

STATE BIRTH DEFECTS SURVEILLANCE PROGRAMS DIRECTORY

Updated May 1999

Prepared by: States Services Branch, Division of Birth Defects and Pediatric Genetics, Centers for Disease Control and Prevention

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

Alabama

South Alabama Birth Defects Registry

Status: Operational

Start date: January 1995

Organizational location: Department of Medical Genetics and Children's and Women's Hospital, University of South Alabama

Population coverage: Mobile and Baldwin Counties – 8,000 births annually

Legislation: None

Case definition

Outcomes covered: All major structural birth defects

Birth status: Live births, stillbirths, pregnancy terminations

Age: Birth to 1 year of age

Gestation: No minimum

Weight: No minimum

Residence: No limit

Surveillance methods

Case ascertainment: Active case ascertainment, population based

Data sources: Prenatal diagnostic center records, labor and delivery records, newborn records, neonatal intensive care database, hospital discharge data, postmortem records, genetic clinic and laboratory records, birth certificates, monthly vital record reports.

Coding: Modified BPA

Data collected: Facilities, transfers, personal identifiers, demographics, family history, prenatal history, risk factors, exposures, and therapeutic/diagnostic procedures, delivery data, infant assessment including measurements, diagnostic procedures, and autopsy results.

Quality assurance: Data audit

Data analysis: Descriptive at this time

Data use: Needs ascertainment, service delivery plans and organization of out-reach programs

Monitoring: Yes

Funding source: Children's and Women's Hospital, Children Rehabilitation Services, Alabama Department of Public Health, Alabama Alliance for the Prevention of Birth Defects.

Staff: Data Collection (2 FTE)

Surveillance reports on file: Last report 12/97

Procedure manual: Modified California and CDC methods

Additional information on file: Description of South Alabama Birth Defects Registry available.

Comments: For other information, please contact the Department of Medical Genetics

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Updated: 5/99

Alaska

Alaska Birth Defects Registry

Status: Legislation in place

Start date: Summer, 1996

Organizational location: Section of Maternal, Child and Family Health

Population coverage: Statewide, 11,000 births annually

Legislation: AAC 27.012 Legislation mandates reporting of birth defects covered by ICD-9 codes 740-759 and other ICD-9 codes, including that referring to fetal alcohol syndrome (FAS) (760.71), by hospitals, physicians, and other health care practitioners.

Case definition

Outcomes covered: ICD-9 codes 237.7, 243, 255.2, 277, 279, 282, 284.0, 331, 334, 335, 343, 359, 362.74, 740-759, 760.71

Birth status: Live births

Age: Birth to age one; Birth through the fifth year of life (to sixth birthday).

Gestation:

Weight:

Residence: State resident at time of diagnosis

Surveillance methods

Case ascertainment: Passive, population based; active for Fetal Alcohol Syndrome

Data sources: Birth and death certificates, physician reports, genetic service clinics, hospital reports, special child health registries, Alaska Native Health Corporations, Infant Learning Programs (early intervention services), Children with Special Health Care Needs, Cleft Lip and Palate registry, Maternal Infant Mortality Review and Medicaid.

Coding: ICD-9

Data collected: From reporting sources: name, date of birth, place of birth, sex, race, community of residence, date of diagnosis, and specific type of each birth defect diagnosed or treated. For enhanced surveillance, autopsy data, medical record data, and vital statistics data.

Quality assurance:

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, capture-recapture analysis, analysis by race, since Alaska has several Alaska Native racial groups.

Data use: Establish baseline rates, needs assessment, service planning and delivery, family support, grant proposals, education

Monitoring:

Funding source: Title V Block Grant, CDC Cooperative

Agreement Grant.

Staff: Program director (1 FTE), registry coordinator (1 FTE), statistician (.10 FTE), systems analyst (.10 FTE), epidemiologist (.10 FTE), clerical assistant (.10 FTE).

Surveillance reports on file: Yes

Procedure manual: in development

Additional information on file: Nothing

Comments: Nothing

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Updated: 4/99

Arizona

Arizona Birth Defects Monitoring Program

Status: Operational

Start date: 1-1-87

Organizational location: Office of Chronic Disease Epidemiology

Population coverage: Statewide, 75,000 births annually

Legislation: ARS 36-133, enacted 6-14-88. Permissive reporting of children up to one year with a diagnosed birth defect. Hospitals, genetic testing centers, and ADHS Children's Rehabilitative Services are covered.

Case definition

Outcomes covered: Major birth defects, genetic diseases, fetal mortality (with birth defects only)

Birth status: Live births, stillbirths

Age: Birth to 1 year

Gestation: >20 weeks

Weight: Any weight (>20 weeks)

Residence: In-state birth to state resident

Surveillance methods

Case ascertainment: Active surveillance; population based

Data sources: Hospital records and logs, hospital discharge index, birth certificates, fetal and infant death certificates, genetic service clinics and laboratories, spontaneous abortion certificates, specialty clinics, special child health registries

Coding: CDC code (6-digit BPA/ICD-9-CM code)

Data collected: Personal, physician, and hospital IDs; demographic data, birth measurements, prenatal exams, malformations, syndromes, family history, cytogenetics, autopsy results, risk factors

Quality assurance: Case finding, case abstraction, data coding and entry

Data analysis: Incidence rates, trend analysis, data analysis for special epidemiology studies

Data use: Epidemiology, monitoring, baseline rates, case identification, registry, grant proposals

Monitoring: Yes

Funding source: State appropriation (100%)

Staff: 1 Program director, 4 abstractors, 1 epidemiologist; 1 secretary

Surveillance reports on file: 1986 through 1991 reports.

Procedure manual: Yes

Additional information on file: Procedures manual, copy of legislation, case record form, case finding log, quality assurance procedures

Comments: System started because of environmental concerns about clusters.

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Updated: 5/99

Arkansas

Arkansas Reproductive Health Monitoring System

Status: Operational

Start date: Late 1979, Legislation was passed in 1985 authorizing ARHMS to be administered by Arkansas Children's Hospital

Organizational location: Private nonprofit pediatric hospital

Population coverage: 36,000 births annually statewide (covers all in-state births and approximately 50% of out-of-state births occurring to Arkansas residents)

Legislation: ASA 82-4608 et seq., passed in 1985.

Contact:

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Case definition

Outcomes covered: All birth defects

Birth status: Live births, stillbirths, elective terminations

Age: Diagnosed by 2 years of age, charts reviewed to age 5

Gestation: Any age

Weight: Any weight

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

Updated: 4/99

Surveillance methods

Case ascertainment: Active surveillance of hospitals and specialty clinics; population based.

Data sources: Hospital medical records and logs, hospital discharge index, genetic service clinics, specialty clinics.

Coding: CDC code (6-digit BPA/ICD-9-CM code)

Data collected: Physician, hospital; demographic data, growth parameters, data on previous pregnancies; malformations, co-occurring diagnoses, syndromes, cytogenetics, autopsy results

Quality assurance: Case finding, case abstraction, data coding and entry, data analysis

Data analysis: Incidence rates, observed vs. expected rates, data analysis for special epidemiology studies

Data use: Epidemiology, baseline rates, needs assessment, service planning, case identification, registry

Monitoring: No

Funding source: State appropriation (75%), CDC grant (25%)

Staff: 4 abstractors, 1 data entry clerk, 1 epidemiologist, 1 field supervisor (TBH), 1 project management analyst

Surveillance reports on file: 4

Procedure manual: yes

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

Comments: None

California

California Birth Defects Monitoring Program (CBDMP)

Status: Operational

Start date: 1-1-1983

Organizational location: State health department program administered by March of Dimes under contract with the state

Population coverage: Regional (11 counties), about 270,000 births annually

Legislation: Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 8/96.

Case definition

Outcomes covered: Major structural birth defects, primarily encompassed within ICD code 740-759.9

Birth status: Live births, fetal deaths > 20 weeks

Age: Birth to one year

Gestation: > 20 weeks

Weight: Any weight

Residence: Births to residents of 11 registry counties

Surveillance methods

Case ascertainment: Active surveillance, population based

Data sources: Hospital medical records, hospital discharge indexes, hospital logs, infant death certificates, physician reports, genetic service laboratories and clinics

Coding: CDC code (6-digit BPA/ICD-9-CM code)

Data collected: Personal identifiers, names of hospitals, names of physicians, demographic data, malformations, syndromes, medical history, family history, cytogenetics, risk factors, autopsy results, type of physician confirming diagnosis, type of test (if any) confirming diagnosis

Quality assurance: Case finding, data coding and entry, case abstraction

Data analysis: Incidence rates, trend analysis, case-control ancillary studies

Data use: Epidemiology, environmental monitoring, baseline rates, case identification for case-control studies, response to allegations of clusters, small area investigations.

Monitoring: Yes

Funding source: State appropriation to maintain surveillance system and public health activities (100%). Federal Title V funds to prepare educational materials and to assist in county planning and evaluation of services. Grant funds (CDC, etc.) are used for case-control interview studies and biological sampling.

Staff: Program director (1 FTE), senior epidemiologists (2 FTE), registry manager (1 FTE), community service manager

(1 FTE), information systems manager (1 FTE), community service staff (3 FTE), programmers, network support (4 FTE), epidemiologists (3 FTE), research associates (5.33 FTE), clerical assistants (3 FTE), coder (1.5 FTE), abstractor supervisors (3 FTE), abstractors (15 FTE), pediatric geneticist (1.2 FTE), secretary/administrative assistants (10.5 FTE), interviewers (5 FTE), statisticians (use consultants)

Surveillance reports on file: Birth Defects in California January 1, 1983 - December 31, 1990; Birth Defects in Eleven California Counties: 1990-1992; Birth Defects in California Counties: 1995.

Procedure manual: Yes

Additional information on file: Publication list, scientific collaboration protocol, confidentiality procedures, cluster protocol, statutes, study summaries, program video

Comments:

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Updated: 4/99

Colorado

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

Status: Operational

Start date: October, 1988

Organizational location: Epidemiology

Population coverage: Statewide, 56,000 births annually

Legislation: CRS 25-1-107, CRS 25-1-122, CCR-1009-7. Legislation mandates reporting by hospital and genetic labs, physician reporting for fetal alcohol syndrome and allows CRCSN access to medical records for birth defects and developmental disabilities

Case definition

Outcomes covered: All birth defects, some genetic diseases, developmental disabilities, very low birth weight (less than 1500 grams), others with medical and maternal risk factors for delay

Birth status: Live births and fetal deaths greater than or equal to 20 weeks gestation; plus neural tube defects, chromosomal abnormalities and other prenatally diagnosed birth defects

Age: Prenatal to 3 years; plus birth to 7 years for fetal alcohol syndrome

Gestation: N.A.

Weight: Any weight

Residence: State resident at time of diagnosis

Surveillance methods

Case ascertainment: Passive, population based; active for special projects.

