



State Birth Defects Surveillance

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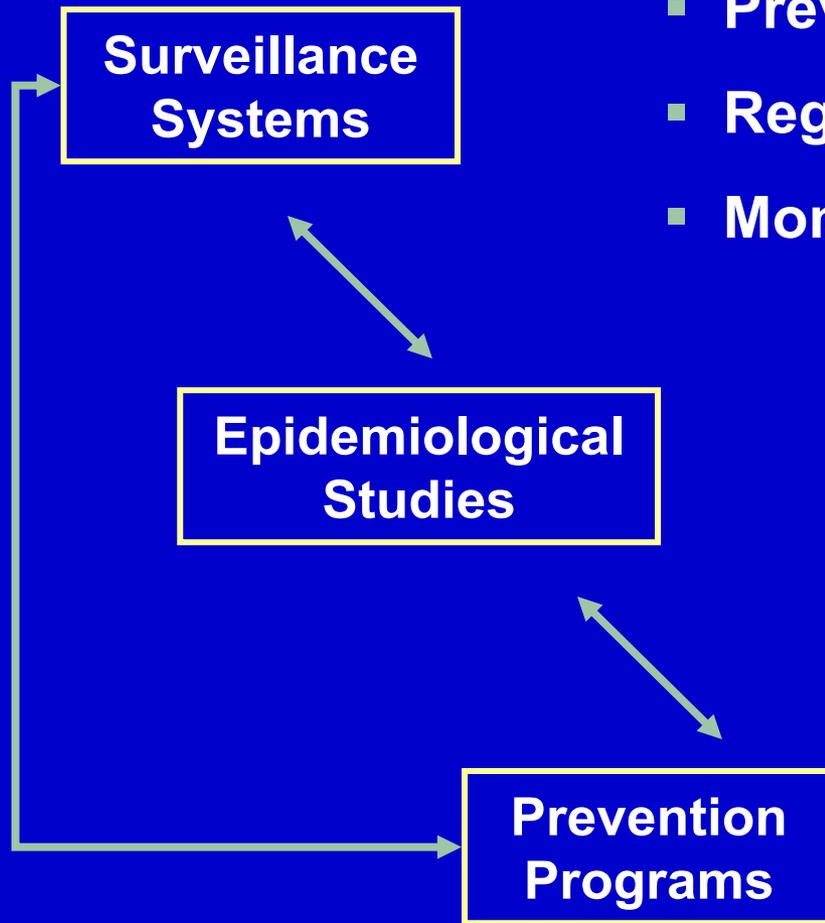
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Public Health Importance of Birth Defects

- 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



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

- Risk factors
- Protective factors
- Public concerns

- Prevention strategies
- Public policy
- Education



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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



