



Surveillance of Autism Spectrum Disorders: Epidemiologic Studies and Prevention Strategies

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**Act Early Region X Summit
Friday, February 5, 2010
Seattle, Washington**

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Background

- **Autism Spectrum Disorders (ASDs) are defined by considerable impairments in social interaction and communication skills, and the presence of unusual behaviors and interests.**
- **Our understanding of both the epidemiology and etiology of these serious developmental disorders is just recently emerging.**





Background



- ASDs include autistic disorder, pervasive developmental disorder - not otherwise specified (PDD-NOS, including atypical autism), and Asperger Syndrome (a.k.a. Asperger's Disorder).
- ASDs can be identified as early as 14 months, and symptoms typically persist throughout a person's life.
- Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations.



Background

- **ASDs are neurobiological disorders, meaning the behavioral symptoms are a result of differences in brain development**
- **For the majority of people with autism spectrum disorders, the cause is not known. There may be multiple causes that are a combination of genetic and environmental factors.**
- **However, research has pointed to some possible risk factors:**
 - **co-occurring with other conditions [Fragile X, PKU]**
 - **sibling recurrence**
 - **family history of psychiatric disorders**
 - **adverse birth events**
 - **advanced maternal and paternal age**
 - **specific environmental exposures such as certain medications [valproic acid, thalidomide] or maternal/child illness [rubella]**



Background

Estimates of population prevalence vary widely within the U.S. and abroad. Two primary factors contributing to this wide variation in prevalence estimates are:

- **differences in case finding and ascertainment methods, and**
- **lack of standardization in evaluating diagnostic criteria for ASDs**



Epidemiologic/Prevalence Studies

- Early epidemiologic studies in the 1970s (Denmark, UK, Japan) estimated the prevalence of autism at 4-5 per 10,000 (1 in 2500)
- Three US studies from 1980's and early 1990's estimated the prevalence of autistic disorder ranging from 3 to 4 per 10,000
- 1998 CDC study in Brick Township, NJ estimated the prevalence of Autistic disorder at 4 per 1,000 and the broader Autism Spectrum (ASD) at 6.7 per 1,000
- Other studies from outside the US in the 1990's estimated the prevalence of Autism/ASD ranging from 1 to 6 per 1,000



Studies Based on ICD 10 or DSM-IV Criteria

Estimates from more recent population-based studies

- **Kadesjo et al. (1999)**
- **Baird et al. (2000)**
- **Chakrabarti & Fombonne (2001)**
- **Bertrand et al. (2001)**
- **Yeargin-Allsopp et al. (2003)**
- **Tebruegge et al. (2004)**
- **Baird et al. (2006)**

- **Autistic disorder: range between 1.7 – 4.0 per 1,000**
- **Autism spectrum: 5.8 to 12.1 per 1,000**
- **Average range of recent estimates: 2-6 per 1,000 for all ASDs**
- **At 2-6 per 1,000 it was commonly estimated that ASD occurs in
“as many as 1 in 166 children”**



Challenges Interpreting Autism Trends

- **Studies conducted in diverse populations using different methods**
- **Changing diagnostic criteria (DSM-IIIR, DSM-IV, DSM-IV (TR), etc.)**
- **Expansion of autism to a “spectrum” of disorders**
- **Changes in level of awareness and use of diagnosis over time**
- **Changes in service eligibility**
- **Autism not a required category for U.S. DOE reporting until 1992**



Statement of Need

- A more precise estimate of the public health impact of ASDs would serve to inform appropriate and well-coordinated responses by planners at the local and national level.



CDC/NCBDDD Role in Birth Defects and Developmental Disabilities Prevention

Surveillance Systems

- prevalence rates
- registry of cases
- monitor prevention

Epidemiologic Studies

- risk factors
- protective factors
- public concerns

Prevention Programs

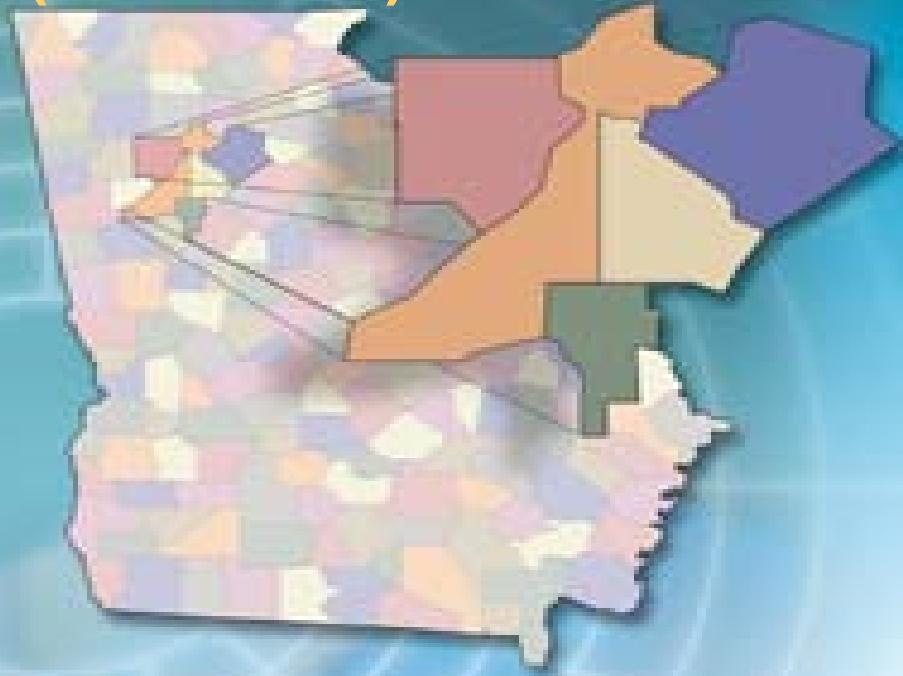
- prevention strategies
- public policy
- education



CDC Autism Prevalence Study

- Incorporated into MADDSP in 1998 because of lack of US prevalence data and increasing public concern
- Challenges
 - Case definition based on description of behaviors
 - Continuum of behaviors – autism spectrum
 - No standard, readily available diagnostic test

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)



- Ongoing, active surveillance program since 1991
- Records-based surveillance
- Multiple sources (education, healthcare, disability services)
- 5 counties of Metropolitan Atlanta
- ASD surveillance since 1998 (1996 surveillance year)



MADDSP Methods: Records-based Surveillance

Identify potential cases at multiple educational and health sources

- Educational: psycho-educational assessments, special education files; range of eligibility categories in special education from public schools
- Health: Discharge diagnoses, billing code, or referral reason at clinics, evaluation centers, etc.

