Medical Center
1 Medical Center Drive
Lebanon, NH 03756
Phone: 603-653-6053; Fax: 603-650-8268
E-mail: john.moeschler@hitchcock.org

Victoria A. Flanagan, BSN, MS
Regional Program for Women's and Children's Health,
Dartmouth Hitchcock Medical Center
1 Medical Center Drive
Lebanon, NH 03756
Phone: 603-650-6137; Fax: 603-650-3434
E-mail: victoria.a.flanagan@hitchcock.org

New Jersey
Special Child Health Services Registry (SCHS REGISTRY)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, environment, child program, advocacy, legislator
Program status: Currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health & Senior Services - Special Child, Adult, and Early Intervention Services
Population covered annually: 114,500
Statewide: yes
Current legislation or rule: NJSA 26:8 et seq., NJAC 8:20 - Enacted 08-04-1983, with effective date of 03-04-1985. Changes to legislation 1990, 1991, 1992. Readopted 05/2000.
Legislation year enacted: 1983

Case Definition

Outcomes covered: All birth defects, including structural, genetic, and biochemical are required to be reported. While not mandated, all special needs and any condition which places a child at risk, eg. prematurity, asthma, cancer, developmental delay, are also reported.
Pregnancy outcome: live births (all gestational ages & birth weights)
Age: mandated reporting of birth defects diagnosed <= age 1, voluntary reporting of birth defects diagnosed > age 1 and all children diagnosed with Special Needs conditions who are <= 21 yrs. of age
Residence: in/out NJ births to NJ res; Because of link with SCHS Case Management system, also enroll anyone becoming NJ res.

Surveillance methods

Case ascertainment: Passive, population-based reporting system with annual quality assurance visits by BDR staff to birthing hospitals, birthing centers and, pediatric care facilities. Medical chart review is conducted on all children registered with any of the defects eligible for participation in the NBDPS.
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, AIDS/HIV registry
Delivery hospitals: disease index or discharge index, discharge summaries, obstetrics logs (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 m period
Midwifery facilities: Yes
Other specialty facilities: cytogenetic laboratories, genetic counseling/clinical genetic facilities
Other sources: M.D. 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 a chart review beyond the newborn period: GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), ocular conditions, any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: SAS

Data Analysis

Data analysis software: SAS, MS Access
Quality assurance: validity checks, double-checking of assigned codes, comparison/verification between multiple data sources, data/hospital audits, clinical review, timeliness, merge registry with birth certificate registry and the death certificate registry
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time-space cluster analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects

System Integration

System links: state registry, final birth file
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).
Procedure manual available: yes
Additional information on file: Information sheet, case record form, copy of legislation, quality assurance audit information

Contact(s)

Leslie M. Beres, MS Hyg
Program Manager
New Jersey Department of Health and Senior Services
PO Box 364
Trenton, NJ 08625-0364
Phone: 609-292-5676; Fax: 609-633-7820
E-mail: Leslie.Beres-Sochka@doh.state.nj.us

Mary M. Knapp, MSN
New Jersey Coordinator
New Jersey Department of Health and Senior Services
PO 364
Trenton, NJ 08625-0364
Phone: 609-292-5676; Fax: 609-633-7820
E-mail: mary.knapp@doh.state.nj.us

New Mexico

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

Purpose: surveillance, research, service, prevention
Partner: university, hospital, child program, legislature
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 27,000
Statewide: yes
Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regulations.
Legislation year enacted: January 1, 2000

Case Definition

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

Surveillance methods

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

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

System Integration

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

Funding

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

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

Contact(s)

Susan Nalder, EdD, MPH, CNM
MCH Epi Program Manager
NM Dept. of Health
2040 S. Pacheco
Santa Fe, NM 87505
Phone: 505-476-8889; Fax: 505-476-8898
E-mail: susann@doh.state.nm.us

Tierney Murphy, MD, MPH
CSTE-MCH Fellow, Mar2004-06
NM Dept of Health
2040 South Pacheco
Santa Fe, NM 87505
Phone: 505-476-8918; Fax: 505-476-8898
E-mail: tierneymurphy@doh.state.nm.us

