Birth Defects and Developmental Disabilities: CDC Activities

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Birth Defects: Impact

- 1 in every 33 babies is born with a major birth defect
- 17 most significant birth defects and cerebral palsy: $8 billion annually
- 30% of admissions to pediatric hospitals
- Leading cause of infant death
- Some causes entirely preventable
10 Leading Causes of Infant Deaths – United States, 2004*

- Birth Defects: 5622
- LBW and prematurity: 4642
- SIDS: 2246
- Maternal complications: 1715
- Unintentional injuries: 1052
- Complications of placenta, cord, and membranes: 1042
- Respiratory distress syndrome: 875
- Spesis: 827
- Neonatal hemorrhage: 616
- Circulatory system disease: 593

*Source: Centers for Disease Control and Prevention, National Vital Statistics System, Mortality
Developmental Disabilities: Impact

- 17% of children 18 years and younger have a developmental disability
- 3% have a severe disability with lifelong consequences
- Significant impact on families and costs for health care and education services
### Estimated Lifetime Economic Costs of Selected Developmental Disabilities – U.S.*

<table>
<thead>
<tr>
<th>Developmental Disabilities</th>
<th>Total Costs (billions)</th>
<th>Average Costs Per Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Retardation</td>
<td>$51.237</td>
<td>$1,014,000</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>$11.470</td>
<td>$921,000</td>
</tr>
<tr>
<td>Hearing Loss</td>
<td>$2.102</td>
<td>$417,000</td>
</tr>
<tr>
<td>Vision Impairment</td>
<td>$2.484</td>
<td>$566,000</td>
</tr>
</tbody>
</table>

*Present value estimates, in 2003 dollars, of lifetime costs for persons born in 2000, based on a 3% discount rate. Source: CDC. MMWR January 30, 2004 53(03); 57-59*
Number of Children with Autism Served under IDEA*, Part B, 1992–93 to 2000-01, 6–21 years

IDEA = Individuals with Disabilities Education Act; State DOE reporting of autism eligibility mandated in 1992
Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS)
CDC Public Health Cycle

Surveillance → Research → Prevention → Surveillance
What's So Important About Numbers?

- Surveillance
  - Documents the impact of health conditions and who they affect
  - Serves as a resource for programs, policymakers, and others (e.g., TFAH Birth Defects Report)

- In addition, surveillance allows us to:
  - Track trends over time
  - Identify potential clusters
  - Identify those at higher risk (e.g., race, ethnic groups)
  - Provide clues to be further pursued in research
Cooperative Agreements for Birth Defects Activities

- Centers for Birth Defects Research
  - Arkansas
  - California
  - CDC
  - Iowa
  - Massachusetts
  - New York
  - North Carolina
  - Texas
  - Utah

2003-2008
- Arizona
- Florida
- Illinois
- New Jersey
- New York
- Ohio
- Puerto Rico
- Vermont