Screen source files for DD indicators (“triggers”)

- Behavioral/physical descriptions consistent with ASD or CP
- Standardized test scores for ID, HL and VI

Abstract source files with triggers



Methods

- Abstraction of records is carried out in the field using a specially-designed MS Access database application.



Associated Features

YES	Abnormalities in eating/drinking/sleeping
YES	Abnormalities in mood or affect
UNKNOWN	Abnormalities in the development of cognitive skills
UNKNOWN	Aggression
YES	Argumentative, oppositional, defiant, destructive
YES	Delayed motor milestones/motor clumsiness
YES	Hyperactivity, short attention span, impulsivity
YES	Lack of fear in response to real dangers, or excessive fearfulness in response to harmless objects/events
UNKNOWN	Odd responses to sensory stimuli
UNKNOWN	Self-injurious behavior
UNKNOWN	Staring spells/seizure-like activity
YES	Temper tantrums

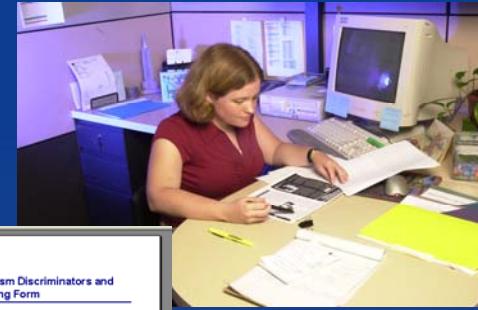


Methods

- Case status is determined by clinicians who review the abstracted records using a systematic coding scheme based on DSM-IV diagnostic criteria.



AU Clinician Review: Abstracted Information - Part 1		
Study ID:	20020001	
Autism Evaluations and Eligibility Reports		
Birthdate:	04/07/1994	
Case Status:	CLOSE	
Case Definition:	AU CONFIRMED CASE	
CP:	END NOT ABSTRACTED	Batched Case End CP no abstraction
ML:	END NOT ABSTRACTED	Batched Case End ML case abstraction
MR:	END TO DATE	Batched Case End MR case abstraction
VI:	END NOT ABSTRACTED	Batched Case End VI case abstraction
Evaluation(s) (in chronological order from 1st to last listed):		
DATE:	05/01/1991	Chronological (year/month): 3;2
Degres:	PSYCHIATRIST, EDD	source type: SCHOOL
Reason for referral:		
Referred to the Child Study Team due to parental request regarding concerns of delayed speech/language development and per the request of her pediatrician, Dr. Bill Simandak.		
Vaccination history and date of diagnosis:		
He was born at term via a normal vaginal delivery on 10/10/1990. He had no complications during his pregnancy with Adam (she was not aware that she was pregnant). He was born at full term via a normal vaginal delivery. There were no problems noted at birth.		
Developmental history:		
Developmental milestones were achieved with the exception of speech/language development. His medical history is remarkable for a hernia operation at 2 months of age. He has also had recurring ear infections, sinusitis, and a bilateral cleft lip/palate repair. He has had no appendicitis or tonsillectomy.		
Further history:		
Adam was first seen by Early Intervention at the following evaluations: Auto-Motor/Feeding Consultation, with resulting recommendations for home and speech/language therapy/intervention; Gross Motor Assessment (11/94), indicating the need for physical therapy intervention; and a developmental evaluation (12/94). It is further noteworthy that when he was in Early Intervention, he demonstrated a 25 % delay in all areas of development.		
Behavioral description of regression or plateau in development at any age:		
Regression of 13-18 Months:		
He initially appeared to be mute, hyperreflexic, and unresponsive to his name and needed encouragement to make eye contact. Report was very gradually established in a positive manner. He was easily able to be engaged through play with objects. He then began to regress in his speech and language skills. His speech was limited and was limited to those words which interested him. Other tasks were met with physical resistance, screaming and throwing. He responded best to a musical key that presented		
Printed: 09/23/2014		ARIONE-V2 Database System





Autism Case Definition

- A child is included as a confirmed autism case if he or she displays behaviors (as described in evaluation reports by a qualified professional) consistent with the DSM-IV-TR diagnostic criteria for Autistic Disorder, PDD-NOS, or Asperger's Disorder, as scored by an ASD clinician reviewer.



Types of Data Collected

Demographic:

- Child and mother identifying information
- Date of birth, race, sex

Educational:

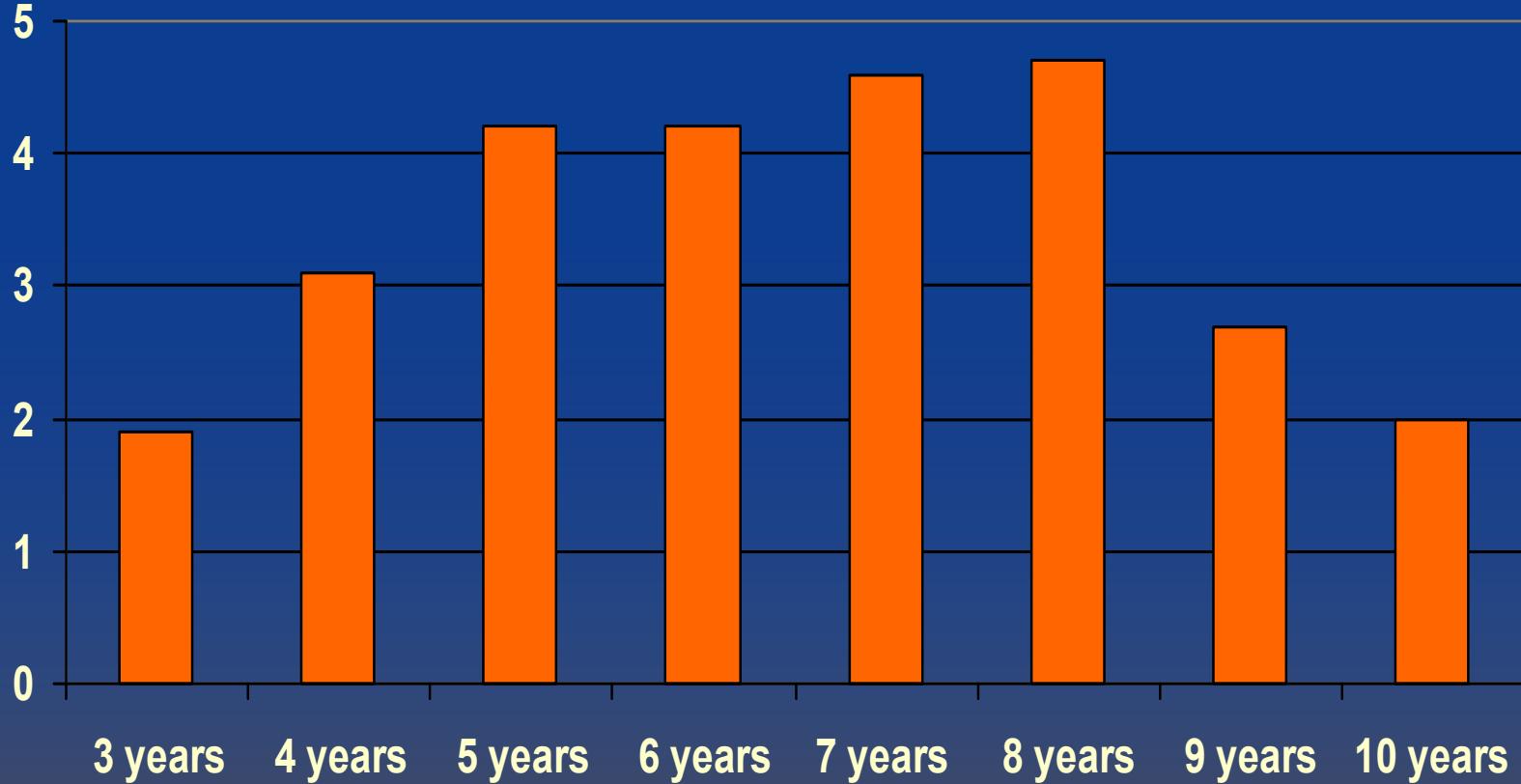
- Primary exceptionality,
- Cognitive, adaptive, and autism test scores

Medical/Clinical:

- Physical findings
- Associated medical conditions
- Other developmental disabilities



