CDC's Public Health Research on Autism

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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)

	Frequency
Mental Retardation	1:103
Hearing Impairment	1:110
Cerebral Palsy	1:357
Vision Impairment	1:1100
Children with multiple disabilities	1:1250
Any Above Disability	1:83

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

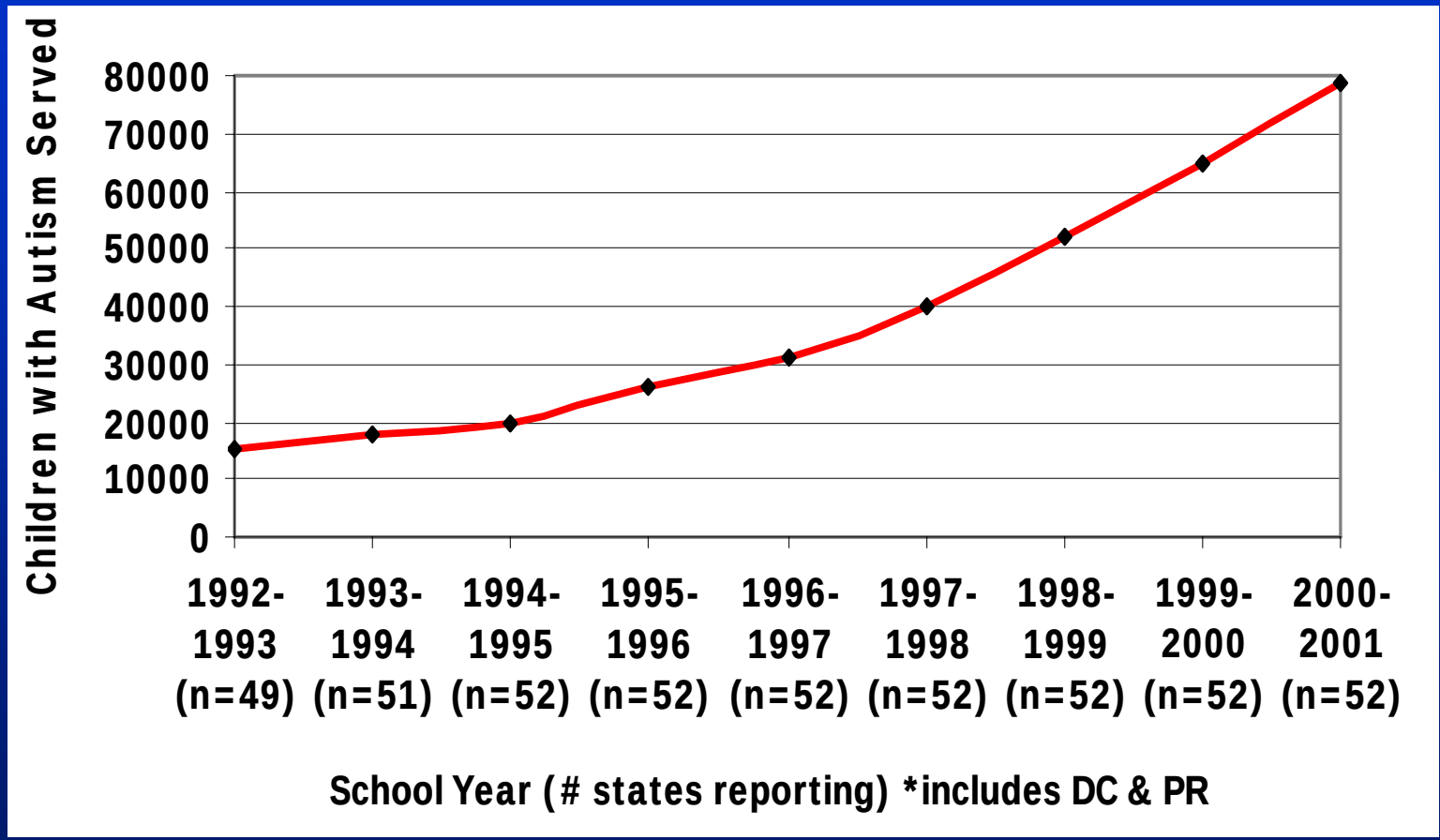
Estimates from outside the US in the 1990's

- 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)

