

A Review of Updated Prevalence of Autism Spectrum Disorders

Maryland Autism Commission

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Outline.

- A. Autism Spectrum Disorders
- B. Prevalence & Trend
- C. ADDM Network
- D. Prevalence estimates from ADDM

Section A.

Autism Spectrum Disorders (ASDs)



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DSM-IV* Categories

Pervasive Developmental Disorders

- Autistic Disorder
 - Asperser Syndrome
 - Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS)
 - Rett Syndrome
 - Childhood Disintegrative Disorder
- } “ASDs”

*Diagnostic and Statistical Manual of Mental Disorders, APA

ASDs

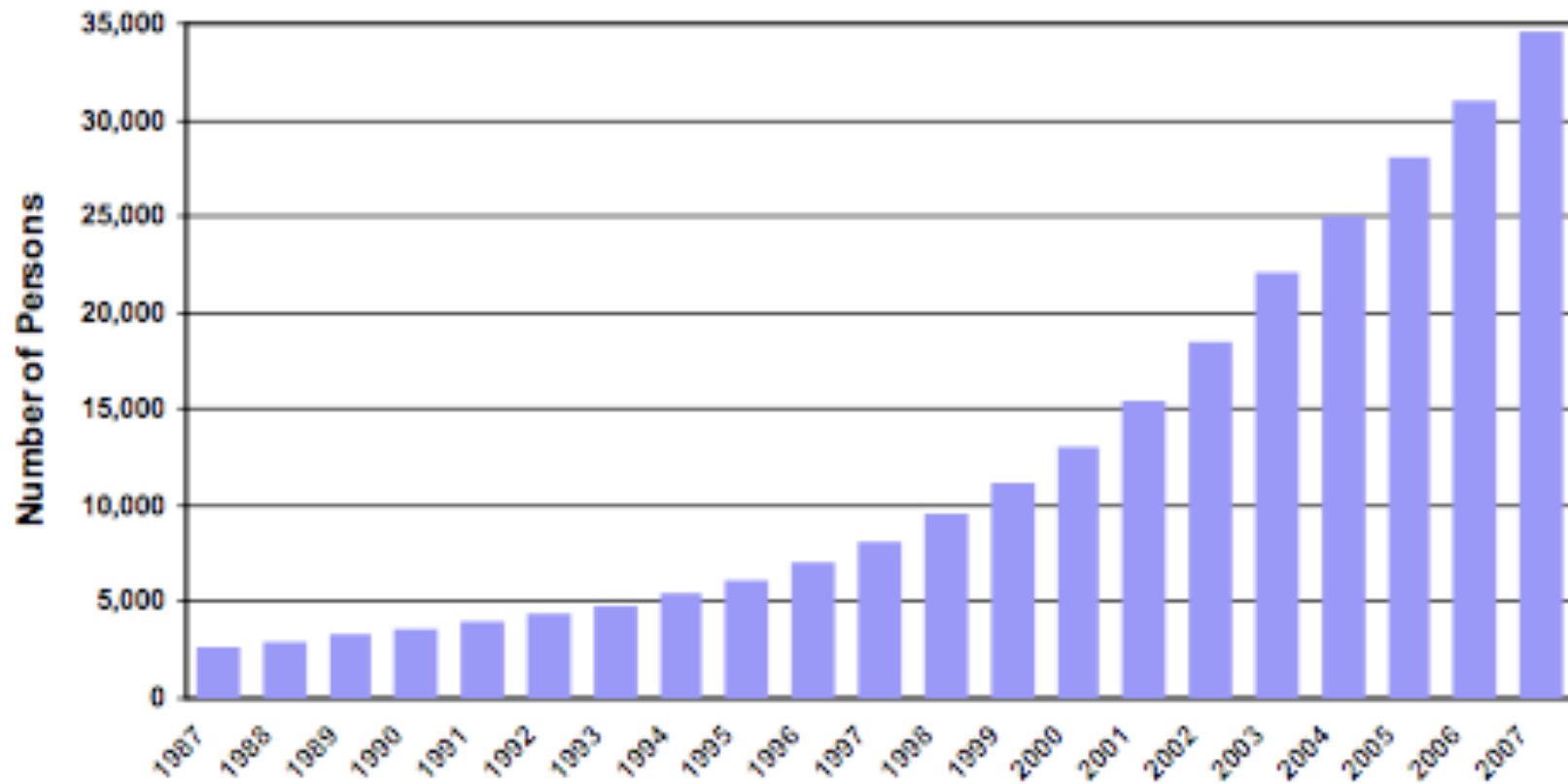
ASDs are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests with symptoms typically present before the age of 3 years.

Section B.