New York
New York State Congenital Malformations Registry (CMR)

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

Case Definition
Outcomes covered: Major malformations, detailed list available upon request.
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: 2 years
Residence: In-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
Case finding/identification sources:
Delivery hospitals: disease index or discharge index, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: disease index or discharge index, ICU/NICU logs or charts
Other sources: physician reports, hospital discharge data

Case Ascertainment
Conditions warranting chart review in newborn period: charts with selected ICD-9CM codes in the 740-759
Coding: CDC coding system based on BPA, ICD-9-CM

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

Data Collection Methods and Storage
Database storage/management: MS Access, FoxPro, Sybase

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

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

Funding
Funding source: general state funds 12%, MCH funds 27%, CDC grant 37%, other federal funding 24%

Other
Web site: http://www.health.state.ny.us/nysdoh/cmr/cmrhome.htm
Surveillance reports on file: Reports for 1983-1997.
Procedure manual available: yes

Contact(s)
Philip K. Cross, BS
Director, Congenital Malformations Registry
New York Department of Health
Flanigan Square, Room 200; 547 River Street
Troy, NY 12180
Phone: 518-402-7990; Fax: 518-402-7959
E-mail: pkc02@health.state.ny.us

Charlotte Druschel, MD, MPH
Medical Director, Center for Environmental Health
New York Department of Health
Flanigan Square, Room 200; 547 River Street
Troy, NY 12180
Phone: 518-402-7990; Fax: 518-402-7959
E-mail: cmd05@health.state.ny.us

North Carolina

North Carolina Birth Defects Monitoring Program (NCBDMP)

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

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

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

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

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

Data Collection Methods and Storage
Database storage/management: MS Access, Mainframe

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

System Integration
System links: state registry, 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

Contact(s)
Robert E. Meyer, PhD
NCBDMP Director
North Carolina Center for Health Statistics
1908 Mail Service Center
Raleigh, NC 27699-1908
Phone: 919.715.4476; Fax: 919.733.8485
E-mail: robert.meyer@ncmail.net

Jennifer Williams
Field Supervisor
North Carolina Center for Health Statistics
1908 Mail Service Center
Raleigh, NC 27699-1908
Phone: 919.733-4728; Fax: 919.733.8485
E-mail: jennifer.williams@ncmail.net

North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

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

Case Definition

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

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked
Coding: ICD-9-CM, ICD 10

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

Funding

Funding source: SSDI Grant

Other

Web site: www.health.state.nd.us/ndhd/admin/vital/
Procedure manual available: yes

Contact(s)

Terry Bohn
SSDI Coordinator
Childern's Special Health Services Division ND
Department of Human Services
600 East Boulevard Avenue, Dept. 301
Bismarck, ND 58505-0200
Phone: 701-328-4963; Fax: 701-328-1412
E-mail: tbohn@state.nd.us

Ohio

Ohio Connections For Children With Special Needs (OCCSN)

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, hospital, child program, advocacy, legislator
Program status: Program has not started collecting data 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: System in development
Current legislation or rule: Ohio House Bill 534 signed into law in July, 2000. "The Director of Health shall establish and, if funds for this purpose are available, implement a statewide birth defects information system for the collection of information concerning congenital anomal
Legislation year enacted: 2000

Case Definition
Outcomes covered: System in development

Surveillance methods
Case ascertainment: System in development

Funding
Funding source: CDC grant 100%

Contact(s)
David P. Schor, MD, MPH, FAAP
Chief, Division of Family and Community Health Services
Ohio Department of Health
246 N. High Street
Columbus, OH 43216-0118
Phone: 614-466-1663; Fax: 614-728-9163
E-mail: dschor@odh.ohio.gov

Anna E. Starr, BS
Genetics Section Administrator
Ohio Dept. of Health
246 N. High Street
Columbus, OH 43215
Phone: 614-995-5333; Fax: 614-564-2424
E-mail: Astarr@odh.ohio.gov

Oklahoma

Oklahoma Birth Defects Registry (OBDR)