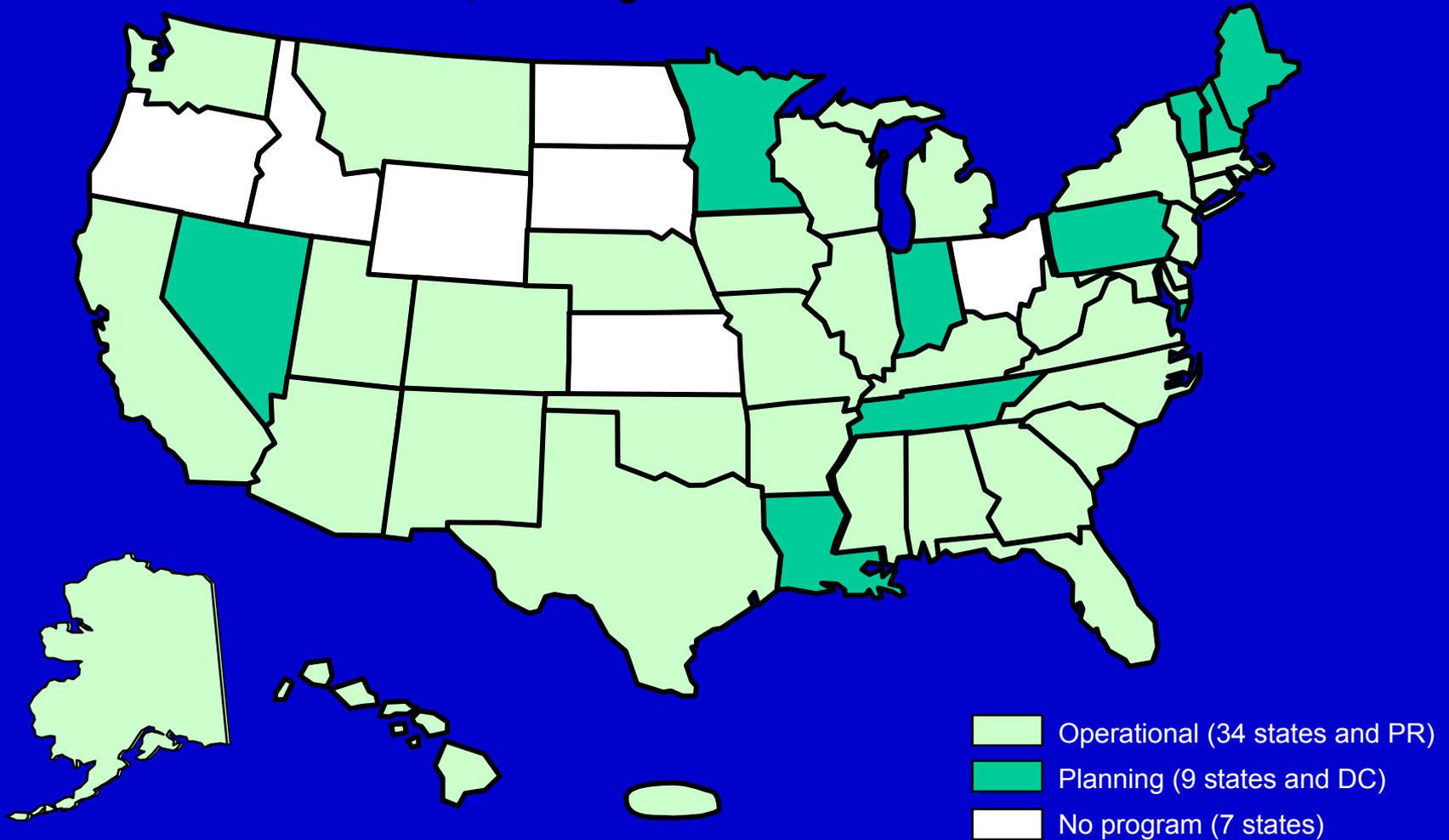
Purposes of a Birth Defects Surveillance Program

- 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



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Cooperative Agreement for Enhanced State-Based Birth Defects Surveillance and Use of Surveillance Data to Guide Prevention and Intervention

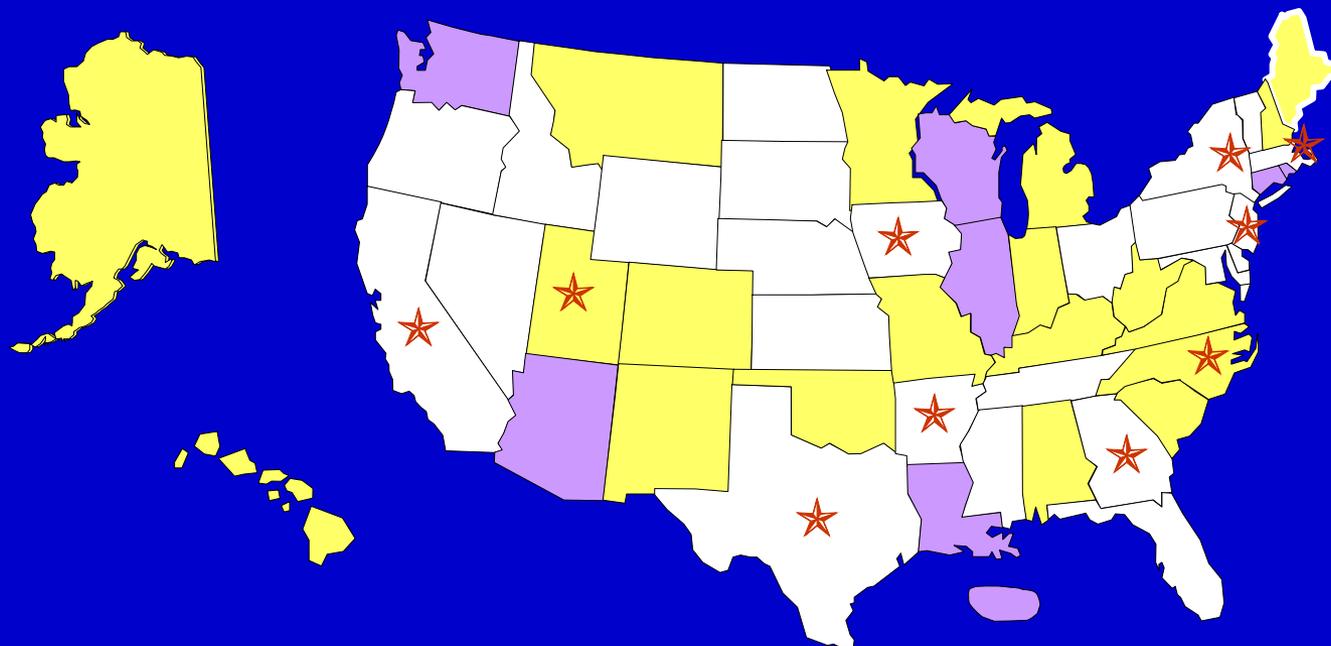
- Improve quality and timely ascertainment of major birth defects
- Improve access to care for children with birth defects
- Improve timely ascertainment of NTD cases
- Work on prevention and intervention programs
- Encourage surveillance of prenatally diagnosed cases
- Evaluate surveillance and intervention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

