CDC’s Public Health Research on Autism

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National Center on Birth Defects and Developmental Disabilities
CDC’s Public Health Research on Autism

1. Tracking and monitoring

2. Studies of *risk factors* and *causes* (includes prevention of secondary conditions)

3. Research and education to increase the *early identification*
Tracking and Monitoring
What questions can we address?

- What is the prevalence of autism in the U.S?
- Are certain groups more likely to develop autism?
- Is the rate increasing?
- What factors may contribute to changes in rates?
- Is the type of autism changing?
Main Focus of CDC Developmental Disabilities Activities

Tracking and Monitoring
- Metropolitan Atlanta Developmental Disabilities Surveillance Program
- Autism and Developmental Disabilities Monitoring Network

Autism Research and Epidemiology
- Centers for Autism & Developmental Disabilities Research & Epidemiology
- CDC/Danish collaborations

Early Diagnosis and Intervention
- Learn the Signs. Act Early.
## Prevalence of Developmental Disabilities

**Among Children 3-10 Years of Age, Atlanta, Georgia (1991-1994)**

<table>
<thead>
<tr>
<th>Disability</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Retardation</td>
<td>1:103</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>1:110</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1:357</td>
</tr>
<tr>
<td>Vision Impairment</td>
<td>1:1100</td>
</tr>
<tr>
<td>Children with multiple disabilities</td>
<td>1:1250</td>
</tr>
<tr>
<td>Any Above Disability</td>
<td>1:83</td>
</tr>
</tbody>
</table>

Source: Metropolitan Atlanta Developmental Disabilities Surveillance Program
Autism Prevalence Rates - Epidemiologic Studies

Three US studies from 1980’s and early 1990’s

- Autistic disorder: 0.3-0.4 per 1,000

CDC studies in specific communities:

Brick, NJ, 1998

- Autistic disorder: 4 per 1,000
- Autism spectrum: 6.7 per 1,000

Atlanta, 1996

- Autism: 3.4 per 1,000

Estimates from outside the US in the 1990’s

- Autistic disorder: 1 per 1,000
- Autism spectrum: 4-5 per 1,000
- Recent estimates: 2-6 per 1,000
  (1:500 to 1:166)

Only 2 trend studies:

- Sweden (increase)
- France (stable)
Number of Children with Autism Served under IDEA, Part B, 1992-93 to 2000-01, 6-21 years

School Year (# states reporting) *includes DC & PR

State DOE reporting of autism eligibility mandated in 1992
Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS)
Autism, Prevalence Rate by Race and Gender, Atlanta, 3-10 year olds

- White
  - Males: 5
  - Females: 1
- African American
  - Males: 5
  - Females: 1
### Autism and Concomitant Conditions, Atlanta, 1996

<table>
<thead>
<tr>
<th>Type of Disability</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolated Autism</td>
<td>376</td>
<td>38</td>
</tr>
<tr>
<td>Autism and Other DD</td>
<td>611</td>
<td>62</td>
</tr>
<tr>
<td>Type of Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Mental Retardation</td>
<td>581</td>
<td>59</td>
</tr>
<tr>
<td>– Cerebral Palsy</td>
<td>49</td>
<td>5</td>
</tr>
<tr>
<td>– Deafness</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>– Blindness</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>– Epilepsy</td>
<td>76</td>
<td>8</td>
</tr>
</tbody>
</table>
Learn the Signs. Act Early.

It’s time to change how we view a child’s growth
Mission

Every child reaches his or her full potential
Campaign Objectives

• Increase **AWARENESS** of developmental milestones and early warning signs
• Increase **KNOWLEDGE** in the benefits of early action and EI service system
• Increase parent-provider **DIALOGUE** on the topic of developmental milestones and disorders
• Increase **EARLY ACTION** on childhood developmental disorders

Learn the Signs. Act Early.
Target Audiences

- **Child health care professionals (HCPs)**
  - Pediatricians, family physicians, physician’s assistants, nurses
- **Parents of young children**
  - Ages 4 and younger
- **Child care and early education providers**
Accomplishments

• Outreach to Health Care Professionals
  – Reached nearly 3 million providers via e-card and matte release
  – Reached nearly 50,000 providers through conferences
  – Distributed more than 14,000 Resource Kits (posters, fact sheets, informational cards, growth chart)