Data sources: Birth, infant death, and fetal death certificates; physician reports; genetic, developmental, and specialty service clinics; genetic laboratories; statewide hospital inpatient and outpatient discharge data; special child health programs, other epi surveillance systems; autopsy reports

Coding: Other modification of ICD-9-CM

Data collected: Personal identifiers, names of hospitals, names of physicians for some records; from birth certificate: demographic data, measurements at birth (birth weight, gestational age, apgars), complications of birth, data on previous pregnancies, risk factors; malformations, syndromes, hospital length of stay, hospital charges and expected pay source, coded procedures, autopsy results

Quality assurance: Case finding (special studies), data coding and entry, data analysis, clinical reviews.

Data analysis: Birth prevalence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analyses for special epidemiological studies

Data use: Epidemiology, needs assessment, monitoring, service planning, baseline rates, service delivery, case identification, family support, registry, grant proposals, education, prevention projects.

Monitoring: Yes

Funding source: State General Fund (57%), CDC grants (34%), other grants (9%).

Staff: Medical director (0.6 FTE), abstractor (2.0 FTE), statistical (2.0 FTE), programmer/analyst (1 FTE), clerical assistant (0.7 FTE), health planner (1 FTE), genetic counselor (0.5 FTE)

Surveillance reports on file: "Birth Defects and Developmental Disabilities in Colorado, 1989-1992" report

Procedure manual: Yes

Additional information on file: Background documents, including: CRCSN Reference Guide, CRCSN Community Notification and Referral Program Site Manual, legislation

Comments: Updated surveillance results are Published at <http://www.cdphe.state.co.us/dc/dccrcsn.html>. Requests for information can be emailed to crdsn@state.co.us.

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Updated: 5/99

Connecticut

Connecticut Birth Defects Prevention and Surveillance Program (CBDPSP)

Status: Operational

Start date: Birth cohorts of 1993.

Organizational location: Division of Environmental Epidemiology and Occupational Health

Population coverage: Statewide

Legislation: Legislation signed into law June , 1998; designated the Connecticut Department of Public Health as the agency responsible for the CBDPSP.

Case definition

Outcomes covered: All birth defects (ICD-9 coded: 740.0-759.9, 760.71)

Birth status: Live births

Age: Birth to 1 year

Gestation: Live births of any gestational age.

Weight: Live births of any weight.

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

Surveillance methods

Case ascertainment: Passive surveillance, population based

Data sources: Birth certificates, infant death certificates, statewide hospital discharge data during first year of life

Coding: Modification of ICD-9-CM code

Data collected: Demographic data, measurements at birth, complications of birth, prenatal examinations, data on previous pregnancies, malformations, syndromes

Quality assurance: Case finding, data coding and entry, data analysis, hospital audits

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates

Data use: Needs assessment, monitoring, baseline rates, registry, grant proposals

Monitoring: Yes

Funding source: State general fund; In-kind contribution by university staff

Staff: Epidemiologist (1.0 FTE)

Surveillance reports on file: 1985 & 1986 surveillance report, Trends of Selected Birth Defects: Connecticut 1983, 1985, 1986, Birth Defects Prevalence: 1993, 1994, 1995

Procedure manual: Under review.

Additional information on file: Bibliography of selected reports, summary statement of activities for 1989/1990, Connecticut Birth Defects Surveillance Project Final Report for Fiscal Year 1988-89, copy of legislation,

report on cleft lip/cleft palate in Connecticut, operating procedures, Report to the Public Health Committee of the Connecticut Legislature (1989), 1998 report in development.

Comments:

Contact:

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Updated: 4/99

Delaware

Delaware Birth Defects Surveillance Project

Status: Operational

Start date: 1996

Organizational location: Division of Public Health, Community Health Care Access Section

Population coverage: Statewide, 10,500 births annually

Legislation: House Concurrent Resolution No.55: Related to data systems for disability prevention, not specific to birth defects; June 20, 1991. Birth defects surveillance legislation has been passed (4/97).

Case definition

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

Birth status: Live births, stillbirths

Age: Birth to 5 years

Gestation: Any gestation for live born, greater than 20 weeks for fetal death

Weight: Any weight

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

Surveillance methods

Case ascertainment: Active and passive surveillance, population-based

Data sources: Vital statistics - birth and death certificates, statewide hospital discharge data, statewide NICU discharge data, physician reports, genetic service clinics

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

Data collected: Personal identifiers, demographic data, names of hospitals, measurements at birth, complications of birth, prenatal test abnormal finding and date performed, malformations, syndromes, autopsy results, alternative methods of conception, risk factors, cytogenetics, payor source, residence at birth, obstetric complications, number of prenatal visits

Quality assurance: Case finding, case abstraction in special studies, data coding and entry, data analysis

Data analysis: Birth prevalence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analysis for special epidemiological studies

Data use: Epidemiological, monitoring, baseline rates, case identification, registry

Monitoring: Yes

Funding source: Federal - CDC Cooperative Agreement

Staff: 1 FTE

Surveillance reports on file: Some data available in test

Procedure manual: Under development pending system modification.

Additional information on file: List of diagnoses

Comments: The surveillance system includes an education and prevention component to be conducted through a Preconceptional Health Care plan, and includes folic acid promotion instituted fall 1997.

Contact:

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Updated: 4/99

District of Columbia

Status: No system, but interest in developing one.

Start date:

Organizational location: Office of Maternal & Child
Health–Data, Policy, Planning and Evaluation Unit

Population coverage: 15,713 births in D.C. (1997)

Legislation: None

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source: none

Staff: pending

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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Florida

Status: Operational

Start date: January 1, 1996

Organizational location: Florida Department of Health, Bureau of Environmental Epidemiology

Population coverage: Approximately 190,000 births and fetal deaths per year, statewide

Legislation: No specific legislation authorizing birth defects registry; Chapter 381, F.S. on reportable diseases provides authority

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Case definition

Outcomes covered: Major structural malformations and selected genetic disorders.

Birth status: Live Births, fetal deaths

Age: Less than one year

Gestation: Greater than 19 weeks

Weight: Any

Residence: Florida

Updated: 5/99

Surveillance methods

Case ascertainment: Passive

Data sources: Birth and fetal death certificates, other administrative data sources, medical record reviews, direct provider reports

Coding: ICD 9

Data collected: Medical and demographic

Quality assurance: Comparison with medical charts in selected hospitals and comparison of data sources statewide.

Data analysis: Prevalence for geographic and demographic subgroups

Data use: Public awareness and prevention

Monitoring: In development

Funding source: State general revenue

Staff: 1 FTE plus \$400,000 annually for contractual services with a consortium of state universities

Surveillance reports on file: First Annual Report planned for summer 1999.

Procedure manual: in development

Additional information on file:

Comments: The Florida Department of Health has received \$461,400 and 1 position during 1997. The Department has contracted out the operation of the registry with a consortium of State universities, including Florida A&M University, the University of Florida, and the University of South Florida.

Georgia

*Metropolitan Atlanta Congenital Defects Program (MACDP)***Status:** Operational**Start date:** 1967**Organizational location:** Division of Birth Defects and Pediatric Genetics, CDC**Population coverage:** Metropolitan Atlanta, 40,000 births annually**Legislation:** State reporting requirement**Case definition****Outcomes covered:** All birth defects and genetic diseases**Birth status:** Live births, stillbirths**Age:** Birth to 6 year**Gestation:** ≥20 weeks**Weight:** ≥500 grams**Residence:** In-state birth to Atlanta resident**Surveillance methods****Case ascertainment:** Active surveillance, population based**Data sources:** Hospital medical records; hospital labor/delivery, nursery, NICU, pediatric, surgery, and autopsy logs; hospital discharge index, birth certificates, fetal death certificates, genetic service laboratories, pediatric hospital records**Coding:** CDC coding system (6-digit BPA/ICD-9-CM code)**Data collected:** Personal, physician, and hospital IDs; demographic data, measurements at birth, complications of birth, prenatal examinations, data on previous pregnancies, malformations, syndromes, cytogenetics, risk factors, autopsy results**Quality assurance:** Case abstraction, data coding and entry, data analysis**Data analysis:** Prevalence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analyses for special epidemiologic studies**Data use:** Epidemiology, monitoring, baseline rates, case identification, registry**Monitoring:** Yes**Funding source:** Federal (CDC) funding**Staff:** Data collection (9 FTE)**Surveillance reports on file:** 8/97**Procedure manual:** Yes**Additional information on file:** Numerous reports and bibliography**Comments:** For surveillance reports and other information regarding the MACDP, contact CDC.**Contact:****Len J. Paulozzi, M.D., M.P.H.****MACDP Director****Surveillance and Epidemiology Branch****Div. of Birth Defects and Pediatric Genetics, NCEH****Centers for Disease Control and Prevention****4770 Buford Highway N.E., Mailstop F-45****Atlanta, Georgia 30341-3724****Phone: (770) 488-7172****Fax: (770) 488-7197****E-mail: lbp4@cdc.gov**

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Updated: 5/99

Hawaii

Hawaii Birth Defects Program (HBDP)

Status: Operational

Start date: 8-15-88

Organizational location: Research Corporation of the University of Hawaii

Population coverage: Statewide, \cong 20,000 births annually

Legislation: None for the HBDP specifically, but one for access to confidential medical record data/information

Case definition

Outcomes covered: CDC recommended "conditions to be monitored" birth defects, genetic diseases, fetal mortality + involved abortions (collected only when prenatal screening/ diagnostic testing/post natal examination showed baby to have a defect), infant mortality when a birth defect was noted (neonatal and postnatal), low birth weight (1500 grams to less than 2500 grams) and very low birth weight (less than 1500 grams) only when associated with a birth defect, neonatal tumors, congenital infections, maternal substance abuse.

Birth status: Live births, stillbirths, prenatally diagnosed, and medical abortions where a birth defect has been diagnosed.

Age: Conception to 1 year after birth

Gestation: From conception

Weight: Any weight; however, some diagnoses have specific weight and age parameters

Residence: In-state birth to state resident; in-state birth to nonresident

Surveillance methods

Case ascertainment: Active, population based

Data sources: Hospital medical records, hospital discharge indexes, hospital molecular biology & cytogenetics laboratory logs, birth certificates, fetal death certificates, infant death certificates, genetic service clinic logs, fetal diagnostic clinic logs, induced abortion records.

Coding: CDC coding system (6-digit BPA/ICD-9-CM code)

Data collected: 100+ items: Personal identifiers, demographic data, names of hospitals, names of physicians, measurements at birth, complications of birth, prenatal test abnormal finding and date performed, data on previous pregnancies, malformations, syndromes, and risk factor information.

Quality assurance: Case finding, case abstraction, data coding and entry (7%-100%)

Data analysis: Incidence rates, trend analysis; data analyses for special epidemiological studies; planned: time-space cluster analysis, observed vs. expected rates.

Data use: Registry, grant proposals, baseline rates, needs assessment, monitoring, collaborative projects, state cluster investigations, dissemination to community and researchers, presentations, publications, and publications in peer review journals. Planned: epidemiology, service planning, and service delivery.

Monitoring: Yes

Funding source: Federal and private grants, contracts, and awards.