Status: 33 states with current awards



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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
- Connecticut
- Illinois
- Louisiana
- Puerto Rico
- Rhode Island
- Washington
- Wisconsin

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

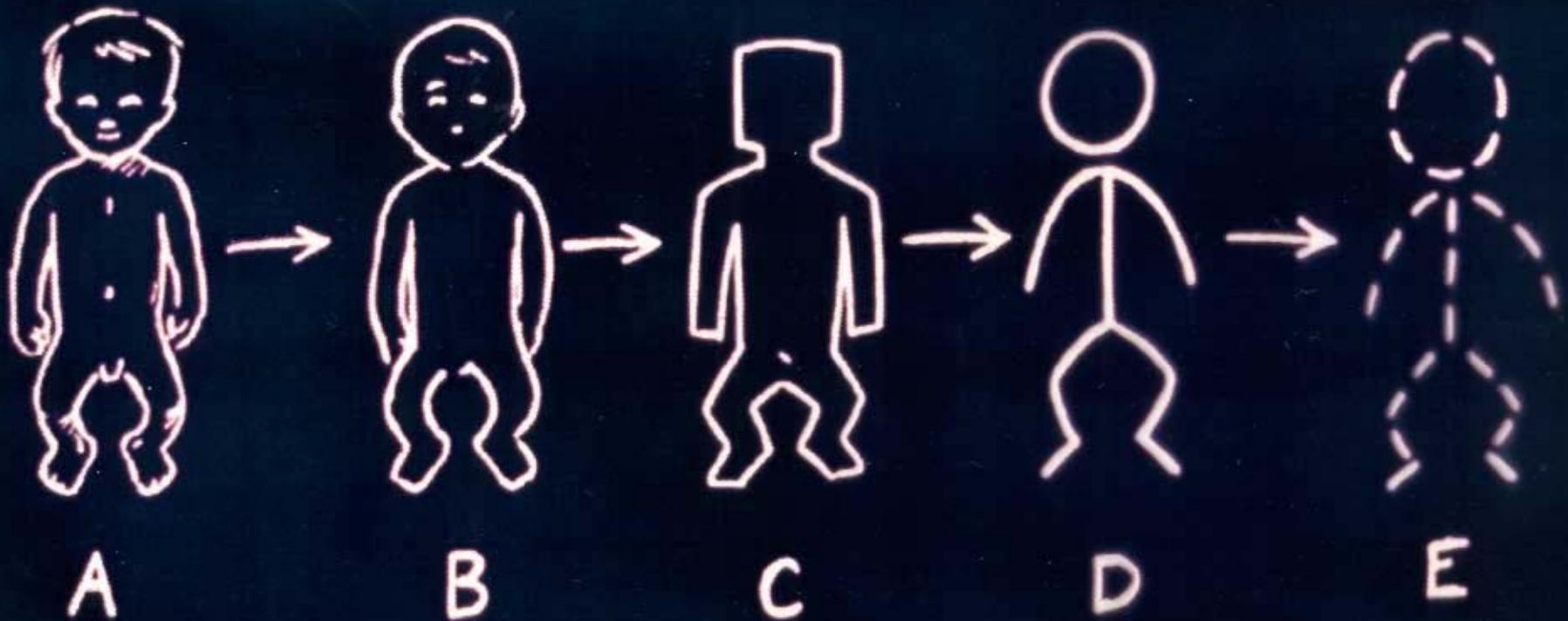


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Case Ascertainment Methods for Identifying Infants with Birth Defects