Prevalence & Trend

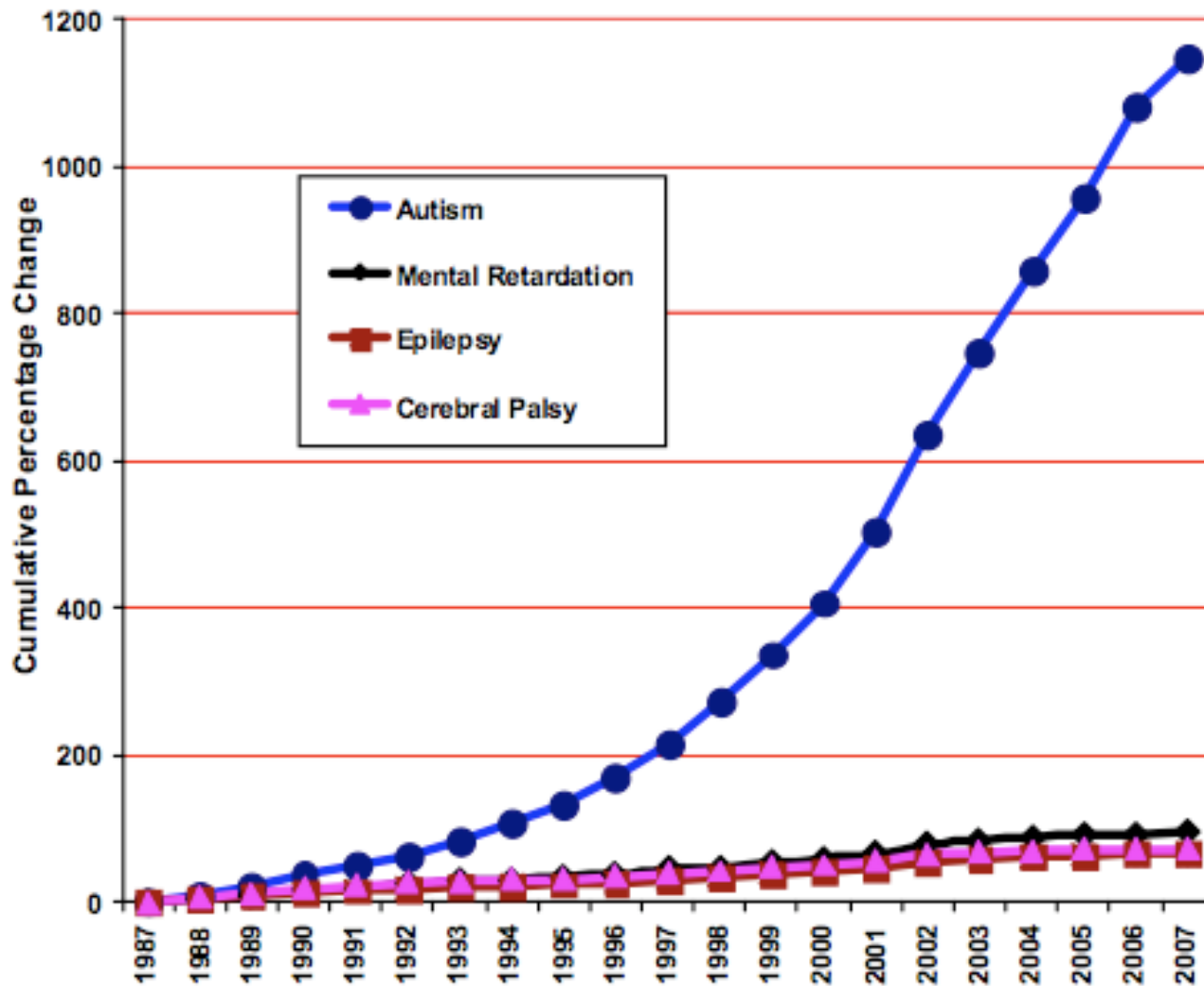


Annual Frequencies of ASD in CA



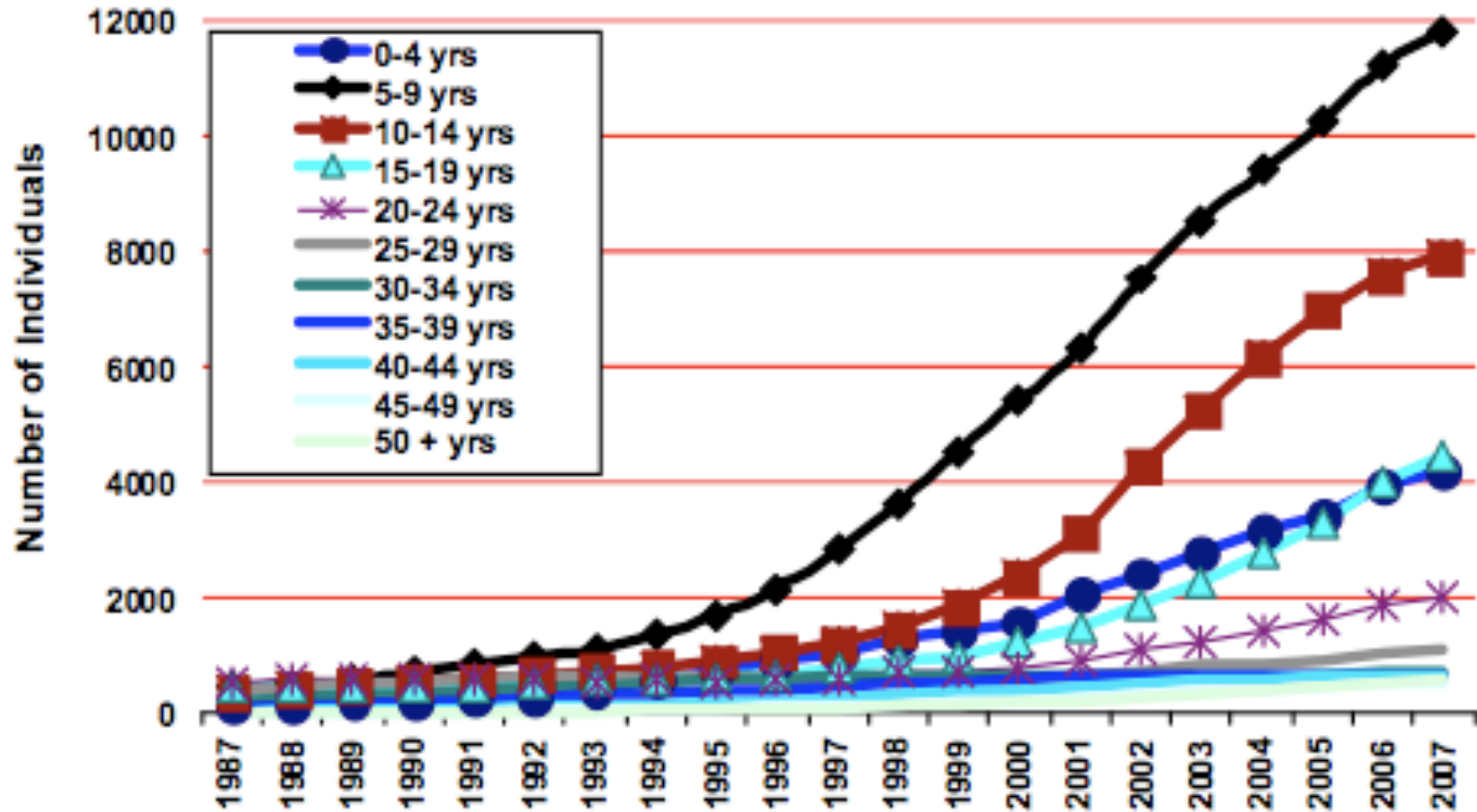
Source: CA State Department of Developmental Services, 2009