Purpose: surveillance, prevention
Partner: hospital, 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
Pregnancy outcome: live births (>= 20 weeks gestation), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), elective terminations (20 weeks gestation and greater)
Age: 2 years
Residence: In-state births to state residents

Surveillance methods

Case ascertainment: population based, active case ascertainment
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates
Delivery hospitals: disease index or discharge index, obstetrics logs (i.e., labor & delivery), regular nursery logs, ICU/NICU logs or charts, pediatric logs, surgery logs, specialty outpatient clinics
Pediatric & tertiary care hospitals: disease index or discharge index, pediatric logs, surgery logs, specialty outpatient clinics
Third party payers: Indian health services, Military hospitals delivering babies
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with a CDC/BPA code
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

Data analysis software: SAS, MS Access, ArcView GIS
Quality assurance: validity checks, re-abstraction of cases, double-checking of assigned codes, timeliness, Editing of all completed abstracts
Data use and analysis: routine statistical monitoring, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time-space cluster analyses, needs assessment, referral, grant proposals, education/public awareness, prevention projects, Program quality assurance

System Integration

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

Funding

Funding source: general state funds 10%, MCH funds 50%, CDC grant 40%

Other

Surveillance reports on file: 1992 & 1993 Annual Report - combined for Oklahoma, Tulsa and Cleveland Counties
1994-1998 Annual Report
Procedure manual available: yes
Additional information on file: PRAMS Gram Vol 8 No 3: Folic Acid Knowledge and Multivitamin Use Among Oklahoma Women; provisional rate tables for 1994-1997.
Comments: Statewide data collection began in 1994. Additional information for case definitions residence: 1995 began abstraction of Oklahoma residents born in Fort Smith, Arkansas.

Contact(s)

Kay A. Pearson, MS
Oklahoma Birth Defects Registry Coordinator
Oklahoma State Department of Health; Screening, Special Services & SoonerStart
1000 NE 10th Street, Room 710
Oklahoma City, OK 73117-1299
Phone: 405-271-9444 Ex 56744; Fax: 405-271-4892
E-mail: kayp@health.state.ok.us

Oregon

Program status: No surveillance program

<u>Contact(s)</u>

Kenneth D. Rosenberg, MD, MPH
MCH Epidemiologist
Oregon Health Department
800 NE Oregon Street #21, Suite 850
Portland, OR 97232
Phone: 503-731-4507; Fax: 503-731-4083
E-mail: ken.d.rosenberg@state.or.us

Pennsylvania

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

Purpose: surveillance, service
Partner: university, hospital, nursing, advocacy
Program status: Program has not started collecting data yet
Start year: 2003
Earliest year of available data: 2003, statewide matched data file being collected
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 142,380 resident live births in 2002.
Statewide: yes
Current legislation or rule: Not applicable

Case Definition

Outcomes covered: 740-759.9 and 760.71 ICD-9
Pregnancy outcome: live births (all gestational ages and birth weights)
Age: birth to 24 months of age
Residence: in-state births to state residents

Surveillance methods

Case ascertainment: population-based, passive
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, Hospital discharge data collected by the Pennsylvania Health Care Cost Containment Council—(PHC4—a state agency).
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, Those checked above will eventually be linked.
Delivery hospitals: discharge summaries, PHC4 data is based on hospital discharge summaries
Pediatric & tertiary care hospitals: discharge summaries, PHC4 data is based on hospital discharge summaries
Other specialty facilities: genetic counseling/clinical genetic facilities

Case Ascertainment

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

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, Mainframe

Data Analysis

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

Funding

Funding source: MCH funds 100%

Other

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

Contact(s)

Steven B. Horner, MS
Public Health Program Administrator
Pennsylvania Department of Health
P.O. Box 90, 7th floor East Wing, Health & Welfare Bldg.
Harrisburg, PA 17108
Phone: 717-783-8143; Fax: 717-772-0323
E-mail: shorner@state.pa.us

Robert F. Staver, MPA
Program Manager
PA Department of Health
P.O. Box 90, 7th floor East Wing, Health & Welfare Bldg.
Harrisburg, PA 17108
Phone: (717) 783-8143; Fax: (717) 705-9286
E-mail: rstaver@state.pa.us