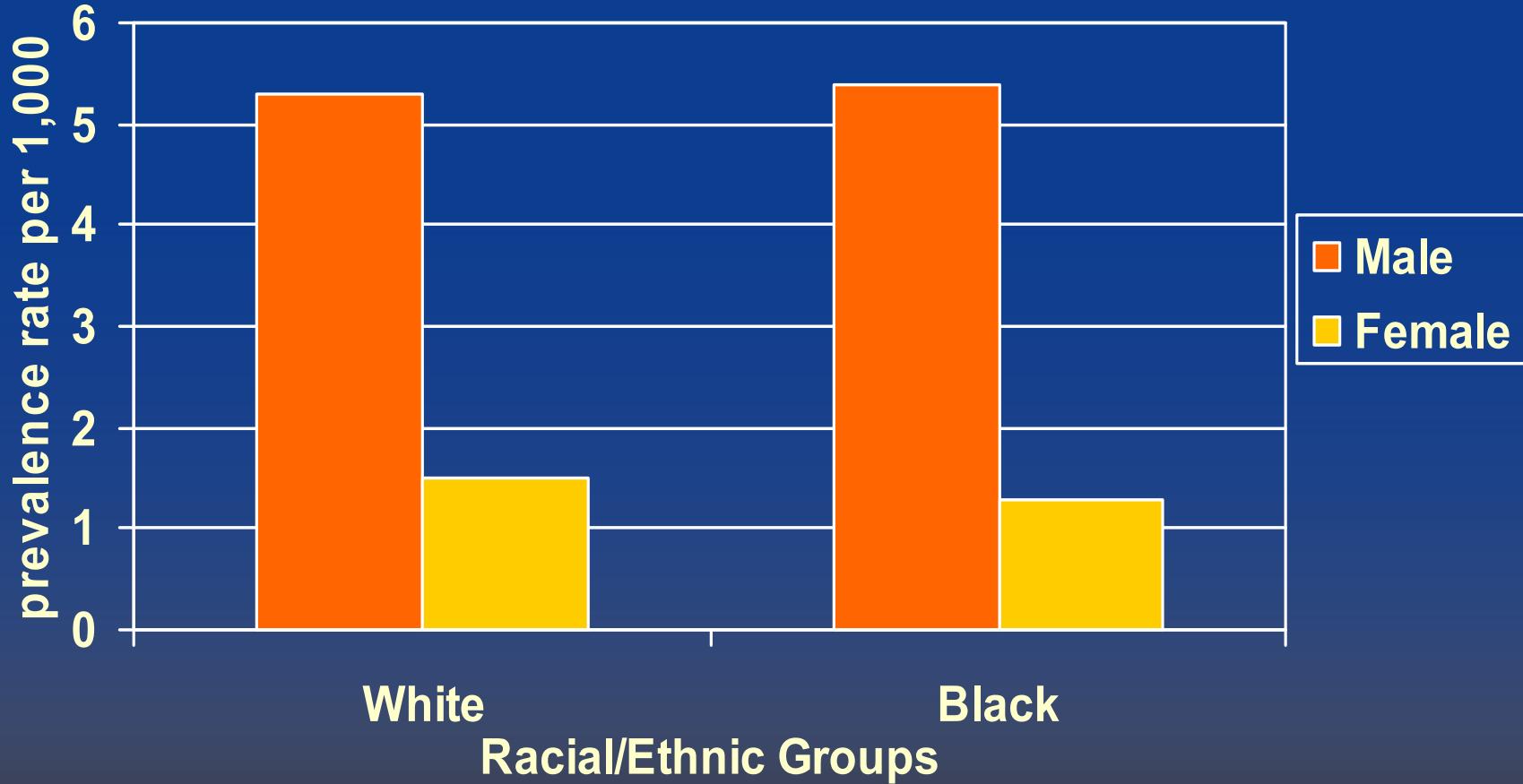
MADDSP '96 Autism Pilot



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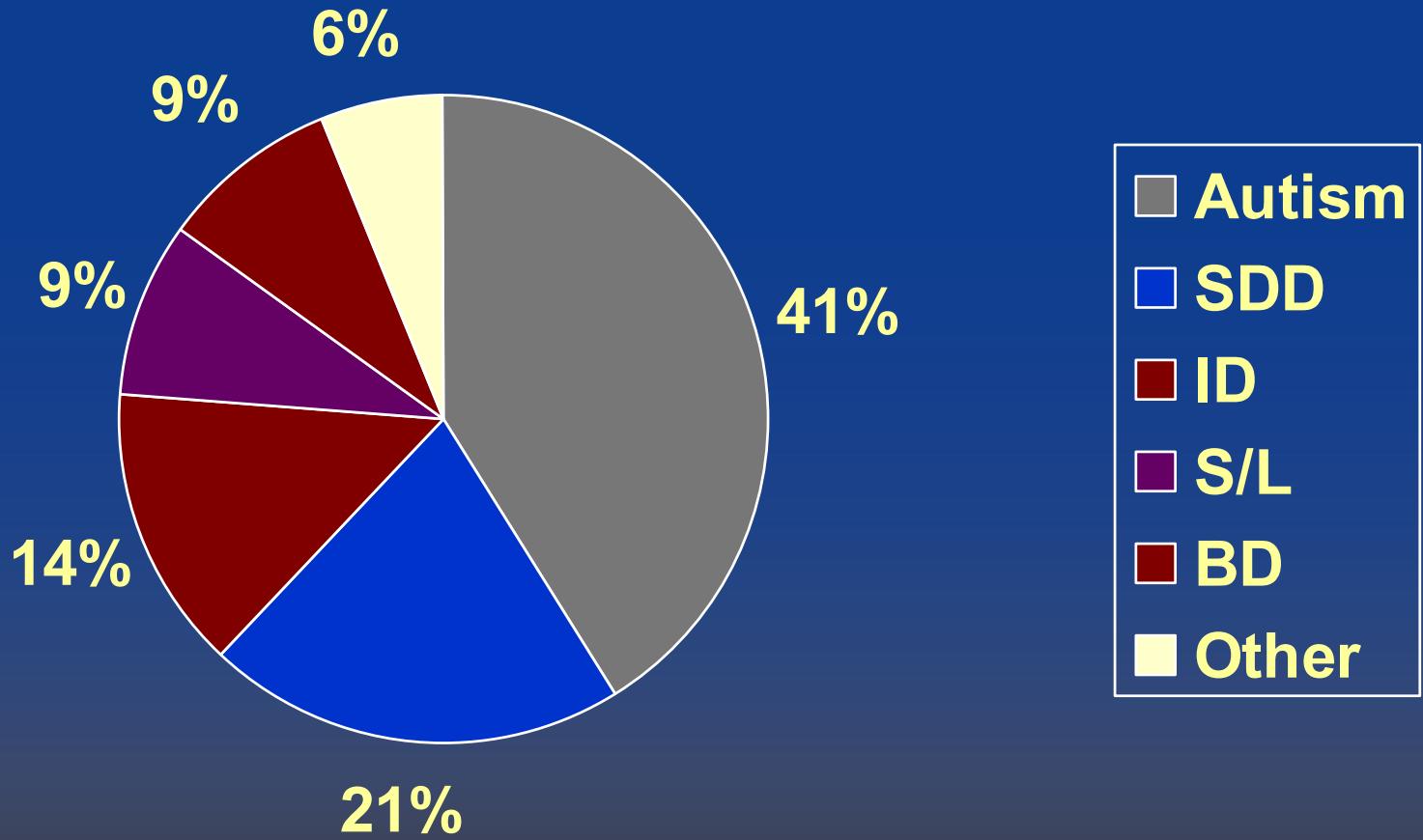