Cumulative Percentage Change of ASD, Cerebral Palsy, Epilepsy, and Mental Retardation in CA



Source: CA State Department of Developmental Services, 2009

Age Distribution of Persons with ASD in CA



Source: CA State Department of Developmental Services, 2009

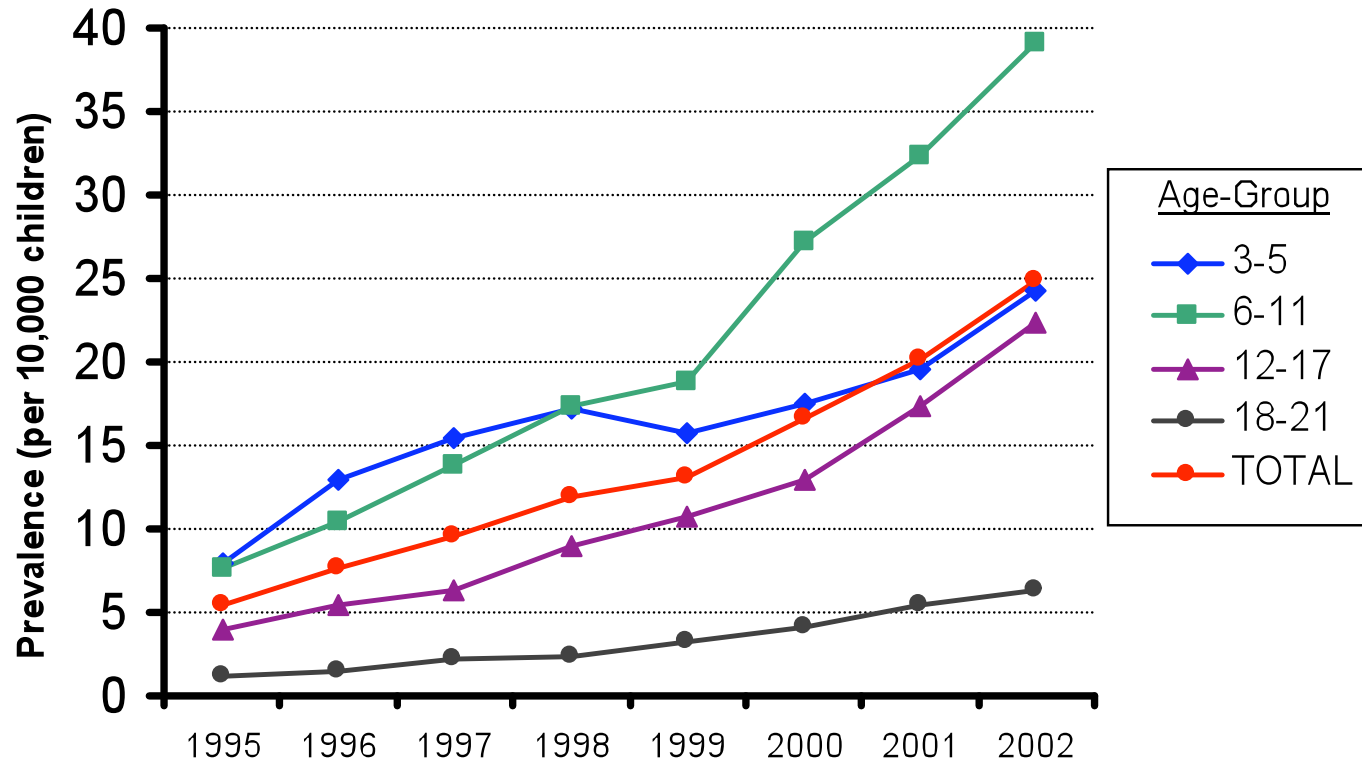
ASD Prevalence: US

National Survey of Children's Health

- Sample size: 78,037 (nationally representative)
- Aged 3 - 17 years
- Prevalence: 11 per 1,000
- Boy to girl: 4 to 1

Source: Kogan et al., Pediatrics 2009

Prevalence* (per 10,000) of children with an autism special education classification in Maryland, by age and year



* Prevalence based on MSDE Special Education Censuses - Autism

Source: MD State Department of Education

Section C.