Puerto Rico

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

Purpose: surveillance, research, service, prevention
Partner: Department of Health, university, nursing, child program, advocacy
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Division of Children with Special Health Care Needs
Population covered annually: 56,000
Statewide: yes
Current legislation or rule: No

Case Definition

Outcomes covered: Neural Tube Defects (Anencephaly, Encephalocele, Myelomeningocele and Meningocele), Cleft Lip and/or Cleft Palate, Gastroschisis, Club Foot, Limb reduction defects, Down Syndrome, Omphalocele, Ambiguous Genitalia, Trisomy 13, Trisomy 18, Conjoints 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
Age: up to 6 years after delivery
Residence: In state birth to state residents

Surveillance methods

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

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all elective abortions, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: failure to thrive, cardiovascular condition, any infant with a codable defect
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access

Data Analysis

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

Funding

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

Other

Web site: http://www.salud.gov.pr/AF/AFindex.htm
Surveillance reports on file: Description of Registry Development, Case Report Form, manual for case report form,
Procedure manual available: yes

Contact(s)

Elia M. Correa, RN, MPH
Coordinator
Puerto Rico Folic Acid Campaign
Birth Defects Surveillance System
PR Department of Health
PO Box 70184
San Juan, PR 00936
Phone: 787-751-3654; Fax: 787-764-4259
E-mail: ecorrea@salud.gov.pr

Diana Valencia, MS, GC
Genetic Counselor
Puerto Rico Folic Acid Campaign
Birth Defects Surveillance System
PR Department of Health
PO Box 70184
San Juan, PR 00936
Phone: 787-274-5671; Fax: 787-764-4259
E-mail: dvalencia@salud.gov.pr

Rhode Island

Rhode Island Birth Defects Surveillance Program

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

Case Definition

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

Surveillance methods

Case ascertainment: 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 biochemical screening program, RI has an integrated database called KIDS NET, which links data from 9 programs including: Universal Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting and Vital Records
Delivery hospitals: discharge summaries, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: specialty outpatient clinics
Other specialty facilities: genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: 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, pregnancy/delivery complications, family history
Father: identification information (name, address, date-of-birth, etc.), demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Database storage/management: MS Access, Oracle

Data Analysis

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

System Integration

System links: state registry, KIDSNET (Universal Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting; 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

Contact(s)

Samara Viner-Brown, MS
Chief of Data & Evaluation
Rhode Island Department of Health
3 Capitol Hill, Room 302
Providence, RI 02908-5097
Phone: 401-222-5935; Fax: 401-222-1442
E-mail: samv@doh.state.ri.us

Michele Quaedvlieg, AS
Data Manager
Rhode Island Department of Health
3 Capitol Hill, Room 302
Providence, RI 02908-5097
Phone: 401-222-4631; Fax: 401-222-1442
E-mail: MicheleQ@doh.state.ri.us

South Carolina

South Carolina Birth Defects Surveillance And Prevention Program

Purpose: surveillance, research, service
Partner: Department of Health, university, hospital
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1993
Organizational location: Greenwood Genetic Center
Population covered annually: 55,873
Statewide: yes

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

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

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

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

Data Collection Methods and Storage
Database storage/management: MS Access

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

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

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

Contact(s)
Roger E. Stevenson, MD
Director: SC BD Surveillance & Prevention Program
Greenwood Genetic Center
1 Gregor Mendel Circle
Greenwood, SC 29646
Phone: 864-941-8146 Fax: 864-388-1707
E-mail: res@ggc.org

Jane H. Dean, RN
Program Coordinator
Greenwood Genetic Center
1 Gregor Mendel Circle
Greenwood, SC 29646
Phone: (864) 941-8138 Fax: (864) 388-1707
E-mail: jane@ggc.org

South Dakota

Program status: No surveillance program

Contact(s)

Quinn Stein, MS, CGC
Genetic Counselor
Sioux Valley Children's Specialty Clinic
1305 W 18th St.
Sioux Falls, SD 57117
Phone: 605-333-4298; Fax: 605-333-1585
E-mail: qstein@usd.edu