Staff: Administrator, 2 Data Collection Specialists

Surveillance reports on file: Data on slides: 1989-91, 1988-1993, 1988-1994, 1988-1995, 1987-1996, 1986-1997, and 1986-1998. Published: Surveillance Reports for Hawaii 1989-1991, 1988-1993, 1988-1994, 1988-1995, 1987-1996, 1986-1997, and 1986-1998.

Procedure manual: Yes

Additional information on file: HBDP informational brochure; organizational chart; copy of legislation; original abstraction forms; revised abstraction forms; revised mini-manual; annual report (FY 88-89); sample of quarterly reports; slides of HBDP data; quality assurance report (completeness, accuracy, timeliness); special study reports (4).

Comments:

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Updated: 4/99

Idaho

Status: No system, but interest in developing one.

Start date:

Organizational location:

Population coverage:

Legislation:

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file: Partially completed questionnaire regarding the Idaho Infant-Toddler Program

Comments: Part of the questionnaire was completed related to Idaho's Infant-Toddler Program. However, this is not a birth defects surveillance system.

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Updated: 5/99

Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Status: Operational

Start date: 8-1-88

Organizational location: Illinois Department of Public Health, Division of Epidemiologic Studies

Population coverage: 180,649 births (1997), Statewide

Legislation: Illinois Health and Hazardous Substances Registry Act, enacted 9-10-84. The purpose of the act was to establish a unified, statewide project to collect, compile and correlate information on public health and hazardous substances. Reporting by delivery hospitals, pediatric hospitals, and regional perinatal centers is mandatory. Legislation amended 4-1-90 to include all infants born with a positive urine test for any drug or infants showing signs of drug toxicity or withdrawal.

Case definition

Outcomes covered: All birth defects, fetal death (≥ 20 weeks), infant mortality, very low birth weight (< 1501 grams), and other conditions specified by statute.

Birth status: Live births

Age: Newborns

Gestation: Any gestation for live born, 20 weeks or greater for fetal deaths

Weight: Any weight

Residence: In-state birth to a state resident, out-of-state birth to state resident (from four hospitals in St. Louis, Missouri)

Surveillance methods

Case ascertainment: Combination of active and passive ascertainment, population based. Cases are identified and reported by hospital staff, but Department abstractors go to hospitals to abstract maternal information.

Data sources: Hospital medical records, discharge index, labor/delivery logs, nursery logs, and NICU logs; fetal death certificates

Coding: ICD-9-CM

Data collected: Personal identifiers, demographic data, hospital ID, birth weight, complications of birth, malformations, other data required by legislation

Quality assurance: Case finding, case abstraction, data coding and entry, data analysis

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analyses for special epidemiological studies

Data use: Epidemiology, needs assessment, service delivery, registry

Monitoring: No

Funding source: State appropriation (100%)

Staff: 1 program director, 3 abstractors, 1 senior data analyst, 3 medical coders/editors, 1 data entry clerk

Surveillance reports on file: "Surveillance of Infants Born with a Positive Toxicity for Controlled Substances" (produced quarterly starting September, 1991); "Trends in the Prevalence of Birth Defects in Illinois and Chicago 1989-1997," "Trends in the Prevalence of Birth Defects in Illinois and Chicago 1989-1996," "Birth Defects in Illinois Surveillance Report 1989-1994", "Birth Defects in Illinois Surveillance Report, 1989-95"; "Cancer in Illinois Infants 1986-1988"; "Epidemiology of Retinopathy of Pre-maturity in Illinois"; "Maternal Smoking and Adverse Pregnancy Outcomes"; and "Potter's Syndrome in Illinois"

Procedure manual: Yes

Additional information on file: Quality control studies, case record form and instructions, computerized record forms, copy of legislation and rules and regulations, assorted memoranda

Comments: None

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Updated: 5/99

Indiana***Indiana Birth Problems Registry***

Status: Operational

Start date: January 1, 1987

Organizational location: Indiana State Department of Health, Epidemiology Resource Center

Population coverage: Statewide, 85,000+ births annually

Legislation: Indiana Code 16-38-4. Changes to legislation in 1991 and 1993

Surveillance reports on file: 1. "Indiana Birth Problems Registry, 1988-1992" (draft); 2. "Indiana Birth Problems Registry, 1989" (1987-1989); 3. "Indiana Birth Problems Registry, 1993" (1987-1991)

Procedure manual:

Additional information on file: Copy of legislation/statute

Comments:

Case definition

Outcomes covered: Congenital anomalies, stillbirths, birth weights less than 2,500 grams

Birth status: Live births and fetal deaths

Age: Newborns

Gestation: Any gestation for live birth; 20 weeks or greater for fetal deaths

Weight: Any weight

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

Contact:

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Indiana Birth Problems Registry

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Surveillance methods

Case ascertainment: Passive, population based.

Data sources: Indiana Certificate of Live Birth and Indiana Certificate of Fetal Death.

Coding: "Yes/No" coding for specific congenital anomalies on birth certificate.

Data collected: Personal identifiers, demographic data, name of hospital, pregnancy history, marital status, educational level, prenatal examination, risk factors of pregnancy, parental occupations, previous high risk pregnancy outcome, concurrent illness, complications of pregnancy, obstetric procedures, method of delivery, complications of labor and delivery, congenital anomalies, abnormal conditions or newborn, indications for cesarean, and hospital transfer (to/from).

Quality assurance: (1) each source reporting a congenital anomaly on the birth certificate is asked to verify the congenital anomaly by sending the Registry a copy of the section of the medical chart that states the diagnoses, and (2) double entry of part of the birth certificate data.

Data analysis: Incidence rates, trend analysis.

Data use: Epidemiology, needs assessment, service delivery, registry.

Monitoring: No

Funding source: The fee for a search of the records for a birth certificate includes a \$2 charge that is earmarked for the birth problems registry fund.

Staff: One full-time program director - vacant; epidemiologist time when needed.

Updated: 5/99

Iowa
Iowa Birth Defects Registry

Status: Operational

Start date: June 1986

Organizational location: University of Iowa,
Department of Preventive Medicine

Population coverage: Statewide, 37,000 births annually

Legislation: Chapter 23 - Birth Defects Institute, Chapter
1 - Notification and Surveillance of Reportable Disease

Case definition

Outcomes covered: All birth defects from 1983-1990,
multiple defects in 1993, all birth defects from 1994 to
present.

Birth status: Live births, stillbirths

Age: Birth to 1 year

Gestation: >20 weeks

Weight: Any weight

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

Surveillance methods

Case ascertainment: Active surveillance, population
based

Data sources: Hospital medical records, discharge index,
labor/delivery logs, nursery logs, NICU logs, pediatric logs,
surgery logs, and autopsy logs; birth certificates, fetal death
certificates, infant death certificates, genetic service clinics,
induced abortion records, spontaneous abortion certificates,
pediatric hospital/clinic records, specialty clinics

Coding: Modified CDC code - British Pediatric Assoc.
Classification of Diseases and ICD

Data collected: Personal, physician, and hospital IDs;
demographic data, measurements at birth, complications of
birth, prenatal exams, data on previous pregnancies,
malformations, syndromes, medical history, family history,
cytogenetics, risk factors, autopsy results

Quality assurance: Case finding, case abstraction, data
coding and entry, data analysis, system reports

Data analysis: Incidence rates, time-space cluster
analysis, data analyses for special epidemiological studies

Data use: Baseline rates, case identification, registry,
grant proposals

Monitoring: Yes

Funding source: CDC grant, State of Iowa

Staff: 1 program director, 1 programmer, 1.8 abstractors, .5
data entry clerk, .5 secretary

Surveillance reports on file: Surveillance report
(1983-1988); Surveillance report (1983-1990)

Procedure manual: Available

Additional information on file: The Iowa Birth
Defects Registry - 1991 Health and Environmental Issues,
copy of legislation

Comments:

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Updated: 5/99

Kansas

Congenital Malformations Reporting

Status: Operational

Start date: 7-1-85

Organizational location: Maternal and Child Health,
Vital Statistics

Population coverage: Statewide, 37,000-38,000 births
annually

Legislation: KSA 65-101 and KAR 28-4-1, enacted in
1985. Purpose was to specify general powers for the
Department of Health and Environment. Mandatory
reporting of congenital malformations by delivery hospitals
and hospital administrators

Case definition

Outcomes covered: All birth defects

Birth status: Live births, stillbirths

Age: Birth to 1 year

Gestation: Any age

Weight: Not included in case definition

Residence: Both in-state and out-of-state births to state
resident

Surveillance methods

Case ascertainment: Passive surveillance, population
based

Data sources: Birth certificates, reports by hospital
administrators

Coding: CDC coding system

Data collected: Personal identifiers, hospital IDs,
malformations

Quality assurance: None

Data analysis: Incidence rates, trend analysis, time-space
cluster analysis

Data use: Epidemiology, needs assessment, baseline rates,
grant proposals

Monitoring: No

Funding source: General state funding of department
(100%)

Staff: 1 nurse, 2 secretaries (all part-time)

Surveillance reports on file:

Procedure manual:

Additional information on file: Case record form

Comments:

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Updated: 5/99

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Kentucky

Birth Surveillance Registry

Status: Operational

Start date: KRS effective July, 1992. Initiated data collection December 1995, with information beginning April 1, 1996.

Organizational location: Department for Public Health

Population coverage: Statewide (52,000 births annually)

Legislation: KRS 211.651-211.670, effective July 1992. The Department for Public Health is authorized to: 1) provide information on the incidence, prevalence and trends of birth defects, stillbirths and disabling conditions, 2) provide information as to the possible causes of birth defects, stillbirths and disabling conditions, 3) develop preventive strategies to reduce the incidence of birth defects, stillbirths and disabling conditions. Other components of KRS 211.651-211.670 include the appointment of an advisory committee with representatives of specified disciplines, review of vital records, and hospital reporting, confidential access to information.

Case definition

Outcomes covered: Major birth anomalies, genetic diseases, and fetal mortality

Birth status: Live births, stillbirths

Age: Birth to 5 years

Gestation: > 20 weeks

Weight: Not specified

Residence: In-state births to state residents, residents diagnosed before 5th birthday.

Surveillance methods

Case ascertainment: Passive surveillance, population based

Data sources: Vital records, hospital billing data, genetic clinics, newborn screening, other

Coding: ICD-9

Data collected: Personal IDs, demographic data, measurements at birth, data on previous pregnancies, prenatal examinations, teratogenic exposures (including tobacco, alcohol, and no-prescription drugs), birth anomalies, cytogenetics, autopsy results

Quality assurance: Limited medical records abstracting of reported cases. Verification through multiple sources.

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analyses for special epidemiological studies

Data use: Epidemiology, needs assessment, monitoring, service planning, baseline rates, service delivery, case identification, family support, registry, grant proposals, education

Monitoring: Yes

Funding source: CDC Cooperative Agreement and education funding from March of Dimes.

Staff: A nurse administrator, data analyst/epidemiologist, central reporting vendor and programmer support through state contract.

Surveillance reports on file: Active hospital reporting from April 1, 1996, preliminary unpublished reporting only.