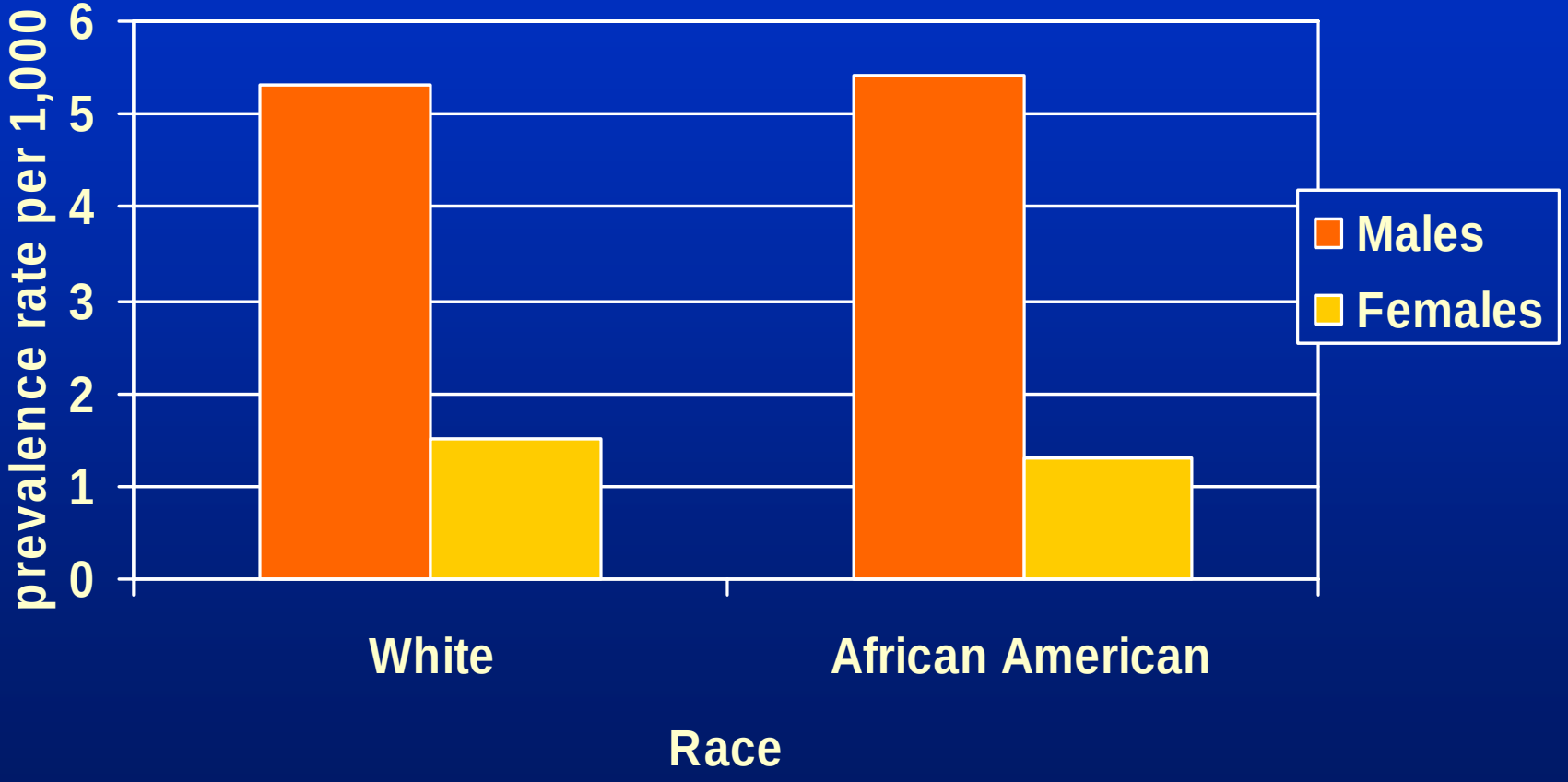
Number of Children with Autism Served under IDEA, Part B, 1992-93 to 2000-01, 6-21 years



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



Autism and Concomitant Conditions, Atlanta, 1996

	N	%
Isolated Autism	**376**	**38**
Autism and Other DD	**611**	**62**
Type of Disability		
– Mental Retardation	581	59
– Cerebral Palsy	49	5
– Deafness	14	1
– Blindness	12	1
– Epilepsy	76	8

Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities



Learn the Signs. Act Early.