MADDSP '96 Autism Pilot





Primary Special Education Exceptionality

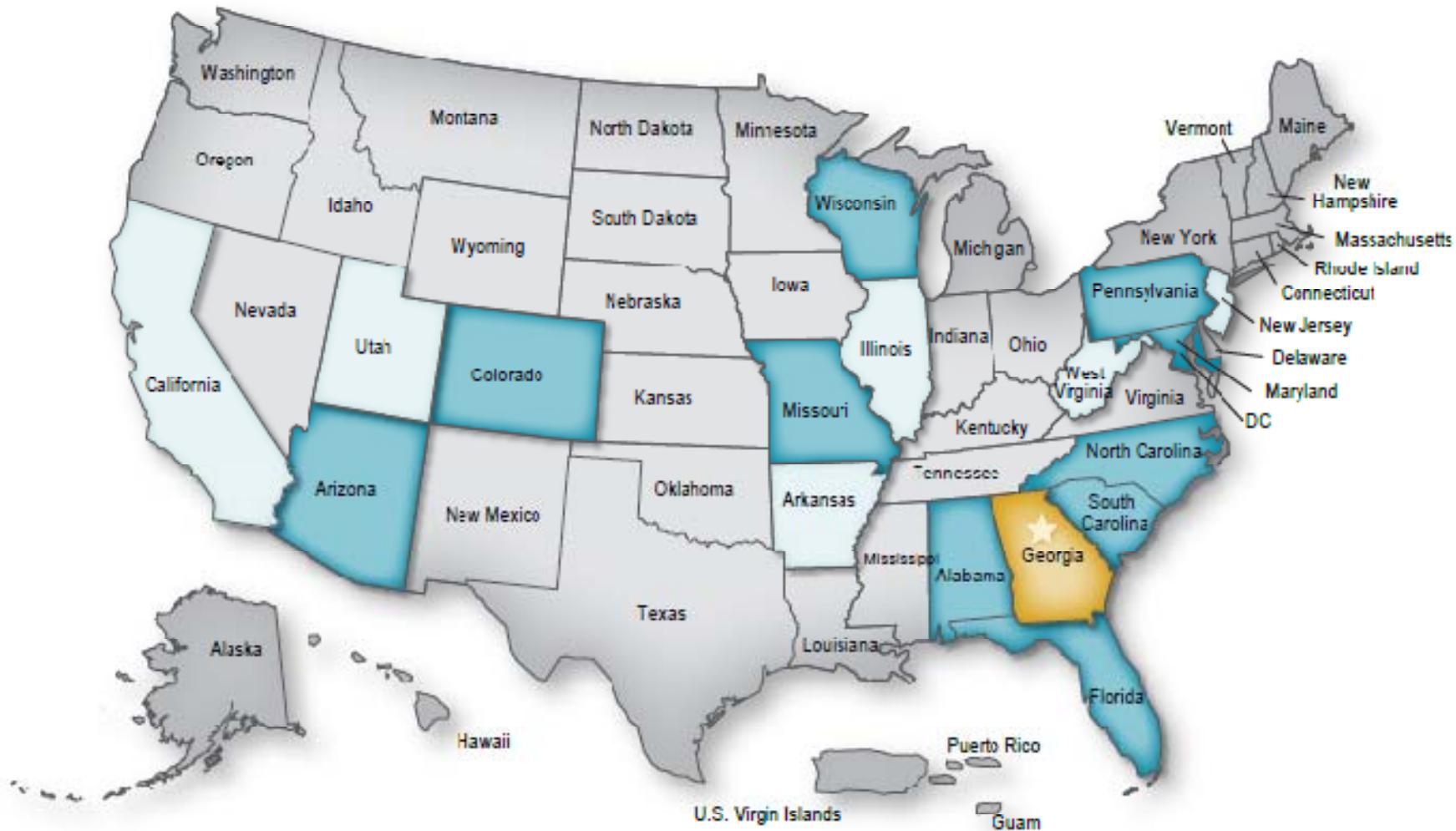




Expansion of Monitoring Activities

- 1998: ASD surveillance study in Brick Township, NJ**
- 1999: WV funded to implement ASD surveillance program**
- 2000: Four additional state health departments funded**
- 2001: Three new state health departments funded**
- 2002: Four new cooperative agreements were funded**
- 2003: Three additional sites were funded**
- 2006: Ten sites competitively funded for Phase 2**
- 2009: Three Phase I sites reinstated**

Autism and Developmental Disabilities Monitoring (ADDM) Network





Mission of the ADDM Network



"Working together to understand the magnitude and characteristics of the population of children with autism and related developmental disabilities to inform science and policy"



ADDM Network Objectives

The objectives of the 14-state ADDM Network are:

- **Determination of reliable ASD prevalence rates in the participating states**
- **Establishment of an ASD surveillance system to determine trends in ASD prevalence, and**
- **Development of population-based data for special studies**

**This is the first and only integrated multi-state
ASD prevalence investigation in the United States**



Strengths

- **Large, population-based study of autism**
- **Multiple-source case ascertainment, including school records**
- **Coding scheme and systematic review of abstracted information on behaviors to arrive at DSM-IV classification**
- **Information on presence of other developmental disabilities**
- **Record review methodology maximizes population coverage**
- **Monitor ASDs in children at age 8 because previous studies have shown that by this age most children with ASDs have been identified for population-based surveillance**



Limitations

- **No clinical validation of case status**
- **Difficult to get severity ratings and to subtype**
- **Underascertainment of children with milder phenotypes,
e.g., PDD-NOS, Asperger's Disorder**



ADDM Surveillance Years

Study Year	Birth Year	# Sites	Status
2000	1992	6	Published
2002	1994	14	Published
2004	1996	8	Published
2006	1998	11	Published
2008	2000	14	In process



ADDM Network: Prevalence of ASDs

Surveillance Year	Birth Year	# sites	8-year-old Population (% of US)	8-year-old children with ASD	Average Prevalence per 1,000 children (Range)
2000	1992	6	187,761 (4.5%)	1,252	6.7 4.5-9.9
2002	1994	14	407,578 (10%)	2,685	6.6 3.3-10.6
2004	1996	8	172,335 (4.3%)	1,376	8.0 4.6-9.8
2006	1998	11	308,038 (7.9%)	2,759	9.0 4.2-12.1
2008	2000	11(14)		In process	