Tennessee

Tennessee Birth Defects Registry (TBDR)

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

Case Definition

Outcomes covered: Major Birth Defects
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (a fetal death 500 grams or more, or in the absence of weight, of 22 completed weeks of gestation or more)
Residence: in and out state births to state resident

Surveillance methods

Case ascertainment: hospital records matched to vital records, 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
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, 760.71
Coding: ICD-9-CM

Data Collected

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

Data Collection Methods and Storage

Database storage/management: MS Access, SQL Server

Data Analysis

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

Funding

Funding source: general state funds 94%, private foundations 6%

Contact(s)

David J. Law, PhD
Director, Tennessee Birth Defects Registry
TN Dept. of Health - PPA
425 Fifth Avenue North, 4th Flr.
Nashville, TN 37247
Phone: 615-253-4702; Fax: 615-253-1688
E-mail: david.law@state.tn.us

Texas

Texas Birth Defects Monitoring Division (TBDMD)

Purpose: surveillance, research, service, prevention
Partner: university, hospital, advocacy
Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 365,000
Statewide: yes
Current legislation or rule: Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87.
Legislation year enacted: 1993

Case Definition

Outcomes covered: All major structural birth defects and fetal alcohol syndrome
Pregnancy outcome: live births (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), elective terminations
Age: Up to one year after delivery - FAS up to 6 years
Residence: In-state births to state residents.

Surveillance methods

Case ascertainment: Active, 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 laboratories, specialty outpatient clinics, Genetics logs, stillbirth logs, radiology logs
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, pediatric logs, postmortem/pathology logs, surgery logs, laboratory logs, cardiac catheterization laboratories, specialty outpatient clinics, genetics logs, radiology logs
Midwifery facilities: Yes
Other sources: licensed birthing centers

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a selected list of ICD9-CM codes outside 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, <34 weeks GA, all stillborn infants
Conditions warranting a chart review beyond the newborn period: CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), cardiovascular condition, any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

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

Data Collection Methods and Storage

Database storage/management: SQL Server

Data Analysis

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

System Integration

System links: Link registry to vital records for demographic data

Funding

Funding source: general state funds 51%, MCH funds 33%, Preventive Health block grant 16%, Note: does not include CDC-funded Texas Birth Defects Research Center funds

Other

Web site: http://www.tdh.state.tx.us/tbdmd/index.htm
Surveillance reports on file: Report of Birth Defects Among 1995 Deliveries. 1996 Birth Defects in the Lower Rio Grande Valley. Report of Birth Defects Among 1996 and 1997 Deliveries. Report of Birth Defects Among 1998 and 1999 Deliveries, Among 1999 and 2000 Deliveries.
Procedure manual available: yes
Additional information on file: copy of legislation; Texas Birth Defects Monitoring Division fact sheet; Texas Center for Birth Defects Research and Prevention fact sheet; Fetal Alcohol Syndrome brochure (English and Spanish); Pregnancy Outcome Patterns for Various Defects; Impact of Including Induced Pregnancy Terminations Before 20 Weeks Gestation on Birth Defect Rates; Birth Defects Glossary; Recent Trends in Neural Tube Defects in Texas.
Comments: Statewide as of 1999 deliveries. Until 2000, the Texas Department of Health also had the Texas Neural Tube Defect Surveillance and Intervention Project along the Texas border with Mexico, which conducted active

surveillance and research on neural tube defects for 14 counties.