- 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





From: Källén, *Epidemiology of Human Reproduction*, 1988



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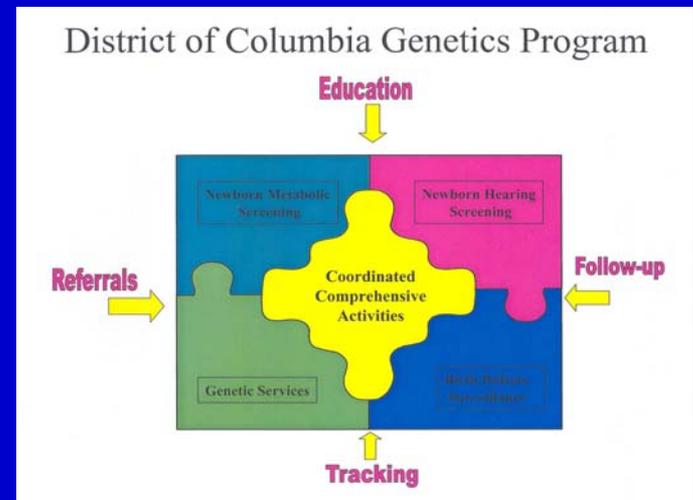
Data Collection Methods

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



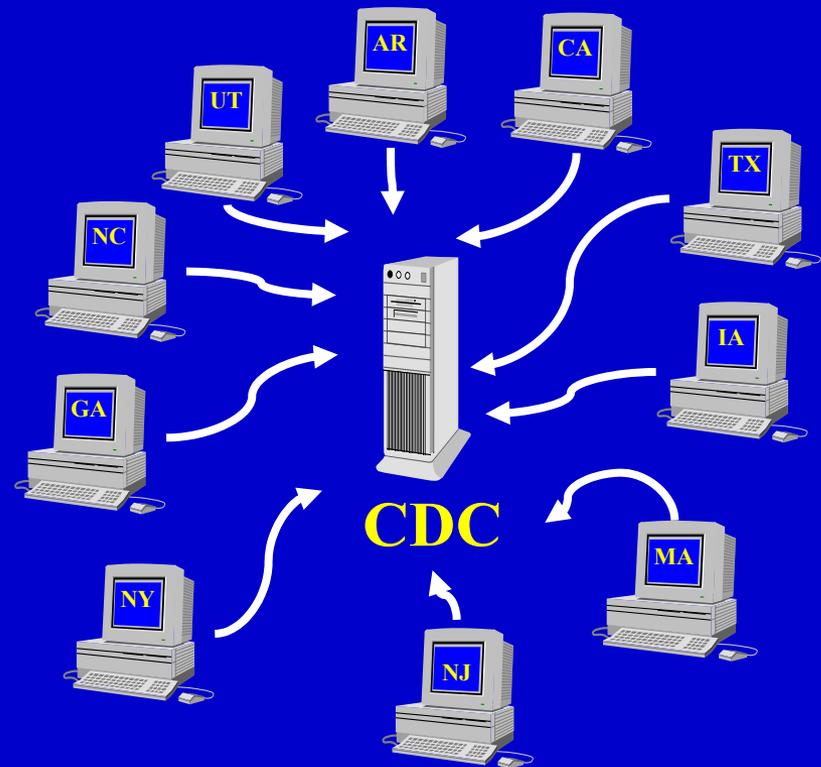
Birth Defects Programs Linkage to Other Programs, Databases or Registries

- 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)



Birth Defects Programs Integration with Other Databases

- Birth Defects Programs integration 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 biologic 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



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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

| <u>Method and Source</u> | <u>Rate</u> |
|----------------------------------|-------------|
| 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



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