Autism and Developmental Disabilities Monitoring (ADDM) Network



ADDM Network Mission

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

Goals

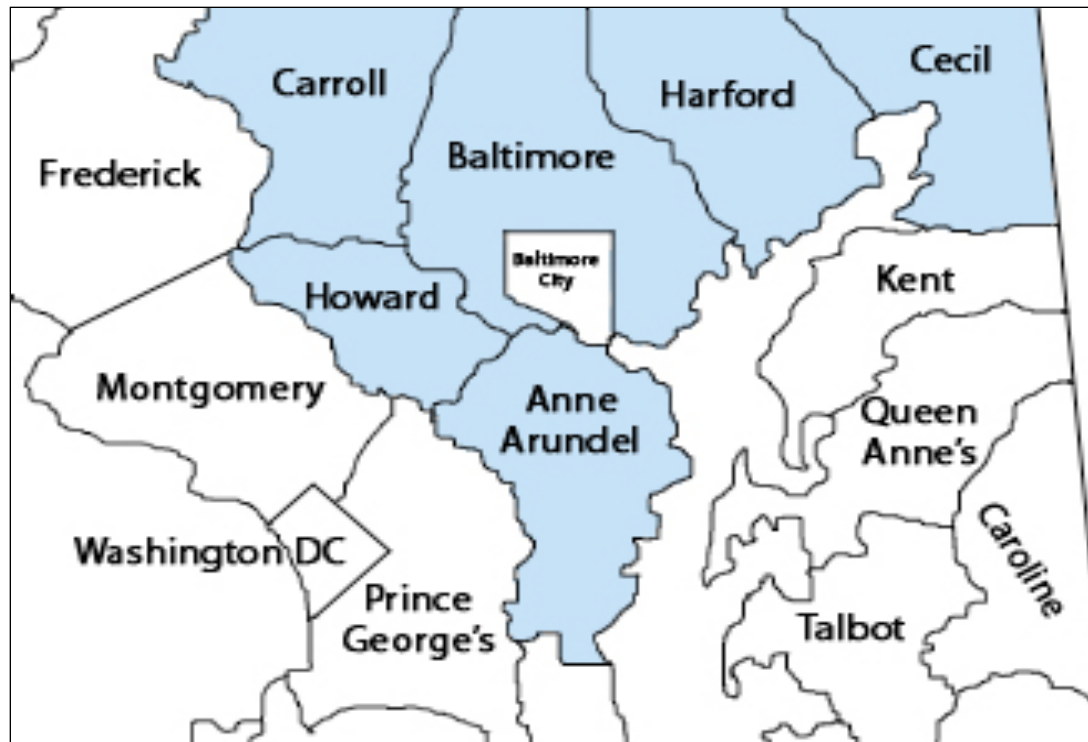
- Obtain as **complete a count as possible** of the number of children with an ASD in each project area
- Provide **comparable, population-based ASD prevalence** estimates in different sites
- Provide data to **characterize the ASD population**
- Study **whether autism is more common in some groups of children than in others and whether rates are changing over time (trends)**
- **Improve the consistency of identification** of people with ASDs

Autism and Developmental Disabilities Monitoring (ADDM) Network



- CDC
- 11 ADDM Sites 2006 - 2010 (10+ CDC)
- + 16 ADDM Sites 2001 - 2006 (15 + CDC)

Catchment Areas in Maryland

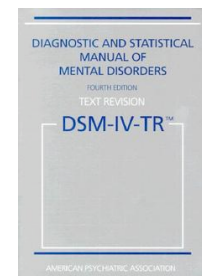


Supporting Agencies

- MD Department of Health & Mental Hygiene (MD DHMH)
- MD DHMH Vital Statistics Administration
- MD State Department of Special Education
- School Districts in participating counties

ADDM Methods

- Active case-finding with broad retrospective records-based screening for ASD classifications or behaviors.
- Focus on children at age 8 to identify peak prevalence.
- Multiple health and education sources of information.
- Detailed behavioral, developmental, and testing information collected.
- Ongoing quality control within and across sites.
- Independent review and clinician confirmation of ASD case status based on the *DSM-IV* criteria.
- Standard for setting ASD prevalence estimates in the U.S.



Section D.

Prevalence Estimates from ADDM



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ADDM Findings I



MMWR

Morbidity and Mortality Weekly Report

Surveillance Summaries

February 9, 2007 / Vol. 56 / No. SS-1

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000;

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002; and

Evaluation of a Methodology for a Collaborative Multiple Source Surveillance Network for Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002

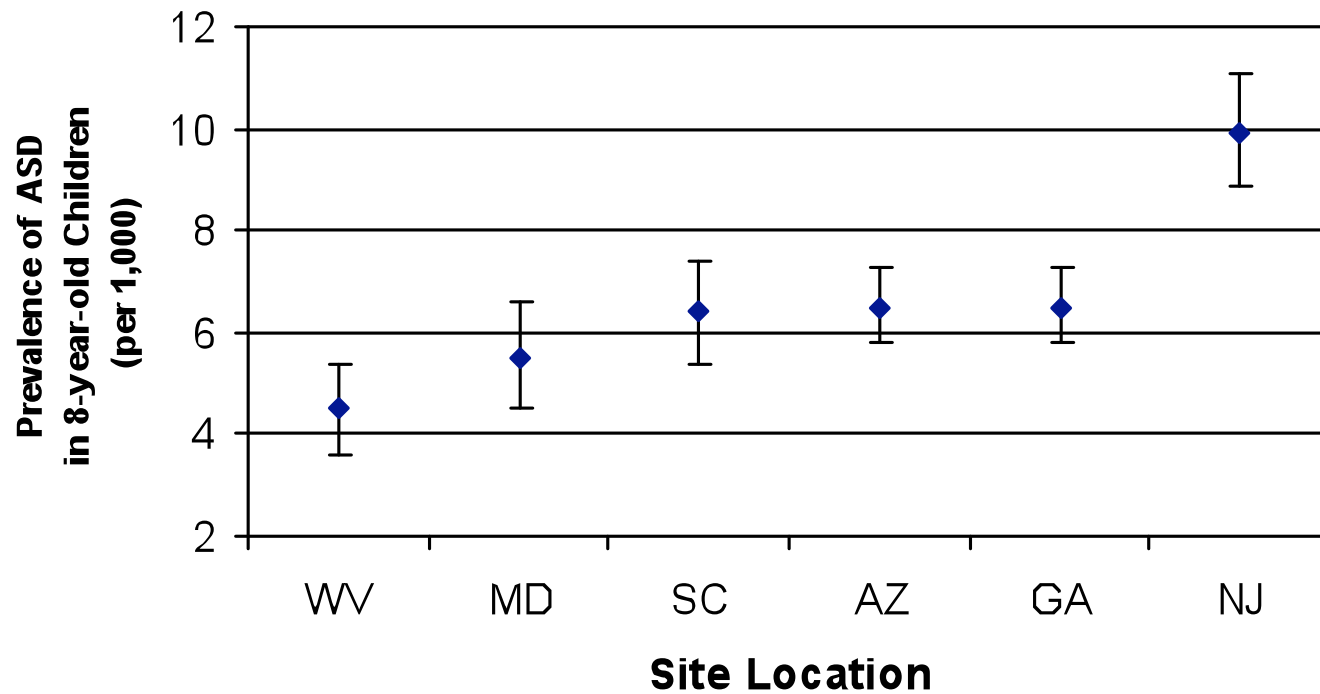
February 2007, the ADDM Network issued its first reports in the *MMWR SS* (surveillance years 2000-2002) indicating