Procedure manual: Yes

Additional information on file: Copy of legislation and hospital reporting administrative regulations, condition definitions, fact sheets, and miscellaneous data sheets

Comments:

Contact:

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Nurse Consultant

**Kentucky Birth Surveillance Registry
Administrator**

Community Health Branch

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Kentucky Department for Public Health

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Updated: 4/99

Louisiana

Status: No system

Start date:

Organizational location:

Population coverage:

Legislation: R.S. 40:1299.144(6), Act No. 343, enacted 8-8-85.

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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Maine

Maine Birth Defects Program

Status: Planning 1999

Start date: 1999

Organizational location: Bureau of Health

Population coverage: Statewide, 13,000-14,000 births annually

Legislation:

Case definition

Outcomes covered: Major birth defects

Birth status: Live births, stillbirths, prenatally diagnosed cases

Age: Newborns to age 1

Gestation: > 20 weeks

Weight: Any weight

Residence: In-state births to Maine residents

Surveillance methods

Case ascertainment: Passive surveillance, population based

Data sources: Birth certificates, fetal death certificates, infant death certificates, induced abortion records, statewide hospital discharge data, physician reports, genetic clinic data

Coding: Modification of ICD-9-CM code

Data collected: Personal, physician, and hospital IDs (vital records only), demographic data, complications of birth, data on previous pregnancies, malformations, medical history, risk factors, autopsy results

Quality assurance: Data coding and entry, data analysis, medical record abstraction

Data analysis: Incidence rates, trend analysis, time-space cluster analysis

Data use: Epidemiology, monitoring, baseline rates, grant proposals; planning for service, prevention and referrals

Monitoring: Yes

Funding source: CDC cooperative agreement

Staff: Coordinator (.5FTE), epidemiologist (.25FTE), medical secretary (.5FTE), dysmorphologist (contract), medical records abstractor (contract)

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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Updated: 5/99

Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

Status: Operational

Start date: January, 1984

Organizational location: Family Health Services and Primary Care, Office for Hereditary Disorders

Population coverage: Statewide, 74,000 births annually

Legislation: Health - General Article, Section 18-206; Annotated Code of Maryland

Case definition

Outcomes covered: Selected birth defects

Birth status: Live births, stillbirths

Age: Newborn

Gestation: >20 weeks

Weight: >500 grams

Residence: In-state births to both residents and non-residents

Surveillance methods

Case ascertainment: Passive surveillance, population based

Data sources: Birth Defects hospital report form is our primary source. The following are additional sources: birth certificates, fetal death certificates, infant death certificates, genetic service clinics, genetic service laboratories, special child health registries, Maryland Maternity Summary, Infant Hearing Screening Program, MARHGN data collected by state

Coding: Modified CDC code/ICD-9

Data collected: Personal, physician, and hospital IDs; demographic data, birth weight, complications of birth, prenatal exams, data on previous pregnancies, malformations, syndromes, medical history, family history, cytogenetics, TORCH titers, risk factors, autopsy date, (autopsy results sometimes available), parent employment, subjective exposures, smoking, ethanol/drug intake, vitamin consumption

Quality assurance: Case finding, data coding and entry, data analysis

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analyses for special epidemiological studies

Data use: Epidemiology, needs assessment, monitoring, service planning, baseline rates, service delivery case identification, family support, registry, grant proposals, education, resource allocation

Monitoring: Yes

Funding source: State appropriation

Staff: Program director (a pediatrician and medical

geneticist), program administrator/nurse, data manager, secretary (all part-time)

Surveillance reports on file: Provisional surveillance report (1984-1992); 1995.

Procedure manual: Guidelines for Hospital Personnel

Additional information on file: Copies of numerous publications, copy of legislation, guidelines for hospital personnel, miscellaneous booklets and other information related to birth defects surveillance in Maryland

Comments:

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Updated: 5/99

Massachusetts***Massachusetts Birth Defects Monitoring System***

Status: Implementation; ongoing development

Start Date: October 1995

Organizational Location: Massachusetts Department of Public Health, Bureau of Family and Community Health, Office of Statistics and Evaluation, Massachusetts Center for Research and Prevention

Population Coverage: All surveillance activities now cover the entire state for Massachusetts residents.

Legislation: Reporting and access to medical records in birthing hospitals for births, stillbirths, fetal deaths; confidentiality protections.

Case Definition

Outcomes Covered: Major structural anomalies of medical, surgical, cosmetic or developmental significance.

Birth Status: Live births, stillbirths and reportable fetal deaths

Age: Initially newborns.

Gestation: Reportable fetal deaths at 350g or 20 weeks.

Weight: Reportable fetal deaths at 350 grams or 20 weeks.

Residence: Massachusetts

Surveillance Methods

Case Ascertainment: Lists and reports from birth hospitals and other clinical sources. Medical record abstraction. Multiple administrative data sources including hospital discharge data, birth certificate, death, and fetal death files.

Data Sources: Hospital/clinical sources (lists, reports, logs, etc.), hospital discharge data, birth file, death file, fetal death file, medical records.

Coding: 6-digit, provided the data source contains sufficient information.

Data Collected: Diagnosis, tests and procedures, sex, race, birth weight, gestational age, complications of labor and delivery, abnormal newborn conditions, prenatal care, previous reproductive outcomes, maternal risk factors, alternative methods of conception, autopsy results.

Quality Assurance: Internal and external validity checks. Comparison of data from multiple passive sources and medical records. Review by clinical geneticist for selected cases.

Data Analysis: Generation of rates for specific malformations, stratified by sex, race, geographic area, maternal age; trends over time; comparison of diagnoses obtained from passive sources with those obtained from medical records.

Data Use: Publication and dissemination of rates, stratified

rates, trends over time, collaboration with other researchers, response to community questions, children with special health care needs service planning.

Monitoring:

Funding Source: State and CDC

Staff: PI, director, hospital coordinator, congenital anomalies research specialist, research analyst, systems analyst abstractors.

Surveillance Reports on File: None. Rates currently available are preliminary from hospital discharge data only.

Procedure manual: In development.

Additional information on file: Protocols, forms, case criteria, exclusion list, list of validity checks for passive data sources

Comments:

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Updated: 5/99

Michigan
Michigan Birth Defects Registry

Status: Operational

Start date: 1-1-92

Organizational location: Division for Vital Records and Health Statistics

Population coverage: Statewide, ~ 150,000 births annually

Legislation: Public Act 236 of 1988

Case definition

Outcomes covered: All birth defects

Birth status: Live births

Age: Birth to 2 years

Gestation: N.A.

Weight: Any weight

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

Contact:

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Vital Records and Health Data Development

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Updated: 5/99

Surveillance methods

Case ascertainment: Passive, population based

Data sources: Hospital medical records, birth certificates, infant death certificates, genetic services laboratories, pediatric hospital/clinic records, specialty clinics

Coding: ICD-9-CM code

Data collected: Personal identifiers, names of hospitals, malformations, syndromes, cytogenetics, autopsy results, information from birth certificates, information from death certificates

Quality assurance: Case finding, case abstraction, data coding and entry, data analysis (all planned)

Data analysis: Incidence rates, trend analysis, observed vs. expected rates (all planned)

Data use: Epidemiology, needs assessment, monitoring, service planning, baseline rates, service planning, case identification, family support, registry, grant proposals, education (all planned)

Monitoring: Yes (planned)

Funding source: General funds

Staff: Program director (0.2 FTE), statistician (0.2 FTE), clerical assistant (0.75 FTE), data entry/coder (nosologist) (0.2 FTE)

Surveillance reports on file: Michigan Birth Defects Registry Report - 1989 (includes: Major Categories of Congenital Anomalies from Michigan Inpatient Data Base for 1987 and 1992-1996) pending incidence report

Procedure manual: No

Additional information on file: Data for birth cohorts 1992, 1993, 1994, 1995, 1996 is currently being evaluated. Data through 1997 expected for August of 1999.

Comments:

Minnesota

Status: Funding for establishment of a birth defects surveillance system was not approved in the 1997 legislature due to concerns about data privacy. These concerns resulted in an attempt to attach a requirement for individual consent before data could be sent to the Health Department. As a result, the bill was pulled. No further legislative efforts are anticipated for the next two years. All development is on hold.

Start date: N/A

Organizational location: N/A

Population coverage: N/A

Legislation: N/A

Case definition

Outcomes covered: N/A

Birth status: N/A

Age: N/A

Gestation: N/A

Weight: N/A

Residence: N/A

Surveillance methods

Case ascertainment: N/A

Data sources: N/A

Coding: N/A

Data collected: N/A

Quality assurance: N/A

Data analysis: N/A

Data use: N/A

Monitoring: N/A

Funding source: N/A

Staff: N/A

Surveillance reports on file: N/A

Procedure manual: N/A

Additional information on file: N/A

Comments: N/A

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Updated: 5/99

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Mississippi

Mississippi Birth Defects Registry

Status: Currently no system, but in process of developing one; Law passed spring of 1997.

Start date: January 1, 2000

Organizational location: Mississippi State Department of Health Genetic Services

Population coverage: Statewide coverage, approximately 42,000 births annually

Legislation: House Bill No. 913, Section 41-21-205 with effective date of July 1, 1997. Legislation to establish a birth defects registry in the State Department of Health; To authorize the state Board of Health to adopt rules to govern the operation of the registry program; To authorize the department to conduct certain investigations; and for related purposes. The law mandates the Board of Health shall specify the types of information to be provided to the birth defects registry and the persons and entities who are required to provide such information to the birth defects registry.

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 cause disease from the time of conception through birth, or later in life. 1)From birth to one year of age certain principle birth defects shall be reported. 2)Other defects found later in life may be reported at any time.

Birth status: Live Births and Reportable Fetal Deaths (fetal deaths of 20 completed weeks of gestation or more, or a weight of 350 grams or more).

Age: 1)From birth to one year of age certain specific birth defects shall be reported. 2)Other defects found later in life may be reported at any time.

Gestation: Live Births at any Gestation and Reportable Fetal Deaths.

Weight: Live Births at any weight and Reportable Fetal Deaths.

Residence: In-state and out-of-state births to state residents/anyone who becomes a state resident by age one.

Surveillance methods

Case ascertainment: Joint passive and active system: A)Passive, mandated population based reporting system; B)Active, follow-up system by genetics staff to birthing hospitals, birthing centers or pediatric care facilities.

Data sources: Newborn Screening Records, Birth and Death Certificates, Hospital Medical Records, Physician Reports, Genetic Clinics, Labs, Special Clinics, Service Providers, Parents, other appropriate Registries.

Coding: CDC Coding System, BPA/ICD-9-CM Code

Data collected: Personal, physician, and hospital; demographic data, malformations, syndromes, cytogenetics, autopsy results.

Quality assurance: Case finding and case abstraction, data coding, and data analysis.

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. Expected rates, data analysis for specific epidemiologic studies.

Data use: Epidemiology, monitoring, baseline rates, needs assessment, notify patient's physician of available health department services and/or resources, case identification, registry, education, grant proposals.