Learn the Signs. Act Early.
Outreach to HCPs

• **Phase 2: Broadening Relationships**
  
  – Build deeper partnerships with HCP and non-profit organizations
  – National conferences
  – State and local outreach (including public health partners)
  – Partner on training/CME for developmental screening
  – More info. on referral resources
American Academy of Pediatrics: Autism Alarm

Autism is prevalent
- 1 out of 6 children are diagnosed with a developmental disability and/or behavioral problem
- 1 in 166 children are diagnosed with an autism spectrum disorder

Listen to parents
- Early signs of autism are often present before 18 months
- Parents usually do have concerns that something is wrong
- Parents generally do give accounts and quality information
- When parents do not spontaneously raise concerns, ask if they have any

Act early
- Make screening and surveillance an important part of your practice (as outlined by the AAP)
- Know the subtle differences between typical and atypical development
- Learn to recognize red flags
- Use validated screening tools and identify problems early
- Improve the quality of life for children and their families through early and appropriate intervention

Refer
- To Early Intervention or a local school program (do not wait for a diagnosis)
- To an autism specialist, in terms of specialists, immediately for a definitive diagnosis
- To audiology and rule out hearing impairment
- To local community resources for help and family support

Monitor
- Schedule a follow-up appointment to discuss concerns more thoroughly
- Look for other features known to be associated with autism
- Educate parents and provide them with up-to-date information
- Advocate for families with local early intervention programs, schools, and local agencies, and insurance companies
- Continue surveillance and watch for additional or late signs of autism and other developmental disorders

For More Information: www.electroaminole.org

Developmental Screening Guidelines for Children

The following guidelines, adapted from key policy statements of the American Academy of Pediatrics and American Academy of Neurology, were developed in order to establish standard practices among physicians, for identifying the screening process, and to ensure that all children receive routine and appropriate screenings and early interventions.

1. General observations and developmental milestones.
   Take a brief account at the start of each well visit to observe how a child behaves, interacts, and communicates with a parent or caregiver.

2. Ongoing developmental screening and assessment.
   A physician, nurse practitioner, or certified autism provider should perform periodic developmental screenings using a high-quality standardized survey at each well visit to identify all children from birth through school age to identify those at risk for typical development.

3. Referral to Early Intervention and for a developmental evaluation.
   When a parent raises a concern, or a developmental screen indicates a possible delay, refer the child for a comprehensive evaluation by a specialist or a team of specialists in early childhood education.

   When a child presents with a developmental delay, refer the child for formal auditory testing.

Learn the Signs. Act Early.
Accomplishments

• Outreach to Parents
  – High-profile launch event resulted in national news media coverage: “Good Morning America,” “Newsweek,” MSNBC, CNBC, AP, NY Times, LA Times…reached an estimated 3.9 million people
  – Long lead media tour produced stories in “Child,” “Parenting,” and “Parents”
  – TV PSA broadcast in 5 cities, including Time’s Square 32 times per day for 30 days – pro bono!
  – Distributed more than 15,000 Parent Kits (growth chart, fact sheets, informational card)

Learn the Signs. Act Early.
Preliminary Data

- **AWARENESS**
  - 43% of pediatricians aware of LTSAE, 1 year after campaign launch
  - 27% of parents aware, 6 mo. after campaign launch

- **KNOWLEDGE**
  - 1/3 more parents know behavior that most suggests a developmental delay (37% to 50%)

- **DIALOGUE**
  - 55% of parents said doctor/nurse asked about child’s development
  - 56% of pediatricians said they have resources to educate parents about developmental milestones

- **EARLY ACTION**
  - 50% decrease in pediatricians who would tell a worried parent to “wait and see” (30% to 14%)

Physicians aware of the campaign are significantly more likely to:

- Discuss full range of developmental milestones
- Believe that autism intervention is best if started early and children as young as 18 months can be diagnosed with autism
- Regularly screen their pediatric patients

Learn the Signs. Act Early.
Thank You
Known Causes of Autism

- Thalidomide
- Congenital Rubella Syndrome
- Fragile X
- Tuberous Sclerosis

Risk Factors
- Twins – Monozygotic