State Birth Defects Surveillance

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Centers for Disease Control and Prevention

National Center on Birth Defects
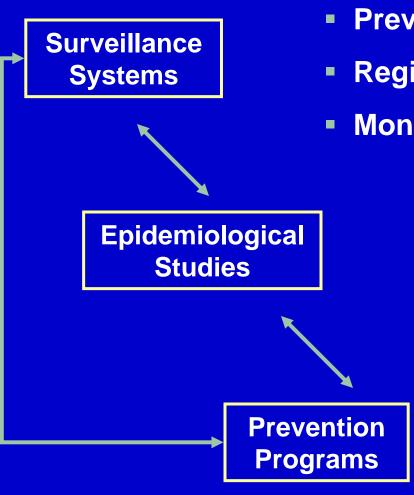and Developmental Disabilities

Public Health Importance of Birth Defects

- **120,000 to 160,000 children are born with major birth defects each year**
- **30% of admissions to pediatric hospitals**
- **17 most significant birth defects: $8 billion annually**
- **Leading cause of infant mortality**
- **Some causes entirely preventable**

CDC's Role in Preventing Birth Defects

Surveillance Systems

Epidemiological Studies

Prevention Programs

- **Prevalence rates**
- **Registry of cases for study referral**
- **Monitor prevention**

- **Risk factors**
- **Protective factors**
- **Public concerns**

- **Prevention strategies**
- **Public policy**
- **Education**

History of Birth Defects Surveillance

- **1960's   International Interest due to Thalidomide**

- **1968   Metropolitan Atlanta Congenital Defects Program started at CDC**

- **1974   3 State programs**

- **1980's   Epidemiologic research and State surveillance programs**

- **1996   Birth Defects Prevention Act**
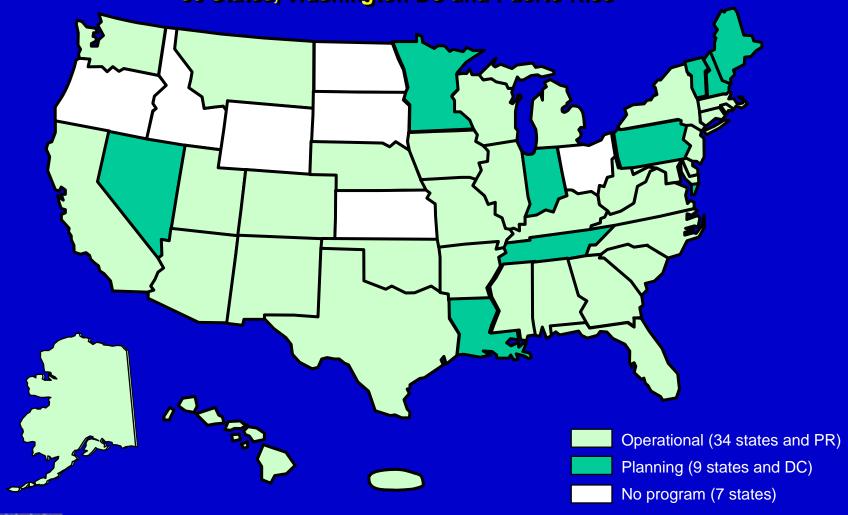
- **2002   35 operational and 10 planning programs**

Purposes of a Birth Defects Surveillance Program

- Detect time trends, epidemics

- Quantify morbidity or mortality

- Evaluate community concerns

- Stimulate epidemiological research

- Evaluate the need for and facilitate access to services

- Guide and assess the progress of intervention and prevention

- Provide information for education and advocacy

U.S. Birth Defects Surveillance Programs
50 States, Washington DC and Puerto Rico

Operational (34 states and PR)

Planning (9 states and DC)