Monitoring: Yes

Funding source: March of Dimes, MCH Block Grant, Newborn Screening fees

Staff: Project director, data Administrator, data entry operator (part time), medical records clerk (part time) and Epidemiologist (part time).

Surveillance reports on file: N/A

Procedure manual: Being Developed

Additional information on file: Numerous reports, Forms, Copy of Legislation, and Birth Defect Registry Education Program.

Comments:

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Updated: 5/99

Missouri

Missouri Multi-Source Birth Defect Registry

Status: Operational

Start date: 1985, including births from 1-1-80

Organizational location: Department of Health -
Center for Health Information, Management, and
Epidemiology

Population coverage: Statewide, 73,000 births annually

Legislation: None

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Case definition

Outcomes covered: All birth defects

Birth status: Live births

Age: Birth to 1 year

Gestation: Any gestation

Weight: Any weight

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

Updated: 5/99

Surveillance methods

Case ascertainment: Passive, population based

Data sources: Birth certificates, infant death certificates,
newborn and pediatric state-wide hospital discharge data,
special child health registries

Coding: ICD-9-CM only

Data collected: Personal identifiers, demographic data,
names of hospitals, names of physicians, measurements at
birth, complications of birth, malformations, medical history,
risk factors (smoking)

Quality assurance: Data coding and entry

Data analysis: Incidence rates, trend analysis, observed
vs. expected rates

Data use: Needs assessment, monitoring, service
planning, baseline rates, grant proposals

Monitoring: Yes

Funding source: MCH block grant, CDC grant

Staff: Research analyst (0.5 FTE), MCH epidemiologist
(0.2 FTE), clerical assistant (0.1 FTE)

Surveillance reports on file: None

Procedure manual:

Additional information on file:

Comments:

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Montana

Montana Birth Outcome Monitoring System (MBOMS)

Status: Under development

Start date: February 1, 1999

Organizational location: Special Health Services (SHS), Family Community Health Bureau, Montana Department of Public Health and Human Services (DPHHS)

Population coverage: Statewide for approximately 11,000 births annually.

Legislation: None at this time.

Case definition

Outcomes covered: Initially will cover neural tube defects (NTD), cleft lip/palate defects, congenital heart defects and congenital hypothyroidism. Plans are to eventually cover all major defects.

Birth status: Live births, stillbirths greater than 20 weeks

Age: 0 - 3 years

Gestation: Greater than 20 weeks

Weight: Any weight

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

Surveillance methods

Case ascertainment: State and local health providers and Montana Medical Genetics Program (MMGP)

Data sources: Hospital labor/delivery, specialty clinics, Vital Records of DPHHS, newborn screening, public health home visiting, Montana Medical Genetics Program, Part C of Individuals with Disabilities Act (IDEA) providers and bringing these all together into a centralized location and database.

Coding: ICD-9-CM code

Data collected: Case identifiers, demographic data, names of hospitals, names of physicians, measurements at birth, complications of birth, prenatal examinations, data on previous pregnancies, malformations, syndromes, medical history, family history, risk factors, environmental data, lifestyle data, diagnosis.

Quality assurance: Matching to eliminate duplicates, include only major defects

Data analysis: Incidence rates and possible clusters

Data use: Timely intervention including prevention education, needs assessment, service planning, service delivery, case identification, family support, registry, grant proposals

Monitoring: Determining if goals are met.

Funding source: CDC grant and in-kind support from SHS staff and Montana Medical Genetics program (contract affiliated with DPHHS)

Staff: MBOMS Program Coordinator. Personnel with

other responsibilities included: Nurse Consultant (SHS), MBOMS Program Manager (SHS), Medical Geneticist (MMGP), Genetics Counselor (MMGP), clerical support and epidemiologist (source of last two no specified at this time).

Surveillance reports on file: None at this time

Additional information on file: CDC grant proposal

Comments: Achieve goals: Timely identification and surveillance of newborns and infants with targeted birth outcomes; Decrease incidence of these birth defects through population and client specific education; Improve services to affected newborns and to promote healthy outcomes for infants and families.

Contact:

(To be hired)

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Updated: 6/99

Nebraska

Nebraska Birth Defects Registry

Status: Operational

Start date: 1973

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

Population coverage: Statewide, 24,000 births annually

Legislation: Laws 1972, LB 1203, ? 1, ? 2, ? 3, ? 4 (alternate citation: Public Health and Welfare [Codes] ? 71-645, ? 71-646, ? 71-647, ? 71-648)

Case definition

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

Birth status: Live births, stillbirths greater than 20 weeks gestation

Age: Birth to 1 year

Gestation: Greater than 20 weeks

Weight: Greater than 500 grams

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

hospitals can use the electronic birth certificate to initially alert the surveillance program of the birth of a child with an anomaly

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Updated: 4/99

Surveillance methods

Case ascertainment: Passive, population based

Data sources: Hospital medical records, hospital discharge indexes, hospital NICU logs, birth certificates, fetal death certificates, infant death certificates, physician reports, genetic service clinics

Coding: CDC coding system (6-digit BPA/ICD-9-CM code)

Data collected: Personal identifiers, demographic data, names of hospitals, names of physicians, data on previous pregnancies, malformations, cytogenetics, autopsy results

Quality assurance: Case finding, data coding and entry

Data analysis: Incidence rates, trend analysis, data analyses for special epidemiological studies

Data use: Epidemiology, baseline rates, registry

Monitoring: No

Funding source: MCH block grant (100%)

Staff: Abstractor (0.5 FTE), statistical assistant (0.12 FTE)

Surveillance reports on file: 1997 report in Vital Statistics Report

Procedure manual:

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

Nevada

Status: No system, but are partnering with the University of Nevada School of Medicine and applying for CDC funding for a Nevada Birth Defects Registry Program

Start date: Cannot be determined at this time.

Organizational location: Will be a joint project of the University of Nevada School of Medicine - Las Vegas and the Nevada State Health Division - Bureau of Family Health Services.

Population coverage: If the grant applications are successful will initially focus on Clark County in the South, with expansion to the North in a future year. Approximately 65% of Nevada's population resides in the South.

Legislation: Nevada Revised Statute (NRS) 396.523 "Genetics Program: Provision of Services. The genetics program must provide the following services:...9. Maintenance of a registry for research and evaluation. (Added to NRS by 1991, 2065)."

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Updated: 5/99

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

Contact:

Gloria Deyhle, R.N.

Bureau of Family Health Services

State Health Division

New Hampshire

Status: No system, but interested in developing one should funding to support a project be identified.

Start date:

Organizational location:

Population coverage:

Legislation:

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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New Jersey

Special Child Health Services: Birth Defects Registry and Special Needs Registry

Status: Operational

Start date: 1928 (selected defects); current law, population based – 1985.

Organizational location: Special Child and Adult Health Services - Title 5 program for children with special health care needs, NJ Department of Health and Senior Services.

Population coverage: Statewide coverage - 115,000 births annually.

Legislation: Current law NJSA 26:8-40 et seq., NJAC 8:20. Enacted 8-4-83 with effective date of 3-4-85. Changes to legislation in 1990, 1991, 1992. Legislation intended to establish a registry, identify children for services, and do epidemiological surveillance because of environmental concerns. Mandatory legislation covering hospitals, physicians, dentists, certified nurse midwives, clinical labs, cytogenetic labs, medical examiners.

Case definition

Outcomes covered: Birth Defects Registry - All birth defects, including structural, genetic and biochemical are required to be reported. Special Needs Registry - all special needs and any condition which placed a child at risk, such as prematurity, asthma, cancer and developmental delay; however, no mandate to report children with these non-congenital conditions.

Birth status: Live births only

Age: Birth Defects Registry - Children diagnosed by age one. Special Needs Registry - Children from birth to age twenty-one.

Gestation: Any gestation if live born

Weight: Any weight

Residence: In-state and out-of-state births to state residents / anyone who becomes a state resident by age one (birth defects) or age 21 (special needs).

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.

Data sources: Hospital medical records and logs, hospital discharge index, physician reports, genetic service clinics and labs, specialty clinics, SCHS county-based case management units, service providers, parents, death certificates, and schools.

Coding: ICD-9-CM

Data collected: Personal, physician, and hospital IDs;

demographic data, malformations, syndromes, cytogenetics, autopsy results.

Quality assurance: Case finding and case abstraction, data coding and entry, hospital audits, review of infant death certificates, review of death files for children up to three years of age, and review of birth certificates.

Data analysis: Incidence rates, trend analysis, observed vs. expected rates, data analysis for epidemiologic studies.

Data use: Epidemiology, monitoring, baseline rates, needs assessment, service planning and delivery, family support, case identification, registry, education, grant proposals. Serves as primary entry point into SCHS case management services (including early intervention).

Monitoring: Yes

Funding source: MCH block grant (90%), revolving fund (10%).

Staff: 1 program manager, 1 research scientist (statistical epidemiologist/programmer), 1 data specialist, 2 nurses, 1 secretary; 5 clerical assistants.

Surveillance reports on file: Special Child Health Services Registry: 1985-1989. Special Child Health Services Registry: 1985-1991. Special Child Health Services Registry, 1985-1994.

Procedure manual: Yes

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

Comments: None

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Updated: 5/99

New Mexico

Birth Defects Prevention and Surveillance System (BDPASS)

Status: Operational

Start date: 10-01-95

Organizational location: Maternal and Child Health Bureau, New Mexico Department of Health

Population coverage: 30,000 births; Statewide

Legislation: Appropriation of \$35,000 per year; NM Statute 14-6-1 is related to health information accessibility; NM Statute 24-1-3 gives power to DOH to "establish programs and adopt regulations to prevent infant mortality, birth defects and morbidity."

Case definition

Outcomes covered: Passive for structural abnormalities; active for neural tube defects and oral-facial clefts; active for prenatal diagnosis

Birth status: Live births; prenatal diagnosis (NTDs only)

Age: Date of diagnosis not specified for new entries

Gestation: Passive: 20 weeks or more. Active: 20 weeks or more, prenatal diagnosis for NTDs

Weight: Passive: greater than 500 grams. Active: greater than 500 grams, prenatal diagnosis for NTDs

Residence: In-state births to in-state residents

Surveillance methods

Case ascertainment: Active and passive

Data sources: Children's Chronic Conditions Registry (3CR); Vital Records and Health Statistics (VHRS); Medicaid; hospitals; private providers. Pending: Indian Health Services (IHS); Hospital Information Discharge Database (HIDD); providers.