Between 1 in 100 to 1 in 300 - with an average of 1 in 150 children were affected with ASD.

Until today, these data have been used as the standard estimate of autism prevalence in the US.

Findings of SY2000

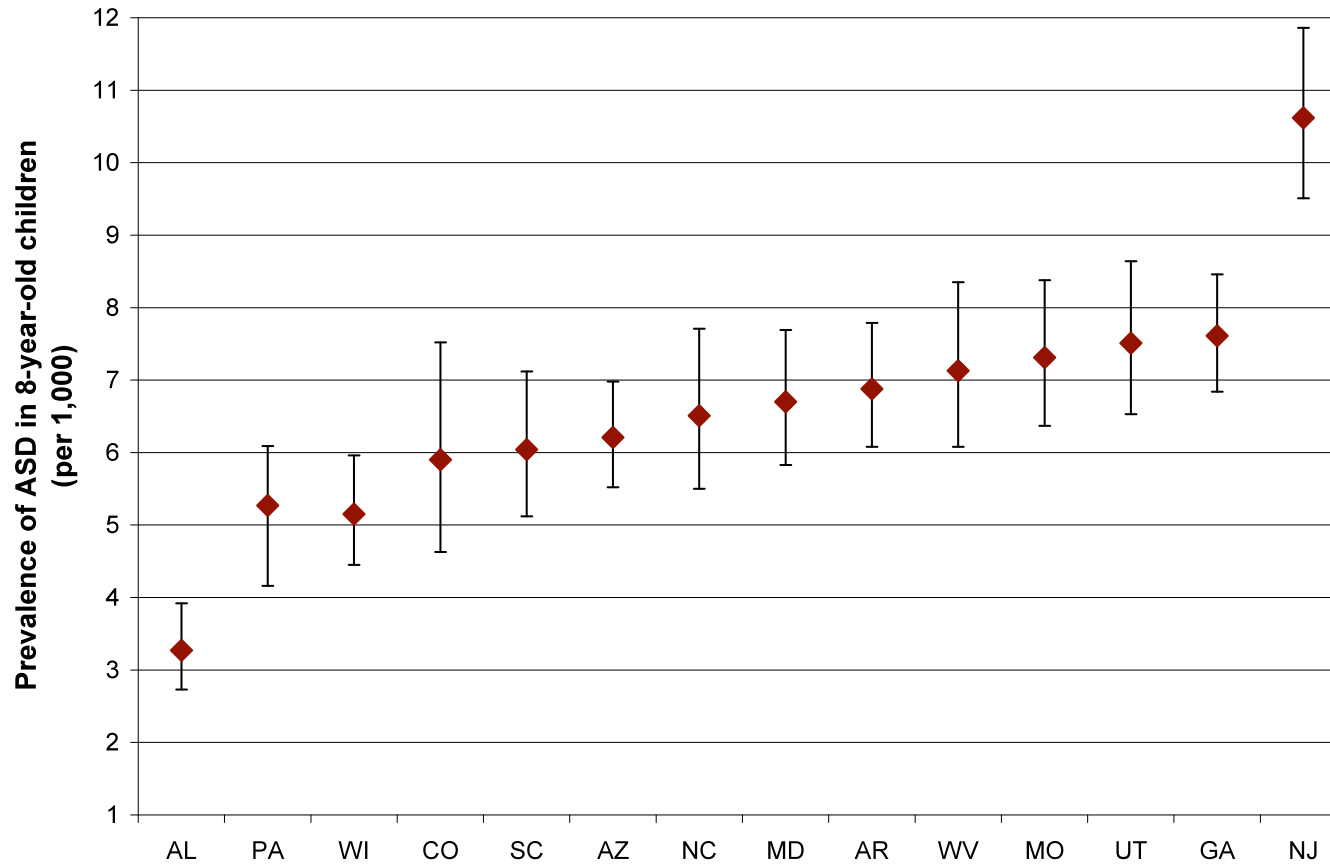
ADDM ASD Prevalence, 2000



Source: MMWR, 56(1), 1-11, Feb 2007

Findings of SY2002

ADDM ASD Prevalence, 2002



Source: *MMWR*, 56(1), 12-28, Feb 2007

ASD Prevalence: Maryland

SY2000

Overall: 5.5 (6.3*)

Boys: 8.6

Girls: 2.2

White, non-Hispanic: 4.9

Black, non-Hispanic: 6.1

SY2002

Overall: 6.7

Boys: 10.2

Girls: 3.0

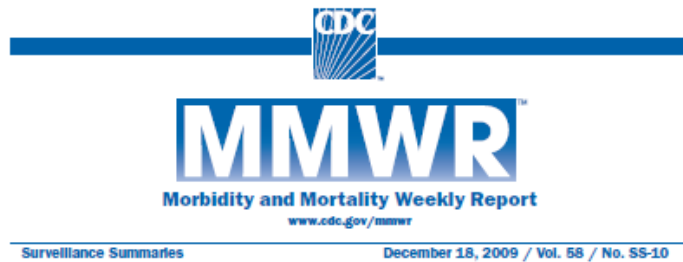
White, non-Hispanic: 7.0

Black, non-Hispanic: 6.2

Hispanic: 1.4

Source: *MMWR*, 56(1), 1-11; 12-28.