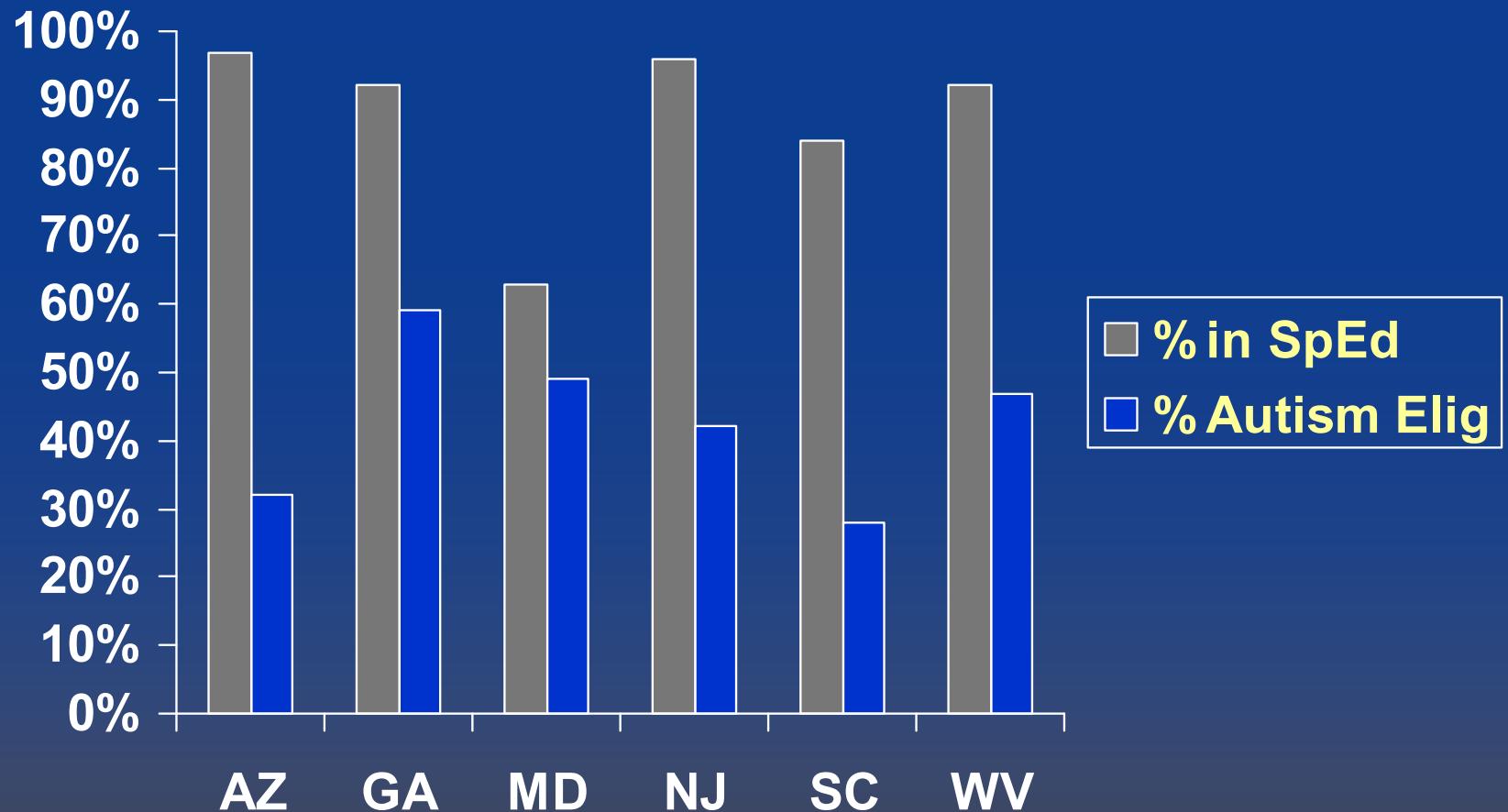


What Do the Latest ADDM Results Tell Us?

- **For every girl with ASD there are 3 to 7 boys identified (4.5:1).**
- **Between 29% (CO) and 51% (SC) of children with an ASD also had cognitive impairment (average 41%). In most sites, girls were more likely to have cognitive impairment than boys.**
- **Among all children meeting the ADDM surveillance case definition for ASD, approximately 77% had a documented ASD classification in their records, ranging from 65% (AZ) to 93% (MD).**
- **Most children identified as ASD surveillance cases were receiving special education services at age 8. The proportion served under a primary exceptionality of autism ranged from 34% (CO) to 76% (MD).**