Contact(s)

Mark A. Canfield, PhD
Director
Texas Birth Defects Monitoring Division
1100 West 49th Street
Austin, TX 78756-3180
Phone: 512-458-7232; Fax: 512-458-7330
E-mail: mark.canfield@tdh.state.tx.us

Peter Langlois, PhD
Senior Epidemiologist
Texas Birth Defects Monitoring Division
1100 West 49th Street
Austin, TX 78756-3180
Phone: 512-458-7232; Fax: 512-458-7330
E-mail: peter.langlois@tdh.state.tx.us

Utah
Utah Birth Defect Network (UBDN)

Purpose: surveillance, research, service, prevention
Partner: university, hospital, advocacy
Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1994
Organizational location: Department of Health, University
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), pregnancy terminations (occuring at any gestational week)
Age: 2
Residence: Maternal residence in Utah at time of delivery

Surveillance methods
Case ascertainment: Population-based combination of active/passive – all medical records are reviewed for all reported poential 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), newborn nursery logs, ICU/NICU logs or charts, postmortem/pathology logs, specialty outpatient clinics, Champions report live births delivered at their respective hospitals
Pediatric & tertiary care hospitals: disease index or discharge index, discharge summaries, ICU/NICU logs or charts, postmortem/pathology logs, surgery logs, specialty outpatient clinics
Other specialty facilities: prenatal diagnostic facilities (ultrasound, etc.), cytogenetic laboratories, genetic counseling/clinical genetic facilities, physician reports, lay midwives

Case Ascertainment
Conditions warranting chart review in newborn period: any fetus or infant with a ICD9-CM code 740-759 suggesting an eligible birth defect, any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, all stillborn infants with suggested minor or major malformations), all neonatal deaths, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases, all fetal deaths certificates, NICU reports, infant deaths are reviewed
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect as listed above.
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
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.), illnesses/conditions, family history

Data Collection Methods and Storage
Database storage/management: Microsoft Access 2000

Data Analysis
Data analysis software: Epi2000, SAS, Microsoft Access, Statview
Quality assurance: logiscal checks, duplicate check in tracking and surveillance module, case record form checked for completeness, comparison/verification between multiple data sources, clinical review, 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, and Utah Center for Birth Defects Research and Prevention

Funding
Funding source: MCH funds 50%, CDC grant 50%

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

Contact(s)
Marcia Lynn Feldkamp, PA, MSPH
Director
Utah Birth Defects Network
44 North Medical Dr/POBox 144697
Salt Lake City, UT 84114-4697
Phone: 801-257-0566 ext 203; Fax: 801-257-0572
E-mail: mfeldkamp@utah.gov

Lynne Margaret MacLeod, M.Stat
Surveillance Project Coordinator
Utah Birth Defects Network
44 N Medical Drive/POBox 144697
Salt Lake City, UT 84114-4697
Phone: 801-257-0566 ext 202; Fax: 801-257-0572
E-mail: lmacleod@utah.gov

Vermont
Birth Information Network

Purpose: surveillance, service, prevention
Partner: Department of Health, university, hospital, advocacy
Program status: Program has not started collecting data yet
Organizational location: Department of Health (Statistics)
Population covered annually: 6500
Statewide: yes
Current legislation or rule: Act 32
Legislation year enacted: 2003

Case Definition
Outcomes covered: major birth defects and genetic diseases, very low birthweight (less than 1500 grams)
Age: up to one year after delivery
Residence: in and out of state births to state residents

Contact(s)
Peggy Brozicevic
Research & Statistics Chief
Vermont Department of Health
P.O. Box 70; 108 Cherry Street
Burlington, VT 05402
Phone: 802-863-7298; Fax: 802-865-7701
E-mail: pbrozic@vdh.state.vt.us

John Burley
Public Health Analyst III
Vermont Department of Health
P.O. Box 70; 108 Cherry Street
Burlington, VT 05402
Phone: 802-863-7611; Fax: 802-865-7701
E-mail: jburley@vdh.state.vt.us

Virginia

Virginia Congenital Anomalies Reporting And Education System (VACARES)

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

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

Surveillance methods
Case ascertainment: Passive, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file
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

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

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

Data Collection Methods and Storage
Database storage/management: Oracle

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

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

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

Other
Web site: www.vahealth.org/genetics
Surveillance reports on file: A 10-Year report (1989-1998) was published in 2002.
Procedure manual available: yes
Additional information on file: Oracle database
Comments: As of March 2004, most hospitals are entering data directly into database from the hospital contacts via Virginia Infant Screening and Infant Tracking Program (VISITS), a web-based tracking and data management system.