2005-2010
- Colorado
- Michigan
- Minnesota
- New Hampshire
- Oklahoma
- Rhode Island
- Virginia
- Texas
- Utah
```markdown
# Estimated Birth Defects Surveillance Cost by Methods*

<table>
<thead>
<tr>
<th>Birth Defects Surveillance Method</th>
<th>Quality of Data</th>
<th>Cost Per Live Birth</th>
<th>Cost Per Case Ascertained</th>
<th>Total Cost for 50,000 births each year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Certificates (1 state)</td>
<td>Poor</td>
<td>---</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Mandatory Hospital Reporting (12 states) - without follow-up</td>
<td>Fair</td>
<td>$1-$5</td>
<td>$25-$125</td>
<td>$50,000 – $250,000</td>
</tr>
<tr>
<td>Mandatory Hospital Reporting (11 states) – with follow-up &amp; quality control</td>
<td>Good</td>
<td>$5-$10</td>
<td>$125-$250</td>
<td>$250,000 – $500,000</td>
</tr>
<tr>
<td>Intensive Surveillance (10 states)</td>
<td>Best</td>
<td>$10-$30</td>
<td>$250-$750</td>
<td>$500,000 – $1,500,000</td>
</tr>
</tbody>
</table>

*These are estimates and can vary greatly depending on the specific methodology used.*
Organizational Location of U.S. Population-based Birth Defects Programs

- DOH, Vital/Health Statistics: 9
- DOH, MCH/CSHCN/Family Health: 27
- DOH, Genetics: 3
- University: 7
- Other (non-profit, hospital, CDC, DOD): 4
CDC Autism Activities

ADDM Phase 1 (2000-2006): 16 Sites (15+CDC)
ADDM Phase 2 (2006-2010): 11 Sites (10+CDC)

CADDRE
CDC
ADDM Phase 1 (2000-2006): 16 Sites (15+CDC)
ADDM Phase 2 (2006-2010): 11 Sites (10+CDC)

SAFER • HEALTHIER • PEOPLE™
CDC Public Health Cycle

Monitoring

Research

Prevention
Most causes of birth defects and developmental disabilities are unknown.

- **Unknown**: 66%
- **Known Genetic Factors**: 28%
- **Uterine Factors**: 3%
- **Teratogens, e.g., Thalidomide**: 3%

From Nelson and Holmes, NEJM January 5, 1989
Public Health Research: Activities and Impact

- Epidemiological & case-control studies
  - Cluster investigations
  - Collaborative research centers

- Impact of research
  - Identifies opportunities to prevent conditions before they occur
  - Provides foundation for strategies to intervene with children with affected conditions
Recent Research Results

Predictors of vitamin use among reproductive aged women

Over the counter medication use in pregnancy

Progestin intake and certain birth defects

Maternal nutrient intake and cleft lip/palate

Claritin® use and certain birth defects

Maternal smoking and certain birth defects
CDC Public Health Cycle

Monitoring  Research  Prevention
Birth Defects and Disabilities: Potential for Prevention and Intervention

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Action</th>
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<tbody>
<tr>
<td>Thalidomide</td>
<td>Restricted Prescription &amp; Distribution</td>
</tr>
<tr>
<td>Prenatal Alcohol Exposure</td>
<td>Brief Interventions with high risk women</td>
</tr>
<tr>
<td>Mental Retardation Caused by Hib Meningitis</td>
<td>Conjugated Hib Vaccine</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>Folic Acid Fortification &amp; Supplementation</td>
</tr>
<tr>
<td>Late Diagnosis of Metabolic Conditions and Hearing Loss</td>
<td>Newborn Screening</td>
</tr>
</tbody>
</table>
Folic Acid Prevents Neural Tube Defects!

- PHS recommendation: 400 micrograms (µg) daily for women capable of becoming pregnant to reduce the risk of having a pregnancy affected with a neural tube defect
- FDA mandates food fortification that began in 1998
NTD Rates by Race/Ethnicity

Prevalence (per 10,000)

Year of birth

Pre-fortification  Optional Fortification  Mandatory Fortification

Source: NBDPN NTD Ascertainment Project
Corn Flour Fortification

No Folic Acid

Corn flour available in the United States

Folic Acid

Corn flour available in other countries, such as Costa Rica
Savings in direct costs of care for children with spina bifida (SB) due to folic acid fortification (conservative estimates):

\[ 600 \times $300,000 = $180,000,000 \text{ SAVINGS} \]

- 600 – babies born free of SB each year
- $300,000 – lifetime savings in direct costs for each child born free of SB
- $180,000,000 – total savings per year in direct cost as a result of folic acid fortification
Screening and Intervention as a Tool for Improving Children’s Health

- Screening to identify health conditions
  - Hearing loss: nation-wide screening for hearing loss improved from 46% to 65%

- Referral and intervention
  - Colorado Birth Defects Program: 65% of families that it refers for intervention services are new to the local system

- Health promotion for people with disabilities
  - Quality of life for children and adolescents with spina bifida
CDC's
National Center on
Birth Defects and
Developmental Disabilities

Promoting the health of babies, children, and adults, and enhancing the potential for full, productive living