Coding: ICD-9-CM, CDC coding system

Data collected: Data from birth and death certificates, hospital discharge data, Medicaid payment data, other information available through active surveillance, data from the 3CR (personal identifiers, demographic data, names of physicians, malformations, syndromes, medical history, medications, diagnosis, hospital admissions)

Quality assurance: Case finding, case abstraction, data coding and entry, data analysis, and joint entries validation

Data analysis: Trend analysis, geographic studies, etiologic studies

Data use: Develop baseline data for selected birth defects to monitor rates and/or clusters; evaluate birth defect prevention efforts; provide an epidemiological sound data base for: etiologic studies of economic impact, studies to assess survival rates and long-assess survival rates and long-term effects of birth defects; identify children in need of services; educate health professionals and communities about health and environmental concerns; and advocacy around health related issues

Monitoring: Monitor for outbreak and cluster identification investigation

Funding source: 60% CDC cooperative agreement; 20% state legislative funds; 20% in-kind services

Staff: Physician (.10 FTE), systems analyst (.25% FTE), coordinator (.75 FTE), data manager (.50 FTE)

Surveillance reports on file: BDPASS: NTD Surveillance Report 1995 and 1996. 3CR: Annual Report published from July 1994; congenital anomalies (1980-1984, 1985-1989) in VRHS report

Procedure manual: Yes (still revising/editing)

Additional information on file: Description of registry development, pediatric chronic disease registry form, parental information release form, abstract forms (BDPASS and Prenatal Diagnosis), Prenatal Diagnosis Provider Survey

Comments: 3CR, a source of the BDPASS, works very closely with the BDPASS. Both the Birth Defects Registry (BDR), the surveillance piece of the BDPASS, and the 3CR are housed in the Department of Health, Public Health Department, Maternal and Child Health Bureau, Children's Medical Services. Collaboration between the BDPASS, the 3CR, Newborn Hearing Screening and FAS is a high priority.

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Updated: 5/99

New York

New York State Congenital Malformations Registry

Status: Operational

Start date: 1982

Organizational location: Bureau of Environmental and Occupational Epidemiology

Population coverage: Statewide, 260,000 to 300,000 births annually

Legislation: Public Health Law, art.2, tit.II, sect. 225(5)(t), and art.2, tit.I, sect.206(i)(j); Codes, Rules, and Regulations, chap. 1, state sanitary code, part 22.3

Case definition

Outcomes covered: Major birth defects, genetic diseases, developmental disabilities if due to a birth defect

Birth status: Live births and stillbirths

Age: Birth to 2 years

Gestation: Any age

Weight: Greater than 1500 grams for certain defects (e.g., certain heart, PDA) known to be common in preemies; greater than 2500 grams for undescended testicles

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 active/passive, population based

Data sources: For all cases: Hospital medical records, hospital discharge indices, physician reports, genetic service clinics, genetic service laboratories. Some hospitals also check: hospital labor/delivery logs, nursery logs, NICU logs, pediatric logs, and pediatric clinic records. Registry staff follow-up with pediatric clinics and physician offices as needed for additional information.

Coding: Modified CDC code

Data collected: Personal identifiers, demographic data, names of hospitals, names of physicians, measurements at birth, malformations, syndromes, medical history, cytogenetics, residence, hospital transfer (to/from), medical record number. Complications of birth, prenatal examinations, and data on previous pregnancies obtained from birth certificates. Autopsy results collected for some cases. For special studies and as needed for diagnosis: prenatal examinations, medical history, family history, risk factors, autopsy results

Quality assurance: Case finding, case abstraction in special studies, data coding and entry, data analysis, routine follow up of certain ICD codes and all conditions reported with too little specificity, pending diagnosis, etc. Matching

of the registry against individual hospital's discharge indices and the Department of Health's statewide hospital discharge database, and requesting missing reports.

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analyses for special epidemiological studies, quantity and timeliness of reports received by hospital

Data use: Epidemiology, needs assessment, monitoring, service planning, baseline rates, service delivery, grant proposals, registry, community health studies, environmental investigations

Monitoring: Yes

Funding source: MCH block grant (48%), Prevent block grant (18%), Superfund (5%), and CDC, federal grant funding (29%).

Staff: Program Director (1 FTE), Medical Director (1 FTE), Research Scientists (5 FTE), Project Specialists (2 FTE), Public Health Specialist (0.5 FTE), Clerical (4.5 FTE), Data Entry (1 FTE), Secretary (0.5 FTE).

Surveillance reports on file: Annual Report: statistical summary of each birth cohort, beginning with children born in 1983 and diagnosed through 1985. The most recent report on file will be on children born in 1995 and diagnosed through 1997.

Procedure manual:

Additional information on file: Copy of legislation, Surveillance Methods New York State Congenital Malformations Registry (Feb. 1992), Congenital Malformations Registry Handbook (Feb. 1992)

Comments:**Contact:**

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Updated: 5/99

North Carolina
North Carolina Birth Defects Monitoring Program

Status: Operational

Start date: 7-1-86

Organizational location: Health statistics

Population coverage: Statewide, 100,000 births annually

Legislation: Chapter 130A, Part 7, effective 1995. Birth Defects Monitoring Program established: to compile, tabulate, and publish information related to the incidence and prevention of birth defects.

Contact:

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Case definition

Outcomes covered: All birth defects.

Birth status: Live births, fetal deaths

Age: Birth to 1 year

Gestation: Any age

Weight: Any weight

Residence: North Carolina resident births

Updated: 4/99

Surveillance methods

Case ascertainment: Combined active/passive beginning 1996, population based

Data sources: Birth certificates, infant and fetal death certificates, statewide hospital discharge data, children's special health services, disease index, medical records

Coding: Other modification of ICD-9-CM code

Data collected: Personal identifiers, demographic data, names of hospitals, measurements at birth, complications of birth, data on previous pregnancies, malformations, medical history, risk factors, autopsy results, obstetric complications, residence at birth, payer source

Quality assurance: Data coding and entry, data analysis

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates (routine monitoring), data analyses for special epidemiological studies

Data use: Epidemiology, needs assessment, monitoring, baseline rates, registry, grant proposals, education, program evaluation

Monitoring: Yes

Funding source: CDC Cooperative Agreement, State appropriation, March of Dimes State Chapters

Staff: Statistician, epidemiologist, field staff

Surveillance reports on file: None

Procedure manual:

Additional information on file:

Comments:

North Dakota

Part 1: Birth Review Program. Part 2: Report of Physically Handicapped Children. Part 3: Metabolic Screening

Status: Operational

Start date: Part 1, 1989; Part 2, 1941-1947; Part 3, 1967 and 1991

Organizational location: Maternal/Child Health (Metabolic Screening); Vital Records or Health Statistics; Diabetes Program; Genetics and Birth Defects Counseling Service of North Dakota; Children's Special Health Services (CSHS), Department of Human Services

Population coverage: Statewide, 8,400 births annually

Legislation: P.L. 99-457 50-10-07 (handicapped children), 50-10-07 (congenital deformities), 25-17-04 (metabolic screening)

Case definition

Outcomes covered: All birth defects, genetic diseases, risk factors for developmental disabilities, fetal mortality, induced abortions, infant mortality (neonatal and postnatal), low birth weight (1500 g to < 2500 g), very low birth weight (<1500 g)

Birth status: Live births

Age: Newborn

Gestation: Not specified

Weight: Any weight

Residence: In-state and out-of-state birth to state resident; in-state birth to nonresident: handicapped report form information mailed to appropriate state

Surveillance methods

Case ascertainment: Passive, population based (North Dakota Early Childhood Tracking System); passive hospital based (Children's Special Health Services (CSHS))

Data sources: Birth certificates, specialty clinics, report of physically handicapped child form

Coding: CDC coding system (6-digit BPA/ICD-9-CM code)

Data collected: Personal identifiers, demographic data, names of hospitals, names of physicians, measurements at birth, complications of birth, prenatal examinations, data on previous pregnancies, malformations, syndromes, family history, risk factors, autopsy results (SIDS); (varies with collection, purpose, agency)

Quality assurance: Data coding and entry, case abstraction

Data analysis: Incidence rates

Data use: Needs assessment, monitoring, service planning, case identification, grant proposals, education

Monitoring: Yes

Funding source: Title V and State general fund

Staff: None, cooperative effort across programs

Surveillance reports on file: Congenital Anomalies in 1991 Maternal and Child Health Assessment of Data

Procedure manual:

Additional information on file: Birth Review Protocol (5-2-96); copy of legislation; report of physically handicapped child form; MCH/CSHS combined needs assessment FY 1992

Comments:

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Updated: 4/99

Ohio

Status: At present, an external task force has been formed to consider the development of a birth defects surveillance system for the State of Ohio.

Start date: 2/24/98

Organizational location: Ohio Department of Health, Columbus, Ohio

Population coverage: Not yet determined

Legislation: No

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

Contact:

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Updated: 5/99

Oklahoma

Oklahoma Birth Defects Registry

Status: Operational

Start date: 8-1-92; statewide 1-1-94

Organizational location: Maternal and Child Health Service, Oklahoma State Department of Health

Population coverage: State-wide, 48,000 births, annually

Legislation: 63 O.S., Section 1-550.2

Case definition

Outcomes covered: Major birth defects, selected birth defects, selected genetic diseases, fetal mortality

Birth status: Live births, stillbirths

Age: Birth to 2 years

Gestation: Any age (<20 weeks entered into a separate database)

Weight: Any weight

Residence: In-state birth to state resident . Expanded to out-of-state births in Fort Smith Arkansas in 1995.

Surveillance methods

Case ascertainment: Active, population based

Data sources: Hospital medical records, hospital labor/delivery logs, hospital nursery logs, hospital NICU logs, hospital pediatric logs, hospital surgery logs, autopsy logs, birth certificates, fetal death certificates, infant death certificates, genetic service clinics, genetic service laboratories, pediatric hospital/outpatient clinic records, specialty clinics

Coding: CDC coding system (6-digit BPA/ICD-9-CM code); modified CDC code

Data collected: Personal identifiers, demographic data, names of hospitals, names of physicians, measurements at birth, complications of birth, prenatal medical conditions & medications, prenatal substance use & environmental exposures, data on previous pregnancies, malformations, syndromes, medical history, family history, cytogenetics, risk factors, autopsy results

Quality assurance: Case finding, case abstraction, editing of abstracts, data coding and entry, data analysis

Data analysis: Descriptive analysis of 1992-1994 data including frequency distributions, cross tabulations, and overall verification of data accuracy. Plan annual reports.

Data use: Establish rates, collaborative research prevention activities, (state-wide NTD occurrence prevention campaign) service (notify parents about early intervention program by letter if child has a disabling condition)

Monitoring: Monitor trend, rates, identify and monitor clusters

Funding source: State appropriation, MCH Block Grant

Staff: Prog. director (1 FTE), abstractor (4 FTE), NTD Prev. Coord. (1 FTE), consultant (.5 FTE)

Surveillance reports on file: Summary data for 1992-94 births, newsletter

Procedure manual: yes

Additional information on file: Copy of legislation, Oklahoma Birth Defects Registry abstraction form and manual

Comments:

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Updated: 5/99

Oregon

Status: No system, but slightly interested in developing one.

Start date:

Organizational location:

Population coverage:

Legislation: None

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Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

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Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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Updated: 5/99

Contact:

Pennsylvania

Status: In development

Start date: July 1996

Organizational location: Bureau of Maternal and Child Health, specifically the Divisions of Maternal and Child Health and Special Health Care Needs

Population coverage: Pennsylvania residents.

Legislation: None.

Case definition

Outcomes covered: In development.

Birth status: Reportable live births.

Age: Newborns up to age one (1).

Gestation: Live births of any gestational age.