No program (7 states)
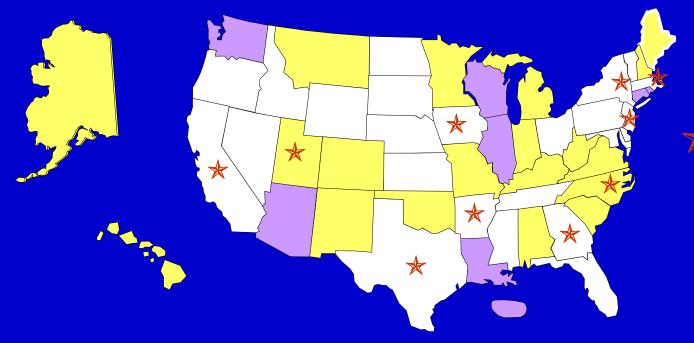
Cooperative Agreement for Enhanced State-Based Birth Defects Surveillance and <u>Use</u> of Surveillance Data to Guide Prevention and Intervention

- Improve quality and timely ascertainment of major birth defects
- Improve access to care for children with birth defects
- Improve timely ascertainment of NTD cases
- Work on prevention and intervention programs
- Encourage surveillance of prenatally diagnosed cases
- Evaluate surveillance and intervention activities

Status: 33 states with current awards

Cooperative Agreements for Birth Defects Activities

Centers for Birth Defects Research and Prevention

Arkansas
California
CDC
Iowa
Massachusetts
New Jersey
New York
North Carolina
Texas
Utah

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Arizona	Puerto Rico
Connecticut	Rhode Island
Illinois	Washington
Louisiana	Wisconsin

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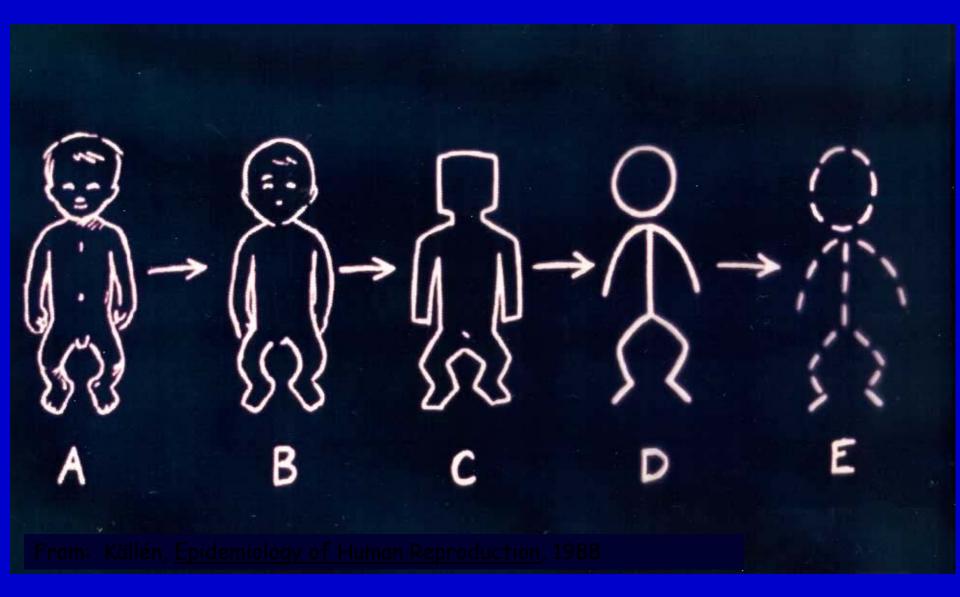|			
Alabama	Indiana	Minnesota	Oklahoma
Alaska	Kentucky	Montana	South Carolina
Colorado	Maine	New Hampshire	Utah
DC	Michigan	New Mexico	Virginia
Hawaii	Missouri	North Carolina	West Virginia

CDC

Case Ascertainment Methods for Identifying Infants with Birth Defects

- **Examine every baby born**

- **Review medical records including hospital data from nurseries, NICU, specialty clinics, laboratories, screening programs**

- **Legislative mandate for hospital or physician reporting**

- **Linkage of multiple data sources**

- **Vital Statistics - births, deaths, fetal deaths**

A   B   C   D   E

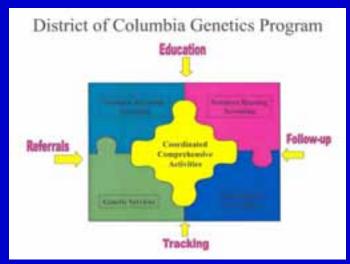From: Källén, Epidemiology of Human Reproduction, 1988