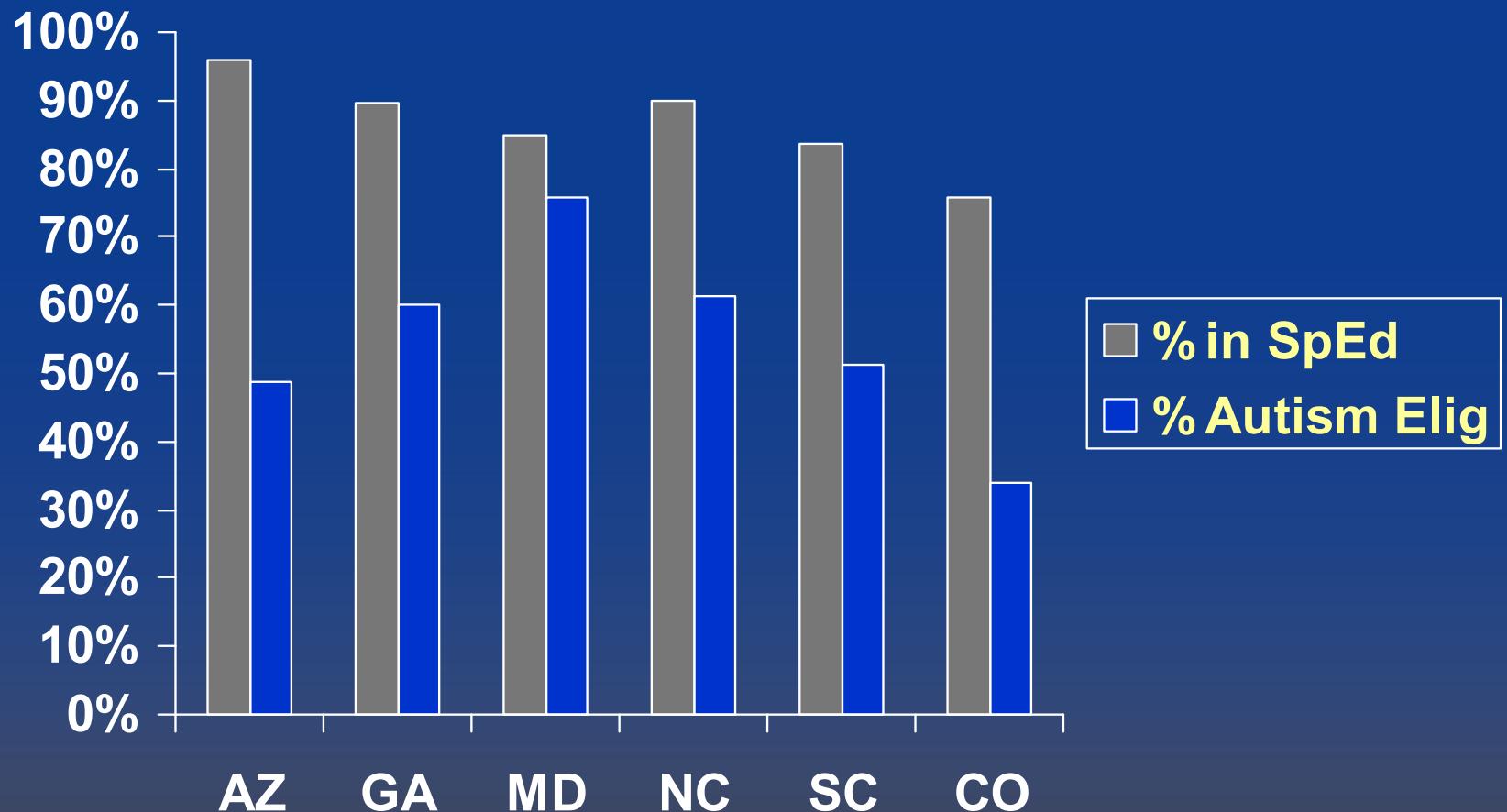
ADDM 2000 Surveillance Year



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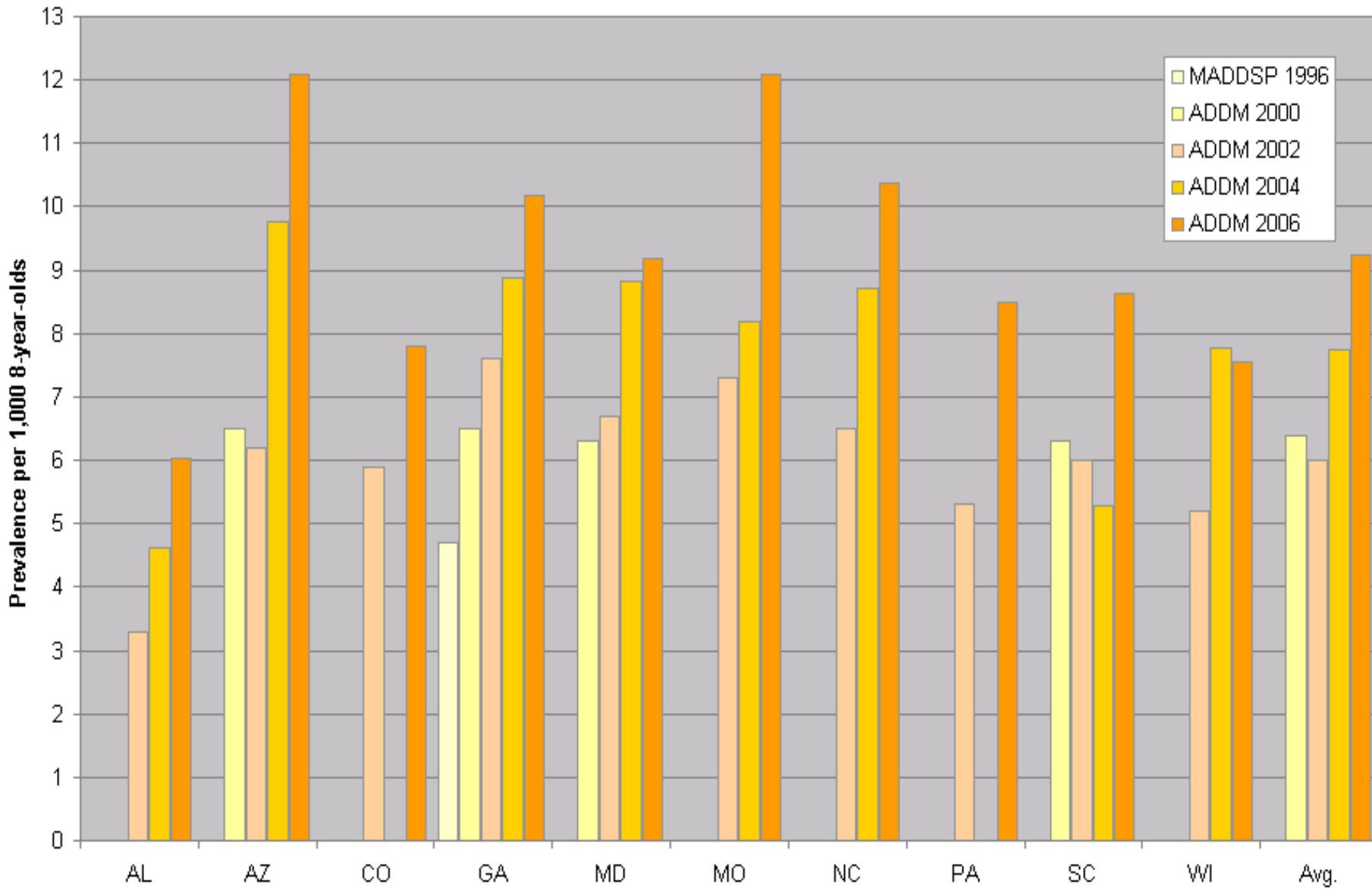


ADDM 2006 Surveillance Year



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ADDM Network - Sites Completing 2002 and 2006 Surveillance Year,
with Additional Data Points Included





ADDM Network: Change in ASD Prevalence 2002 to 2006, 10 Sites by Total, Sex, Race or Ethnicity

	Total	Males	Females	NH White	NH Black	Hispanic
Avg % Change	57%	60%	48%	55%	41%	91%

The overall trend reflects increases in ASD prevalence
- overall and among subgroups.