ADDM Findings II



Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, United States, 2006

Dec. 18, 2009

Updated ASD prevalence estimates:

- SY2006 (birth yr=1998) for 11 sites: Prevalence changes in 10 ADDM sites from the years 2002 to 2006
- SY2004 (birth yr=1998) (in appendix) for 8 sites

Overall Findings of the Updated Reports

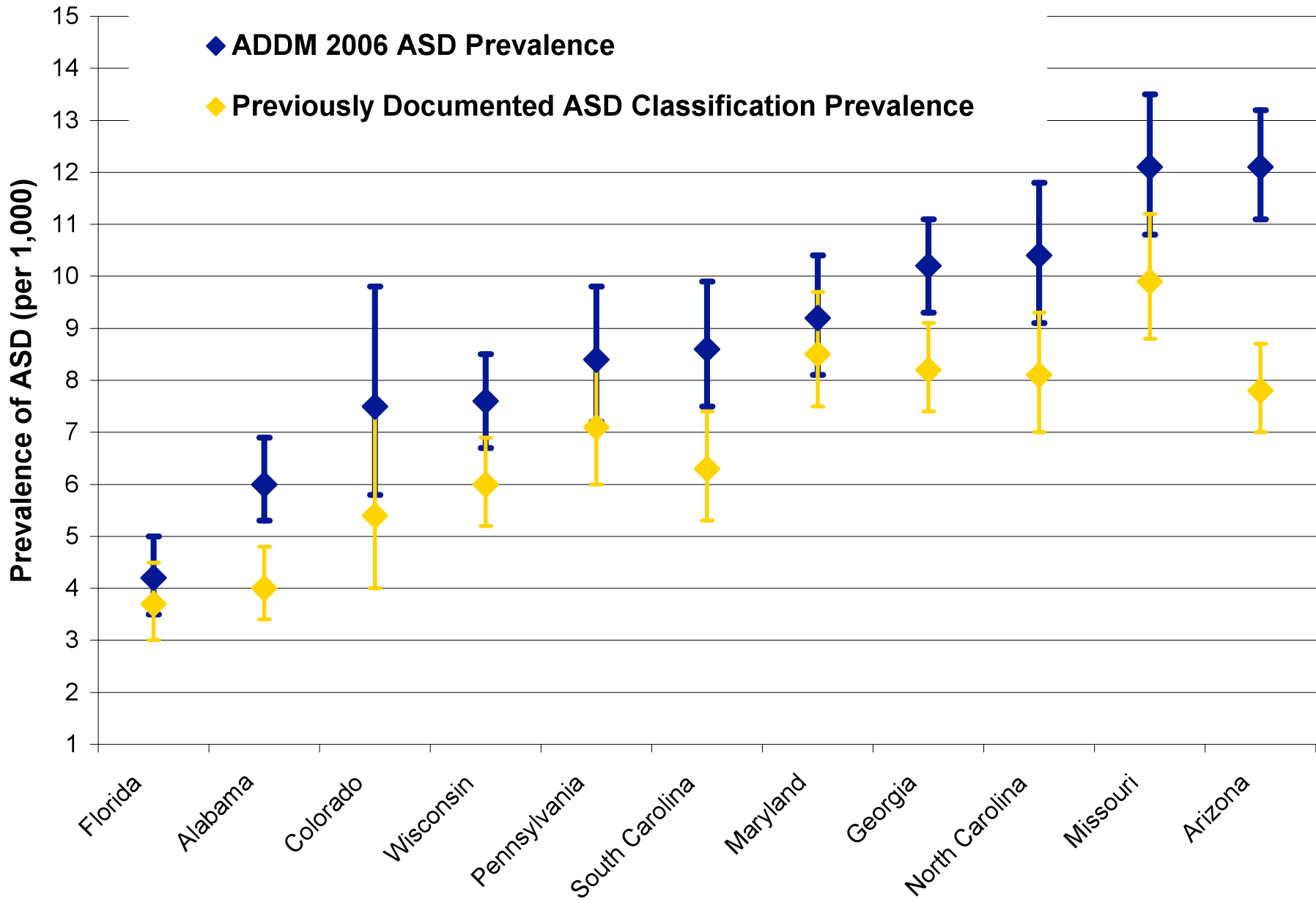
- Average prevalence of ASD approaching 1% of 8-year-old children
 - ✓ Average = about *1 in 110 children* (range 1 in 80 to 1 in 240)
 - ✓ Approximately 1 in 70 boys and 1 in 315 girls
 - ✓ Similar to other recent studies in Europe, Asia, and North America.
- Prevalence increased 57% between 2002 and 2006
- No single factor explains changes in ASD prevalence
 - Some increases due to better documentation in records
- Despite slight improvements in age of diagnosis significant delays persist
- These data provide the most current and complete estimates of ASDs in the population

Surv Year	Birth Year	# sites	8-year-old Population	8-year-old children with an ASD	Average Prev / 1,000 w/ Range
2000	1992	6	187,761	1,252	6.7 4.5-9.9
2002	1994	14	407,578	2,685	6.6 3.3-10.6
2004	1996	8	172,335	1,376	8.0 4.6-9.8
2006	1998	11	307,790	2,759	9.0 4.2-12.1
2008	2000	11(14)		In process	

ADDM 2006 Surveillance Year Overall Identified Prevalence

- From 4.2 per 1,000 (FL) to 12.1 per 1,000 8-year-old children (AZ and MO)
= about 1 in 80 to 240 children
- Average across all 11 sites of **9.0 per 1,000**,
approaching 1% of 8-year-old children
= *about 1 in 110 children*
- **Maryland = 9.2 per 1,000**