It's time to change how we view a child's growth

Learn the Signs. Act Early.

Mission

Every child reaches his or her full potential

Learn the Signs. Act Early.

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**

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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)**

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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

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American Academy of Pediatrics: Autism Alarm

AUTISM A.L.A.R.M.

Autism is prevalent
- 1 out of 6 children are diagnosed with a developmental disorder and/or behavioral problem
- 1 in 166 children are diagnosed with an autism spectrum disorder
- Developmental disorders have subtle signs and may be easily missed

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 accurate 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 endorsed 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, or team of specialists, immediately for a definitive diagnosis
- To audiology and rule out a 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, respite care agencies, and insurance companies
- Continue surveillance and watch for additional or late signs of autism and/or other developmental disorders

For More Information: www.medicalhomeinfo.org

CDC

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

MEDICAL HOME INITIATIVES

The recommendations in this document do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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DEVELOPMENTAL SCREENING GUIDELINES FOR CHILDREN

The following guidelines, adapted from key policy statements of the American Academy of Pediatrics and American Academy of Neurology,[1] were developed in order to establish standard practices amongst physicians, to simplify the screening process, and to ensure that all children receive routine and appropriate screenings and timely interventions. These recommended guidelines are critical for ensuring that young children stay on a healthy development path.

Step 1 — **General observations and developmental milestones** — Observe how the child behaves, interacts, and communicates

Step 2 — **Ongoing Developmental Screening and Surveillance** — at every well visit

If screening results show the need for referral, proceed with steps 3-6. If not, rescreen at next well visit.

Step 3 — **Refer to Early Intervention** — AND to specialist for further development evaluation

Step 4 — **Lead Screening** — if pica present

Step 5 — **Formal Audiological Assessment**

Step 6 — **Autism Screening**

Step 7 — **Formal Diagnostic Evaluation** — by developmental pediatrician, pediatric neurologist, psychiatrist, psychologist, or an autism specialty team

1. **General observations and developmental milestones.** Take a brief moment 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 surveillance.** A physician, nurse practitioner, or certified physician assistant should perform routine developmental screenings using a highly validated parent survey at each well visit on all children from birth through school age to identify those at risk for atypical development.

3. **Referral to Early Intervention and for a developmental evaluation.** When a parent raises a concern, or a developmental surveillance/screening indicates a possible delay, refer the child for a comprehensive evaluation by a specialist or a team of specialists experienced in making the diagnosis of autism. At the same time, refer the child to a local early intervention program. A tentative or provisional diagnosis of "delay" is sufficient to initiate services.

4. **Lead screening.** If risk factors, such as a developmental delay and/or pica, are present, conduct a lead screening to rule out lead poisoning. If elevated lead levels are found, refer the child to a local health department.

5. **Formal audiological assessment.** When a child appears to have a developmental delay, refer the child for formal audiological testing.

6. **Autism screening.** If a parent or ongoing developmental screening and surveillance raise concerns, follow up with an autism screening.

7. **Referral for diagnostic evaluation.** If autism screening raises a concern, refer the patient for a comprehensive autism evaluation by a specialist or a team of specialists experienced in making the diagnosis of autism. If the child has not already been referred (Step 3), refer him/her to a local early intervention program. Do not delay a referral to an intervention program while the patient is waiting for a specialist appointment, lab tests, or imaging studies. Later, if and when a definitive diagnosis is made, intervention services can then be revised accordingly.

[1] Screening Guidelines were compiled and adapted from the following sources: American Academy of Pediatrics. (2001). Committee on Children with Disabilities. Policy Statement: The pediatrician's role in the diagnosis and management of autistic spectrum disorders in children, *Pediatrics, 107*, 1221-1226; American Academy of Pediatrics. (2001). Committee on Children with Disabilities. Technical Report: The pediatrician's role in the diagnosis and management of autistic spectrum disorder of children, *Pediatrics, 107*. Filipek, P.A., et al. Practice parameter: Screening and diagnosis of autism. *Neurology* 2000; 55: 468-79.

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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)**

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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

Learn the Signs. Act Early.

Known Causes of Autism

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

- Risk Factors
  - Twins – Monozygotic