There was variation across sites.



ADDM Network: Change in ASD Prevalence 2002 to 2006, 10 Sites by Level of Cognitive Functioning

	Cognitive Impairment (IQ≤70)	Borderline Range (IQ=71-85)	No Cognitive Impairment (IQ>85)
Avg % Change	48%	55%	41%

The overall trend reflects increases in ASD prevalence
- overall and among subgroups.

There was variation across sites.



Changing Prevalence of ASDs Over Time

- **1 in 2500 (early 1970s)**
- **1 in 166 (late 1990s)**
- **1 in 150 (early 2000s)**
- **1 in 110 (mid 2000s)**



ADDM Surveillance Years 2000 - 2006

- In all reports, the majority of children identified with ASD had documented concerns by a parent or professional before 3 years of age, such as concerns about the child's language, social, or play development, but the median age of earliest ASD diagnosis was approximately 4 ½ to 5 ½ years.
- Over the 4 year period from 2002 to 2006, the age of earliest documented ASD diagnosis declined for all 10 sites included in both surveillance years, from 1 month (WI) to 15 months (AL), but the median age for most sites remains in the 50-60 month range.



Conclusions

- **We do not know the prevalence of autism in most communities in the United States, but there are more children diagnosed with autism today than in the past.**
- **We do not know the etiology of most cases of autism.**
- **Recent attention to autism issues has the potential to lead to more answers through research.**
- **CDC is conducting research with many partners in an attempt to understand more about the prevalence, causes, and how to best support communities and families of children with autism and other developmental disabilities.**



Other Epidemiologic Studies

Study to Explore Early Development (SEED)

- Funded by CDC; currently being implemented in 6 U.S. sites
- Enrolling children with ASD and 2 comparison groups
- Detailed family histories and biomarkers

Baby Sibling Studies

- High-risk group
- Prospective accounts of pregnancy and early development
- Early physical (head circumference) and developmental (language, eye gaze) characteristics



Prevention Strategies

- Purpose of etiologic studies is to identify risk factors that can help us identify children at risk and start intervening when treatments are most effective.
- Children with autism identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational placement.
- Brain is most responsive to retraining efforts during early childhood. Flip side is that the young child is also more susceptible to side effects from medications.



Prevention Strategies: Developmental Screening

- In the United States, 17% of children have a developmental or behavioral disability, but less than 50% are identified before school, by which time significant delays may have already occurred and opportunities for treatment have been missed.
- Developmental screening is a procedure designed to identify children who should receive more intensive assessment, or diagnosis, for potential developmental delays. It can allow for earlier detection of delays and improve health and well-being for identified children.



Prevention Strategies: Developmental Screening

- **The American Academy of Pediatrics recommends developmental screening at 9, 18, and 24 or 30 months, or whenever a parent or provider concern is expressed.**
- **Administration of a brief standardized tool is best practice.**
- **Studies sponsored by AAP show that only about 35% of pediatricians feel adequately trained in assessing children's developmental status.**



Prevention Strategies: Developmental Screening

The Centers for Disease Control and Prevention has established the following goals to help children reach their full potential:

1. Develop and test programs in primary care settings to screen children early on, identify those with autism and other delays, and ensure that these children receive appropriate care.
2. Increase health care providers' knowledge and skill in developmental screening by incorporating training into professional health care education programs.
3. Raise awareness about the need for and benefits of developmental screening to identify and care for children with autism and other developmental disabilities or delays.



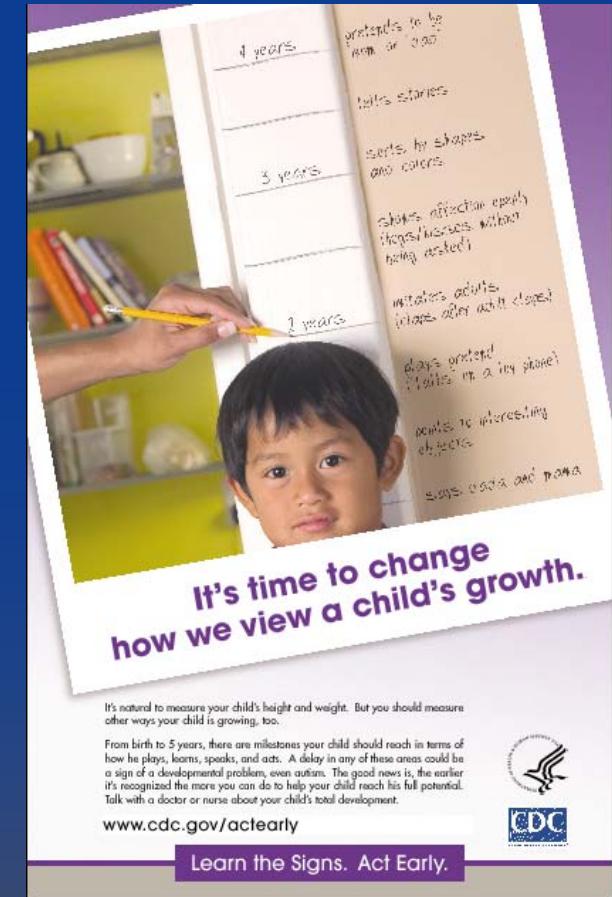
CDC Public Health Response



Partnerships to increase awareness

“Learn the Signs: Act Early” campaign

- American Academy of Pediatrics (AAP)
- Association of University Centers on Disabilities (AUCD)
- Autism Society of America (ASA)
- Autism Speaks
- First Signs
- Organization for Autism Research (OAR)





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*