Weight: Live births of any weight.

Residence: Pennsylvania.

Surveillance methods

Case ascertainment: In development.

Data sources: Possible data sources: live birth certificates, newborn screening program records, and hospital medical records.

Coding: ICD-9-CM

Data collected: In development

Quality assurance:

Data analysis:

Data use: 1) To identify infants born with birth defects and genetic disorders in order to collect data on the incidence and prevalence of birth defects in Pennsylvania. 2) To provide information to the Department of Health and to families in an effort to maximize resource utilization, and, thereby, minimize the mortality, morbidity and losses to the Commonwealth caused by genetic disorders and birth defects.

Monitoring: In development

Funding source: Federal State systems development initiative grant.

Staff: Workgroup composition: staff from the divisions of Maternal and Child Health, and Special Health Care Needs, assisted by the Division of Health Statistics and Research, and the Bureau of Epidemiology.

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

Contact:

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Updated: 5/99

Puerto Rico

Puerto Rico Birth Defects Surveillance System

Status: Operational

Start date: Late 1995.

Organizational location: Puerto Rico Department of Health, Division of Maternal, Child and Adolescent Health, and Division of Habilitation Services, Folic Acid Campaign.

Population coverage: Population based, more than 60,000 live births annually Island wide, (covers 97% of all live births).

Legislation: None

Case definition

Outcomes covered: Neural Tube Defects: Anencephaly, Encephalocele, Myelomeningocele and Meningocele. Cleft Lip and Palate since 1999.

Birth status: Live births, stillbirths, and elective termination after prenatal diagnosis.

Age: Any gestational age through first three years old.

Gestation: Any age

Weight: Any weight

Residence: Birth to Puerto Rico residents

Surveillance methods

Case ascertainment: Combination of active and passive case ascertainment; population based.

Data sources: Active, population based: hospital medical records, hospital labor/delivery logs, hospital nursery logs, hospital NICU logs, hospital pediatric logs, hospital surgery room logs, autopsy logs.

Coding: Modification of ICD-9 coding

Data collected: Date of birth, personal identifiers, demographic data (including current residence, parent names, residence at birth), maternal risk factors, folic acid used, prenatal diagnosis, prenatal substance use and environmental exposures, data on previous pregnancies, malformations, medical history; day of birth, sex, birth defects, names of hospital, weight at birth, discharge data, surgical interventions during first hospitalization, referral for prevention of recurrence and referral information for habilitation services.

Quality assurance: Case finding, case abstraction, data coding and entry.

Data analysis: Incidence rates, descriptive analysis at this time.

Data use: Epidemiology, education, baseline rates, needs assessment, service delivery plans and organization of out-reach programs, registry.

Monitoring: NTD's rates to determine if changes occur.

Funding source: Title V Block Grant, Division of Child with Special Health Care Needs and CDC Visiting Fellow Support

Staff: 4 abstractors, 1 CDC Visiting Fellow, 1 Genetic Counselor (part time), and 1 Folic Campaign Coordinator.

Surveillance reports on file: Results from Puerto Rico NTD's Registry Data 1995-1997

Procedure manual: In development.

Additional information on file: Description of registry development, abstracts forms, case report form, instructions for case report form, prevention of recurrence counseling referral form.

Comments: Surveillance for other birth defects is being developed and plans to start on year 2000.

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Folic Acid Campaign

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Updated: 9/99

Rhode Island

Status: No system, but interested in developing one.

Start date:

Organizational location:

Population coverage:

Legislation:

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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South Carolina

South Carolina Neural Tube Defect Surveillance, Prevention, and Research Initiative

Status: Operational

Start date: 10-1-92

Organizational location: J. C. Self Research Institute of Human Genetics

Population coverage: Pilot, northeast region, 1993; statewide, 1994

Legislation: None

Surveillance reports on file: NTD: 10-1-92 to 6-30-98; Selected Birth Defects Statewide, 1981-1988

Procedure manual:

Additional information on file: Protocols, Newsletters, videos, public awareness materials

Comments: Surveillance for cardiac defects and limb defects to begin 10-1-99.

Case definition

Outcomes covered: Neural tube defects

Birth status: Live births and stillbirths

Age: Any age

Gestation: Any age for fetal loss; greater than 20 weeks for stillbirth

Weight: Any age for fetal loss; greater than 350 grams for stillbirth

Residence: In-state births to state residents

Surveillance methods

Case ascertainment: Active, population based

Data sources: MSAFP Program, prenatal diagnosis program, physician office reporting, hospital delivery and nursery units, hospital medical records units, hospital fetal/neonatal pathology units, birth certificates, infant death certificates, fetal death certificates

Coding: Modified CDC code

Data collected: Personal identifiers, demographic data, names of hospitals, names of physicians, measurements at birth, complications of birth, prenatal examinations, data on previous pregnancies, malformations, syndromes, medical history, family history, cytogenetics, risk factors, autopsy reports

Quality assurance: Case finding, case abstraction, data coding and entry, data analysis

Data analysis: Incidence rates, trend analysis, time-space cluster analysis, observed vs. expected rates, data analyses for special epidemiological studies

Data use: Epidemiology, monitoring, baseline rates, service delivery, case identification, education

Monitoring: Yes

Funding source: State appropriation; CDC grant

Staff: Project Director (.15 FTE), Clinical Geneticist (.20 FTE), Laboratory Director (.20 FTE), Epidemiologist (.25 FTE), Project Coordinator (1 FTE), Genetic Case Workers (3.6 FTE), Prenatal Testing Records Abstractor (.30 FTE), Secretary (.50 FTE)

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Updated: 5/99

South Dakota

Status: No system

Start date:

Organizational location:

Population coverage:

Legislation:

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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Updated: 4/99

Tennessee
Tennessee Birth Defects Registry

Status: Pilot project

Start date: 10-1-98, started pilot project design. Former design covered births occurring in 1991, 1992, and 1993.

Organizational location: Office of Health Statistics and Information (HSI), Tennessee Department of Health

Population coverage: Selected areas of state

Legislation: Permissive legislation designed to establish a genetics program and genetics testing to insure availability of services. TCA 68-5-504 (b)(9) (effective date of legislation 1985)

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Updated 5/99

Case definition

Any birth or fetal death occurring in Tennessee to a Tennessee resident with a birth defect diagnosed before age one.

Outcomes covered: Selected major birth defects.

Birth status: Fetal deaths and live births.

Age: Fetal deaths and live births up to one year of age.

Gestation: Within definitions of fetal death or live birth.

Weight: Within definitions of fetal death or live birth.

Residence: Events occurring in-state to state residents.

Surveillance methods

Case ascertainment: Combination of active and passive surveillance.

Data sources: Vital records, Regional Perinatal Center reporting.

Coding: ICD-9-CM

Data collected: Personal identifiers, demographic data, physicians, hospitals, measurements at birth, complications of birth, data on previous pregnancies, malformations, medical histories, cytogenetics, and risk factors

Quality assurance: Comparing to other data sources; i.e., Hospital Discharge Data System

Data analysis: NTD reports, feedback (data reporters) reports, summary reports, published summary reports

Data use: Epidemiologic studies and provision of services

Monitoring:

Funding source: State funds.

Staff: Statistical Analyst

Surveillance reports on file: 1991-1993 only.

Procedure manual: In development for pilot project

Additional information on file: System design, grant application

Comments: 1991-1993 cover congenital anomalies and more.

Texas

Texas Birth Defects Monitoring Division

Status: Operational

Start date: 1-1-94

Organizational location: Texas Department of Health, Bureau of Epidemiology

Population coverage: The State of Texas, (330,000 births annually).

Legislation: Health and Safety Code, Title 2, Subtitle D, Section 1, Chapter 87

Case definition

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

Birth status: Live births, stillbirths, elective pregnancy terminations

Age: Birth to 1 year, with the exception of fetal alcohol syndrome (birth to 6 years)

Gestation: 20 weeks or greater

Weight: 500 grams or greater

Residence: Births to residents of Texas

Surveillance methods

Case ascertainment: Active, population based

Data sources: Hospital medical records, hospital logs, hospital discharge indexes, birthing centers, midwives, birth certificates, infant death certificates

Coding: CDC code (6-digit BPA code)

Data collected: Data on facilities, transfers, personal identifiers, demographics, reproductive history, maternal illness/conditions, family medical history, maternal exposures, prenatal visits, prenatal and delivery complications, prenatal screening and diagnostic procedures, delivery/termination, postnatal complications, postnatal diagnostic/ therapeutic procedures, autopsy, and birth defects diagnoses.

Quality assurance: Case finding, case abstraction, data coding and entry

Data analysis: Basic descriptive analysis.

Data use: Epidemiologic reports, cluster investigations, epidemiologic research

Monitoring: Yes

Funding source: State appropriation, federal block grant (one-half), CDC research grant (one FTE)

Staff: 1 program director, 3 epidemiologists, 1 data manager, 1 programmer analyst, 1 systems support specialist, 1 quality control manager, 1 information specialist, 1 Research Center coordinator, 6 regional managers, 8 regional field supervisors, 30 abstractors, 8 administrative technicians

Surveillance reports on file: Report of Birth Defects

Among 1995 Deliveries, 1996 Birth Defects in the Lower Rio Grande Valley.

Procedure manual: Yes

Additional information on file: Copy of legislation; Procedures Manual [State Program file: Brochure on the Texas Birth Defects Monitoring Division (English and Spanish); brochure on Fetal Alcohol Syndrome (English and Spanish); Recent Trends in Neural Tube Defects in Texas; Leading Causes of Infant Mortality in Texas, 1993 by Ethnicity; Summary Report on Birth Defect Cluster Investigations Conducted, 1994-1997; list of conditions included in the Birth Defects Registry; Texas Birth Defects law and Board of Health Rules; Departmental policies; newsletters]; www.tdh.state.tx.us/tbdmd/index.htm

Comments: Currently, the Texas Department of Health also has the Texas Neural Tube Defect Surveillance and Intervention Project along the Texas-Mexico border, which conducts active surveillance and research on neural tube defects. It is working closely with the Texas Birth Defects Monitoring Division for effective coverage of the whole state, with concentrated effort in specific geographic areas.

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Updated: 4/99

Utah

Birth Defects Registry

Status: Surveillance of birth defects is operational with identification of all structural major malformations collected as of January 1, 1999.

Start date: January 1, 1994 for NTDs, adding oral-facial clefts and trisomies (13, 18, 21) in 1995, limb reduction defects, abdominal wall defects, arthrogryposis, skeletal dysplasias, conotruncal and left sided heart lesions and all chromosomal abnormalities in 1997.

Organizational location: Utah Department of Health, Division of Community and Family Health Services

Population coverage: Statewide –1997- 43,009 live births, 211 stillbirths (Total: 43,220)

Legislation: Rule for Birth Defects Reporting to be in place summer 1999

Case definition

Outcomes covered: Effective 1/1/99, all structural major malformations are collected.