Contact(s)
Sharon K. Williams, MS, RN
Virginia Genetics Program Manager
Virginia Department of Health
109 Governor Street, 8th Floor
Richmond, VA 23219
Phone: 804-864-7712; Fax: 804-864-7721
E-mail: Sharonk.Williams@vdh.virginia.gov

Nancy C. Ford, MPH,RN
Director, Pediatric Screening and Genetic Services
Virginia Department of Health
109 Governor Street, 8th Floor
Richmond, VA 23219
Phone: 804-864-7691; Fax: 804-864-7721
E-mail: nancy.ford@vdh.virginia.gov

Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: surveillance, service
Partner: university, hospital
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 provisionally 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 eight for FAS/FAE, Cerebral Palsy and Autism.
Residence: resident births; children born or diagnosed in-state

Surveillance methods

Case ascertainment: passive
Case finding/identification sources:
Vital records: birth certificates, death certificates, fetal death certificates, elective termination certificates
Delivery hospitals: disease index or discharge index
Pediatric & tertiary care hospitals: disease index or discharge index
Other sources: Currently developing data sharing with University-based FAS/FAE clinic.

Case Ascertainment

Coding: ICD-9-CM, FAS/FAE coding scheme will be utilized in data collection and case description for FAS/FAE cases.

Data Collected

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

Data Collection Methods and Storage

Database storage/management: Web-based SQL server

Data Analysis

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

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 2004 Washington State Birth Defects
Surveillance System: Status Report 1995 — 2002
Procedure manual available: yes

Contact(s)

Riley Peters, PhD
Manager, MCH Assessment
Washington Dept. of Health; Maternal and Child Health
P.O. Box 47835
Olympia, WA 98504-7835
Phone: 360-236-3553; Fax: 360-236-2323
E-mail: riley.peters@doh.wa.gov

West Virginia

West Virginia Congenital Abnormalities Registry, Education And Surveillance System (WVCARESS)

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

Case Definition

Outcomes covered: Congenital anomalies of ICD-9 codes 740-759, 760, 764, 765, 766
Pregnancy outcome: (all gestational ages and birth weights), fetal deaths—stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), (all gestational ages and birth weights), elective terminations (20 weeks gestation and greater)
Age: 0-6
Residence: In and out of state births to state residents

Surveillance methods

Case ascertainment: active, population-based
Case finding/identification sources:
Vital records: birth certificates, death certificates, matched birth/death file, fetal death certificates, elective termination certificates
Other state based registries: programs for children with special needs, newborn hearing screening program, newborn biochemical screening program, cancer registry, AIDS/HIV registry, SIDS
Delivery hospitals: Hospital personnel complete Birth Defect Reporting forms, reports also sent from Genetics Program.
Pediatric & tertiary care hospitals: Hospital personnel complete Birth Defect Reporting forms, reports also sent from Genetics Program.
Other specialty facilities: genetic counseling/clinical genetic facilities
Other sources: physician reports, Pediatric referrals of children diagnosed after delivery and discharge

Case Ascertainment

Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with selected procedure codes, any chart with selected defects or medical conditions ie abnormal facies, congenital heart disease, any birth certificate with a birth defect box checked, less than 2500 grams or less than 37 weeks, all stillborn infants, all neonatal deaths, all elective abortions, all infants with low APGAR scores, all infants in NICU or special care nursery, all prenatal diagnosed or suspected cases
Conditions warranting a chart review beyond the newborn period: facial dysmorphism or abnormal facies, failure to thrive, developmental delay, CNS condition (ie seizure), GI condition (ie intestinal blockage), GU condition (ie recurrent infections), cardiovascular condition, all infant deaths (excluding prematurity), childhood deaths between 1 and 6, ocular conditions, auditory/hearing conditions, any infant with a codable defect
Coding: ICD-9-CM, ICD-10-CM

Data Collected

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

Data Collection Methods and Storage

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

Data Analysis

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

System Integration

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

Funding

Funding source: CDC grant 100%

Other

Web site: www.wvdhhr.org
Comments: Contact person 3: Jackie Newson, BA; Program Coordinator; 350 Capitol Street, Room 427; Charleston, WV 25301; Phone: 304-58-7258; Fax: 304-558-3510; E-mail: jackienewson@wvdhhr.org