ADDM SY2006

Average identified ASD prevalence for

Boys = 14.5 per 1,000 (1 in 70); Girls = 3.2 per 1,000 (1 in 315)

Maryland:

Boys = 15.6 per 1,000 (1 in 65); Girls = 2.4 per 1,000 (1 in 415)

Race/ethnicity

White, non-Hispanic children with highest ASD prevalence, but variability

White, non-Hispanic: average 9.9 per 1,000 (1 in 100)

Black, non-Hispanic: average 7.2 per 1,000 (1 in 140)

Hispanic: average 5.9 per 1,000 (1 in 170)

Maryland:

White, non-Hispanic: 9.3 per 1,000 (1 in 105)

Black, non-Hispanic: 7.9 per 1,000 (1 in 125)

Hispanic: 6.3 per 1,000 (1 in 160)

ADDM SY 2006

- Developmental Concerns and Age of Earliest Documented ASD Diagnosis

- ✓ 70-95% with a documented developmental concern before the age of 3 years

Maryland= 70%

- ✓ 13–30% of children had a reported developmental regression by 24 months of age

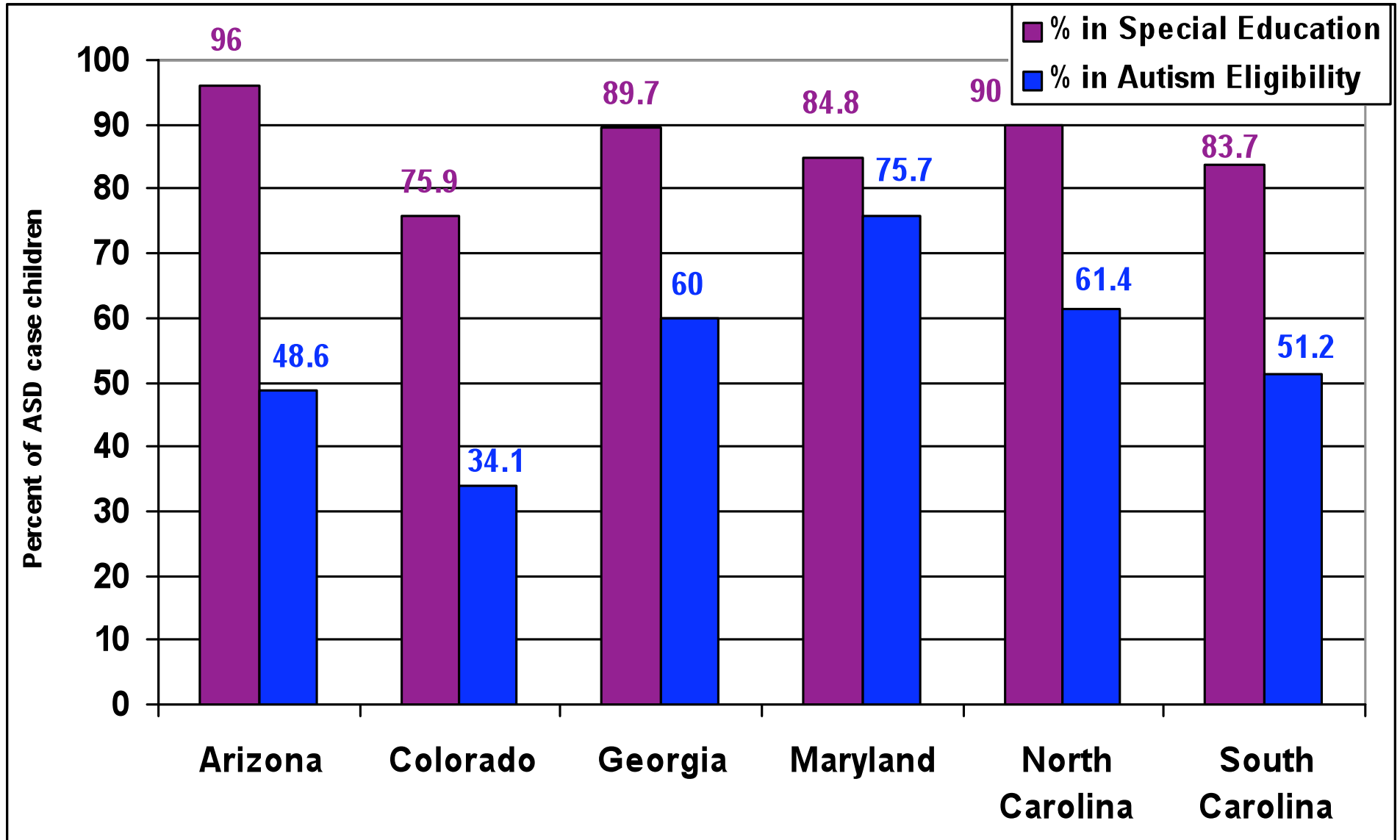
Maryland=23.0%

- ✓ Average age of earliest ASD diagnosis was 4 years 6 months; ranging from 3 years 5 months to 5 years