Data Collection Methods

- <u>Printed</u> abstract/report filled out by staff – 22 programs
- <u>Printed</u> abstract/report submitted by other agencies (hospitals, etc.)   -- 16 programs
- <u>Electronic</u> file/report filled out by staff at facility (laptop, web-based, etc.) –17 programs
- <u>Electronic</u> file/report submitted by other agencies (hospitals, etc.) – 17 programs
- <u>Electronic</u> <u>scanning</u> of printed records – 1 program

Birth Defects Programs <u>Linkage</u> to Other Programs, Databases or Registries

- Link to other state registries/databases
  - CO, DC, GA, IA, IN, KS, ME, NJ, NM, NC, RI, VA (11 programs)

- Link case finding data to final birth file
  - AK, AR, CA, CO, DC, GA, IA, IN, KY, ME, MA, MI, MO, MT, NV, NJ, NM, NY (18 programs)

- Link to environmental databases
  - IA (1 program)

- No current linkage
  - AL, AZ, DE, IL, LA, MN, MS, NE, NH, ND, OK, PA, PR, SC, TN, UT, WA (17 programs)

District of Columbia Genetics Program

Education

Referrals

Coordinated Comprehensive Activities

Follow-up

Tracking

Birth Defects Programs <u>Integration</u> with Other Databases

- Birth Defects Programs <u>integration</u> with other databases
  - CT, KY, MT, NJ, NM, and VA (6 programs)
- CBDRP, National Birth Defects Prevention Study
  - Case control study of major birth defects
  - 10 surveillance programs
  - Integration of clinical, interview, and biologics databases

Challenges

- Access to data/release of data for intervention activities (HIPAA/FERPA/confidentiality issues)

- Legislative restraints

- Funding

- Data integration, e.g. technological issues

- Continuous improvement in timely and quality data collection

- Prenatal surveillance

- Continuous momentum of prevention activities and partnership collaboration

Accomplishments/Successes

- NBDPN – forum for exchanging ideas and developing uniform methods

- NBDPN annual data collection from 30+ programs

- NTD Ascertainment Project from 26 programs

- CBDRP – clinical, biologics, and CATI electronic integrated databases

Future Plans

- NBDPN Surveillance Guidelines and Standards

- New cooperative agreements in September 2003

- Encourage integration of surveillance systems

- Continue to provide technical support

Case Ascertainment methods for Identifying Infants with Birth Defects (II)

- **Legislative mandate for hospital or physician reporting**
    - **New York, New Jersey**

- **Linkage of multiple data sources**
    - **North Carolina, Missouri, Colorado**

- **Vital Statistics - births, deaths, fetal deaths**

- **Other data sources - Prenatal diagnosis, Genetic clinics, Medicaid, Special Health Care Needs Programs, physician records, special surveys**

Case Ascertainment methods for Identifying Infants with Birth Defects (I)

- **Examine every baby born**
    - **Collaborative Perinatal Project**

- **Review medical records including hospital data from nurseries, NICU, specialty clinics, laboratories, screening programs**
    - **Metro Atlanta, Hawaii, Iowa**

- **Identify records for review with hospital discharge summaries or disease indexes**
    - **Arizona, California**

- **Use existing hospital discharge data and outpatient data**
    - **National BDMP, H-CUP, Connecticut**

Data Sources for Surveillance

- Vital Records

- Hospital Records (Discharge summaries or disease indexes, nursery logs, NICU logs, specialty clinics)

- Administrative databases (Medicaid, state hospital discharges, HMO's)

- Special Data Sources (Special Health Care Need Programs, specialty clinics)

- Prenatal Diagnosis Center

- Clinical Examination (CCP, hospital-based surveillance, special studies)

Rates of Major Birth Defects Determined by Various Data Sources

Method and Source	Rate
Birth Certificates*	1.5%
Newborn hospital discharge§	4.3 - 7.1%
Mandatory hospital reporting¶	3.4%
Linked data sources * *	4.7%
Active hospital surveillance §§	3.2%
Physical exam of infants ¶¶	8.3%

* Birth Certificates - 1996
§ Florida 1996
¶ New York - 1994-96

* * North Carolina - 1995-96
§§ MACDP 1995-99
¶¶ Collaborative Perinatal Project - 1959-96