Birth status: Live birth, stillbirth, terminations

Age: Born or diagnosed anytime after 1-1-95

Gestation: No restriction

Weight: No restriction

Residence: Mother's residence at delivery in Utah

Surveillance methods

Case ascertainment: Hospitals, cytogenetic lab, pathology, vital records, specialty clinics, prenatal diagnostic units, medical genetics

Data sources: Hospital physicians & nurses, vital records, cytogenetics, medical genetic consults, NICU discharge summaries, pediatric cardiology, prenatal diagnostic centers, Pathology Departments, Utah Women's Health Center, Specialty Clinics (Craniofacial, ENT, GI, General Surgery, Nephrology, Neurosurgery, Ophthalmology, Pulmonary, Spina Bifida, Urology).

Coding: CDC modified version of BPA

Data collected: Patient identification, prenatal information, infant physical exam information, detail of congenital malformation(s), family history, exposures of concern, maternal history (reproductive and illnesses). Based on MACDP case record form.

Quality assurance: Once case is abstracted, Marcia Feldkamp and Dr. John Carey review case to determine minor vs. major malformations, classification (e.g., isolated, multiple, sequence, syndrome). Each case entered into database will be checked by Marcia Feldkamp or Coordinator for accuracy prior to analysis. All heart defects

are reviewed by Dr. Lucianna Pagotto, pediatric cardiologist.

Data analysis: Descriptive analysis of each congenital malformation by geographic distribution, maternal age, maternal race/ethnicity, classification by isolated, multiple, or syndrome

Data use: Monitor congenital malformations for Utah, determine service needs, geographic distribution, trends, etc. Assess prevention efforts of folic acid educational campaign. Provide annual data to CDC. Determine standards of care, and access and referral to services.

Monitoring: NTDs specifically to determine if changes in rates occur due to folic acid educational campaign and folic acid food supplementation.

Funding source: CDC Cooperative Agreement, in-kind Title V funds.

Staff: BDR Committee Chair, Director, Coordinator, Community Health Specialists, Dysmorphologist and Pediatric Cardiologist consultants.

Surveillance reports on file: NTD Surveillance Report 1994; Utah Birth Defects Registry Report: Activities and 1995 Cases; Utah Birth Defects Registry Report 1994-1996, 1996, 1998.

Procedure manual: on file

Additional information on file:

Comments: Expanded the surveillance to other birth defects and conditions in 1997. Will expand again in the near future.

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Updated: 4/99

Vermont

Status: No system, with no immediate plans for developing one.

Start date:

Organizational location:

Population coverage:

Legislation:

Case definition

Outcomes covered:

Birth status:

Age:

Gestation:

Weight:

Residence:

Surveillance methods

Case ascertainment:

Data sources:

Coding:

Data collected:

Quality assurance:

Data analysis:

Data use:

Monitoring:

Funding source:

Staff:

Surveillance reports on file:

Procedure manual:

Additional information on file:

Comments:

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Updated: 11/99

Virginia

VaCARES: Virginia Congenital Anomalies Reporting and Education system.

Status: Operational

Start date: Jan 1, 1987

Organizational location:

Population coverage: Statewide (approximately 95,000 births annually)

Legislation: Yes, 1985. Code of Virginia 32.1-69.1 and 32.1-69.2. Mandatory reporting by hospitals. Legislation established registry for epidemiological surveillance and identifying children for services

Case definition

Outcomes covered: Birth defects and genetic diseases

Birth status: Live born

Age: Birth to age 2

Gestation: NA

Weight: Any

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

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Surveillance methods

Case ascertainment: Passive, hospital based. Hospital staff sends data directly to surveillance program. Vital records are sent to program.

Data sources: Medical records and birth certificates

Coding: CDC coding system (6-digit BPA/ICD-9-CM)

Data collected: Personal identifiers, hospital name, names of physicians, demographic data, malformations, complications of birth

Quality assurance: Data analysis

Data analysis: Incidence rates, trend analysis, special epidemiologic studies

Data use: Epidemiology studies, monitoring, registry, baseline rates, education

Monitoring: Yes

Funding source: State appropriation and MCH block grant

Staff: 1 Statistician, 1 Nurse, 1 data entry clerk, and 1 secretary

Surveillance reports on file: Annual Surveillance Report

Procedure manual:

Additional information on file: VaCARES summary, list of diagnoses, copy of legislation

Comments:

Contact:

Updated: 5/99

Washington

Washington State Birth Defects Registry

Status: Operational

Start date: Active: 1-1-86 through 12-31-91. Passive: 1-1-92 to present.

Organizational location: Department of Health/Community and Family Health/Children with Special Health Care Needs

Population coverage: Statewide, 80,000 births annually

Legislation: Public Health Law RCW 70.58.3000-70.58.350 was repealed by Legislature 1999. Specific conditions were added to the Notifiable Conditions Legislation.

Case definition

Outcomes covered: Active: All birth defects, specific genetic diseases, FAS/E, fetal deaths with birth defects. Passive: All birth defects, specific genetic diseases, FAS/E.

Birth status: Active: Live births and stillbirths. Passive: Live births.

Age: Birth to 4 years

Gestation: Greater than 22 weeks

Weight: Any weight

Residence: In-state and out-of-state birth to state resident; in-state birth to nonresident; in-state diagnosis/treatment of in-state or out-of-state child; out-of-state diagnosis/treatment of state child resident

Surveillance methods

Case ascertainment: Active: Medical Facility-generated log (medical records department personnel). Passive: Same.

Data sources: Active: Medical Facility (birth and pediatric hospitals and out-patient clinics, including genetics) records. Vital Statistics Certificates (Birth, Death, Fetal Death) database. Passive: Medical Facilities only.

Coding: Active: British Pediatric Association (BPA). Passive: ICD-9-CM.

Data collected: Active: Name, date of birth, demographic data (including current residence, parent names, residence at birth), name of hospital, names of physicians, measurements at birth, diagnoses (including date, mode [i.e., type of examination or test], and type of provider making diagnosis), syndromes (either named or determined by the medical consultant), medical history, pertinent family history, cytogenetic analysis, discharge disposition, medical record number. Passive: Name, date of birth, diagnosis, ICD-9 code, discharge date, discharge disposition, zip code, medical record number.

Quality assurance: Active: Reabstraction of predetermined percentage of cases of each field worker.

Passive: None; planned for data coding and entry, data analysis.

Data analysis: Active: Incidence rates. Passive: Data comparison to previous incidence and to other current data collection systems in state.

Data use: Active: Epidemiology, needs assessment, monitoring, service planning, baseline rates, service delivery, education. Passive: Same, once data quality assured

Monitoring: Active: Yes

Funding source: Active: CDC Grant. Passive: MCH block grant (60%), state general funds (40%).

Staff: Active: Program director, quality assurance coordinator, 5 field state data abstractors, epidemiologist, secretarial support staff, data manager. Passive: Program director (.1 FTE), data entry (.05 FTE).

Surveillance reports on file: Brighter Futures Technical Report - statistical summary of children born in 1987 and 1988

Procedure manual: Active: Yes

Additional information on file: Copy of legislation

Comments: Washington was an active case ascertainment system from 1987 to 1991; when funds were cut, the system became passive. Recent internal and external processes have resulted in a change in the surveillance system that will be implemented during 1999 and 2000.

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Updated: 5/99

West Virginia

West Virginia Adverse Reproductive Outcome Registry

Status: Operational

Start date: 7-1-90

Organizational location: Bureau for Public Health:
Epidemiology and Health Promotion; Maternal and Child
Health Research

Population coverage: Statewide, 22,000 births annually

Legislation: West Virginia Code Chapter 16, Article 5,
Section 12A

OMCH

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Case definition

Outcomes covered: All birth defects, genetic diseases,
developmental disabilities, infant mortality (neonatal and
postnatal)

Birth status: Live births, stillbirths greater than 20 weeks

Age: Birth through 6 years

Gestation: Greater than 20 weeks

Weight: Any weight

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

Updated: 6/99

Surveillance methods

Case ascertainment: Passive, population based

Data sources: Hospital medical records, genetic service
clinics

Coding: ICD-9-CM

Data collected: Personal identifiers, demographic data,
names of hospitals, names of physicians, measurements at
birth, complications of birth, data on previous pregnancies,
malformations, syndromes, family history, cytogenetics, risk
factors

Quality assurance: Data coding and entry

Data analysis: Incidence rates, trend analysis

Data use: Epidemiology, monitoring, baseline rates,
family support, registry

Monitoring: Yes

Funding source: State appropriation (100%)

Staff: Epidemiologist, programmer, medical geneticist,
microcomputer specialist, genetic counselor

Surveillance reports on file: None

Procedure manual: West Virginia Birth Defects
Registry Reporting Manual (December, 1989)

Additional information on file: Copy of legislation

Comments:

Contact:

Pat Moss, Director

Wisconsin***Birth and Developmental Outcome Monitoring Program (BDOMP)***

Status: Operational (see comments)

Start date: January 1990

Organizational location: Center for Health Statistics

Population coverage: Statewide, 68,000+ births annually

Legislation: WIS. S. 146.028

Case definition

Outcomes covered: All birth defects, genetic diseases, developmental disabilities, fetal mortality (stillborn), infant mortality (neonatal and postnatal), low birth weight (1500 grams to less than 2500 grams), very low birth weight (less than 1500 grams)

Birth status: Live births, stillbirths

Age: Birth to 6 years

Gestation: (unspecified)

Weight: Any weight

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

Surveillance methods

Case ascertainment: Passive, population based

Data sources: Birth defect information is available from a linked file of birth, birth and infant death match, hospitalization and Medicaid claims files.

Coding: Modification of ICD-9-CM code

Data collected: Personal identifiers, demographic data, names of hospitals, names of physicians, complications of birth, malformations, syndromes, agents was mother exposed to during pregnancy

Quality assurance: Data analysis

Data analysis: Incidence rates, trend analysis, data analyses for special epidemiological studies

Data use: Monitoring, service planning, baseline rates, service delivery

Monitoring: Yes

Funding source: State appropriation (100%)

Staff: None

Surveillance reports on file: 1991 (draft)

Procedure manual:

Comments: No staff has been assigned to the Birth and Developmental Outcome Monitoring Program since the fall of 1995.

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Updated: 5/99

Additional information on file: Copy of legislation; BDOMP Report Form; BDOMP Request for Information Form; Excerpt from the 1992 Compendium of Health Effects Data Bases In the Greater Lakes Region (Volume I)

Wyoming

Status: No system, but currently developing one

Start date: 1999

Organizational location: Genetic Program

Population coverage: Statewide

Legislation: NA

Case definition

Outcomes covered: birth defects/genetic disease

Birth status: live births

Age: birth - 19y

Gestation: >20 wks

Weight: >500 grams

Residence: births by residence

Surveillance methods

Case ascertainment: population based

Data sources: VR, MCH, specialty clinics

Coding: open

Data collected: NA

Quality assurance: NA

Data analysis: NA

Data use: NA

Monitoring: NA

Funding source: MCH

Staff: Genetic Program Manager (.25 FTE)

Surveillance reports on file: Under Development

Procedure manual: Under Development

Additional information on file: Under Development

Comments: NA

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