Contact(s)

Kathryn G. Cummons, MSW
Director, Research, Evaluation
OMCFH
350 Capitol St.
Charleston, WV 25301
Phone: 304-558-7171; Fax: 304-558-3510
E-mail: kathycummons@wvdhhr.org

Melissa A. Baker, MA
Epidemiologist
OMCFH
350 Capitol St.
Charleston, WV 25301
Phone: 304-558-7247; Fax: 304-558-3510
E-mail: melissabaker@wvdhhr.org

Wisconsin
Wisconsin Birth Defects Registry (WBDR)

Purpose: surveillance, research, service
Partner: Department of Health, university, hospital, child program, advocacy
Program status: Currently collecting data
Start year: 2004
Earliest year of available data: 2004
Organizational location: Department of Health and Family Services (CSHCN)
Population covered annually: ~67,000
Statewide: yes
Current legislation or rule: Statute 253.12
HFS 116—Took effect April 1, 2003
Legislation year enacted: 2000

Case Definition

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

Surveillance methods

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

Database storage/management: Oracle

Data Analysis

Data analysis software: SAS
Quality assurance: validity checks, comparison/verification between multiple data sources
Data use and analysis: baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigations, time trends, capture-recapture analyses, observed vs expected analyses, epidemiologic studies (using only program data), identification of potential cases for other epidemiologic studies, needs assessment, service delivery, referral, grant proposals, education/public awareness, prevention projects, 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 35%, MCH funds 23%, CDC grant 42%

Other

Web site: http://www.dhfs.state.wi.us/dph_bfch/cshcn
https://www.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.

Contact(s)

Elizabeth Oftedahl
CSHCN Epidemiologist
Division of Public Health, Department of Health and Family Services
1 West Wilson, PO Box 2659
Madison, WI 53701
Phone: 608-261-9304; Fax: 608-267-3824
E-mail: OftedEJ@dhfs.state.wi.us

Peggy Helm-Quest, MSEd, MHA, CHES
CSHCN Supervisor
Division of Public Health, Department of Health and Family Services
1 West Wilson, PO Box 2659
Madison, WI 53701
Phone: 608-267-2945; Fax: 608-267-3824
E-mail: helmqp@dhfs.state.wi.us

Wyoming

Program status: Interested in developing a surveillance program

Contact(s)

Dorothy Ailes, RN-C, MSN, PNP
Program Manager, Children Special Health
WY Department of Health, Community and Family Health Div.
4020 House Avenue
Cheyenne, WY 82002
Phone: 307-777-5413; Fax: 307-777-7215
E-mail: dailes@state.wy.us

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

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

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

Surveillance methods
Case ascertainment: Electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries, combination, population-based
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 is performed by active case ascertainment and chart review of a random sample of births from both military and civilain facilities.

Case Ascertainment
Conditions warranting chart review in newborn period: any chart with a ICD9-CM code 740-759, any chart with a CDC/BPA code, Validation of standardized electronic data is performed by active case ascertainment and chart review of a random sample of births from both military and civilain facilities.
Conditions warranting a chart review beyond the newborn period: any infant with a codable defect
Coding: ICD-9-CM

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

Data Collection Methods and Storage
Database storage/management: MS Access, SAS

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

System Integration
System links: DoD databases
System integration: DoD databases

Funding
Funding source: other federal funding 100%

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

Contact(s)
Margaret Ryan, MD, MPH
Director, DoD Birth and Infant Health Registry
DoD Center for Deployment Health Research, Code 25,
Naval Health Research Center
P.O. Box 85122
San Diego, CA 92186-5122
Phone: 619-553-8097; Fax: 619-553-7601
E-mail: ryan@nhrc.navy.mil

Rosha Aran, BS
Coordinator
DoD Birth and Infant Health Registry
NHRC, PO Box 85122
San Diego, CA 92186-5122
Phone: 619-553-9255; Fax: 619-553-7601
E-mail: aran@nhrc.navy.mil