Maryland= 4 years 10 months

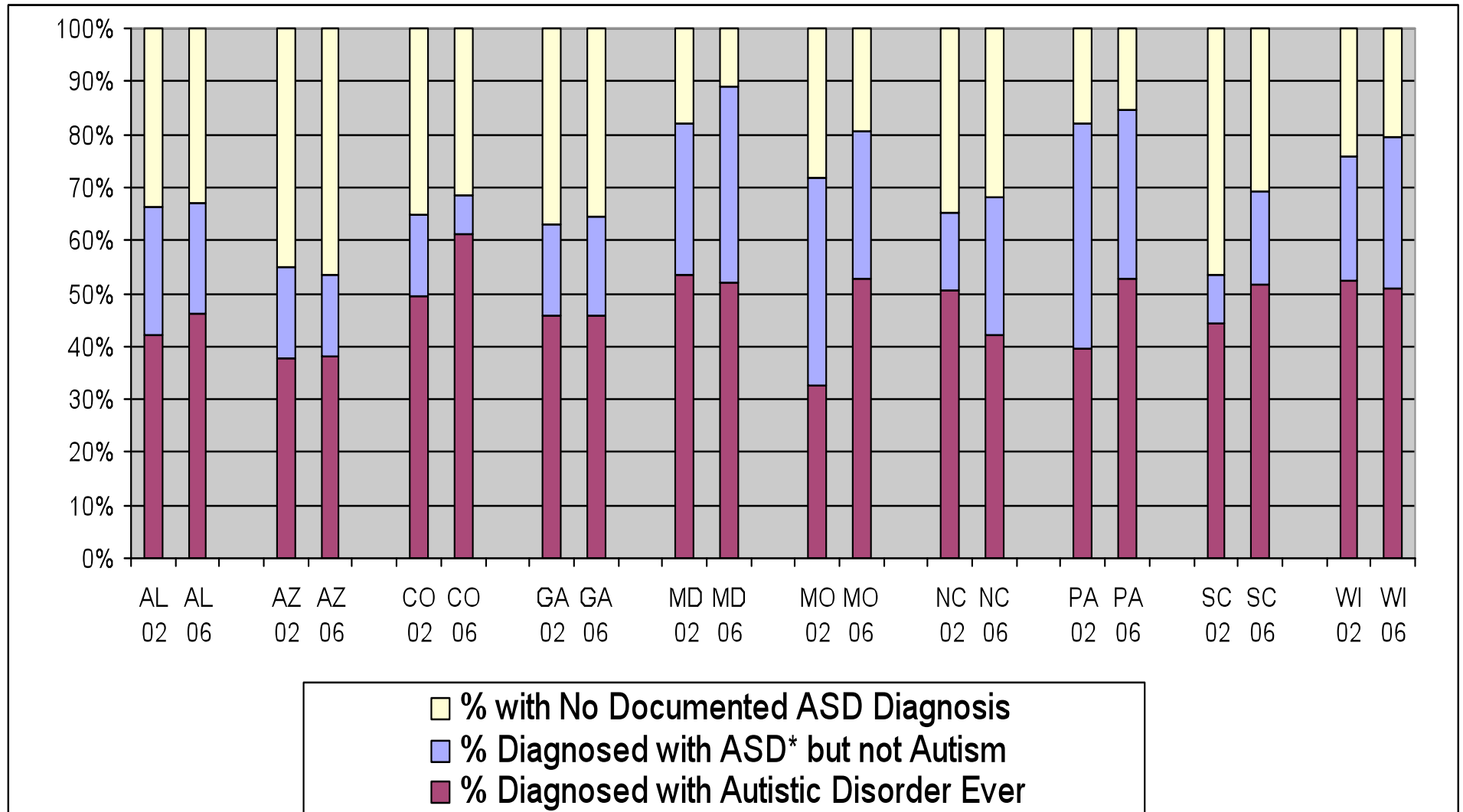


ADDM 2006: Special Education



92%

ASD Subtype as Identified by a Community Professional



Autistic disorder ever average: 45% in 2002; 47% in 2006

General Issues: Why is the identified prevalence of ASD rising?

- **Changes in diagnostic criteria over time**
- **Increased awareness in the community**
- **Changes in availability of services**
 - ✓ Parents as advocates
 - ✓ Development of specialty services
 - ✓ Training of professionals
- **Recognition that ASDs can occur with severe ID, higher intellectual functioning, and other medical and psychiatric disorders**
- **True increase in symptoms in the population**
 - ✓ Increased risk due to environmental and/or genetic factors

Why is the identified prevalence of ASD increasing from 2002 to 2006 in ADDM?

- No single explanation -multiple factors at play
- Identification issues which contributed to small increases across sites:
 - ✓ more evaluation records (4 vs. 5)
 - ✓ better quality of documentation
 - ✓ some sites able to locate more records
 - ✓ some sites had a more stable population
 - ✓ some sites better identification of Hispanic children (AZ)
 - ✓ some sites more identification of children without cognitive impairment
- Unexplained
 - ✓ Could be additional ascertainment issues
 - ✓ Possible that there is a true increase in risk
- Likely a combination of all of the above
 - ✓ Still in the midst of a changing landscape
 - ✓ Need to continue monitoring over time to follow trends
 - ✓ Further analyses to sort out factors noted above

CDC Public Health Actions

- **Surveillance:**
 - ✓ Document and understand changes in prevalence over time
 - Expand monitoring to include additional populations
- **Research:**
 - ✓ Study to Explore Early Development (SEED)
 - Identify potential risk and protective factors for ASD
- **Awareness:**
 - ✓ Learn the Signs. Act Early.
 - Improve early identification of developmental delays and ASD
- **Collaboration:**
 - ✓ CDC is part of Department of Health and Human Services
 - ✓ Interagency Autism Coordinating Committee (IACC)
 - Public/Private Coordination of efforts to address ASDs

Implications

- ASDs are an urgent public health issue.
- A coordinated and collaborative response is needed to:
 - ✓ Intensify search for what puts people at risk;
 - ✓ Improve early identification and access to intervention;
 - ✓ Better understand how to intervene to help reduce the debilitating symptoms of ASDs;
 - ✓ Address the many needs of affected persons and to provide coordinated support services which improve daily functioning and long-term life outcomes.
- Prevalence estimates can be used to plan policy, educational, and intervention services needs for persons with ASDs.

For more information

ADDM Reports in CDC's *MMWR Surveillance Summaries*

www.cdc.gov/mmwr

Updated autism website

www.cdc.gov/autism



Learn the Signs. Act Early.

www.cdc.gov/actearly

Thanks to

You

