



Prevalence of the Autism Spectrum Disorders (ASDs)

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Prevalence of the Autism Spectrum Disorders (ASDs)

Update from the
Autism and Developmental Disabilities Monitoring
(ADDM) Network



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The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention

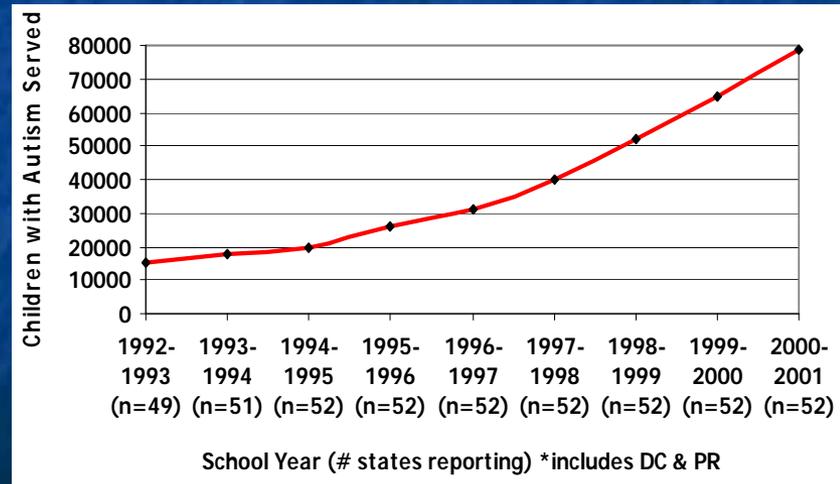


Concerns over increases in people with autism



- It is clear that more children are identified with an Autism Spectrum Disorder (ASD) than in the past.
 - ◆ Children **receiving services** under a specific classification
 - ◆ Children **diagnosed** in a medical or clinical setting

Quarterly Trends in Number of Persons with Autism Added to the System (1994-2004)



How do we know who has an ASD?

- Who else may have the condition(s)?
 - ◆ Little **population-based** data of the features of ASDs
 - ★ Behaviorally-defined
 - ★ Prevalence studies involve **population screening**
 - Direct screening – who participates?
 - Parent report - validation
 - Records-based screening





Prevalence Estimates

- ◆ 1960's – '80's: estimated about 1 in 2,000 children with *autism*
- ◆ *Since 1994 DSM-IV and ICD-10 criteria - spectrum*
 - ★ Average estimates: 6-7 per 1,000 children
 - ★ More recent studies higher...



2009 Articles: ASD Prevalence in US

CDC collaborated with HRSA in the analysis of national survey and has a multi-site ASD surveillance program.

National Survey of Children's Health:

Kogan MD, Blumberg SJ, Schieve LA, Boyle CA, Perrin JM, Ghandour RM, Singh GK, Strickland BB, Trevathan E, van Dyck PC. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*. 2009 Nov;124(5):1395-403. Epub 2009 Oct 5.

Autism and Developmental Disabilities Monitoring (ADDM) Network. Prevalence of Autism Spectrum Disorders (ASDs) —Autism and Developmental Disabilities Monitoring (ADDM) Network, 2006. *MMWR SS*. 2009 Dec; 58, SS-10.

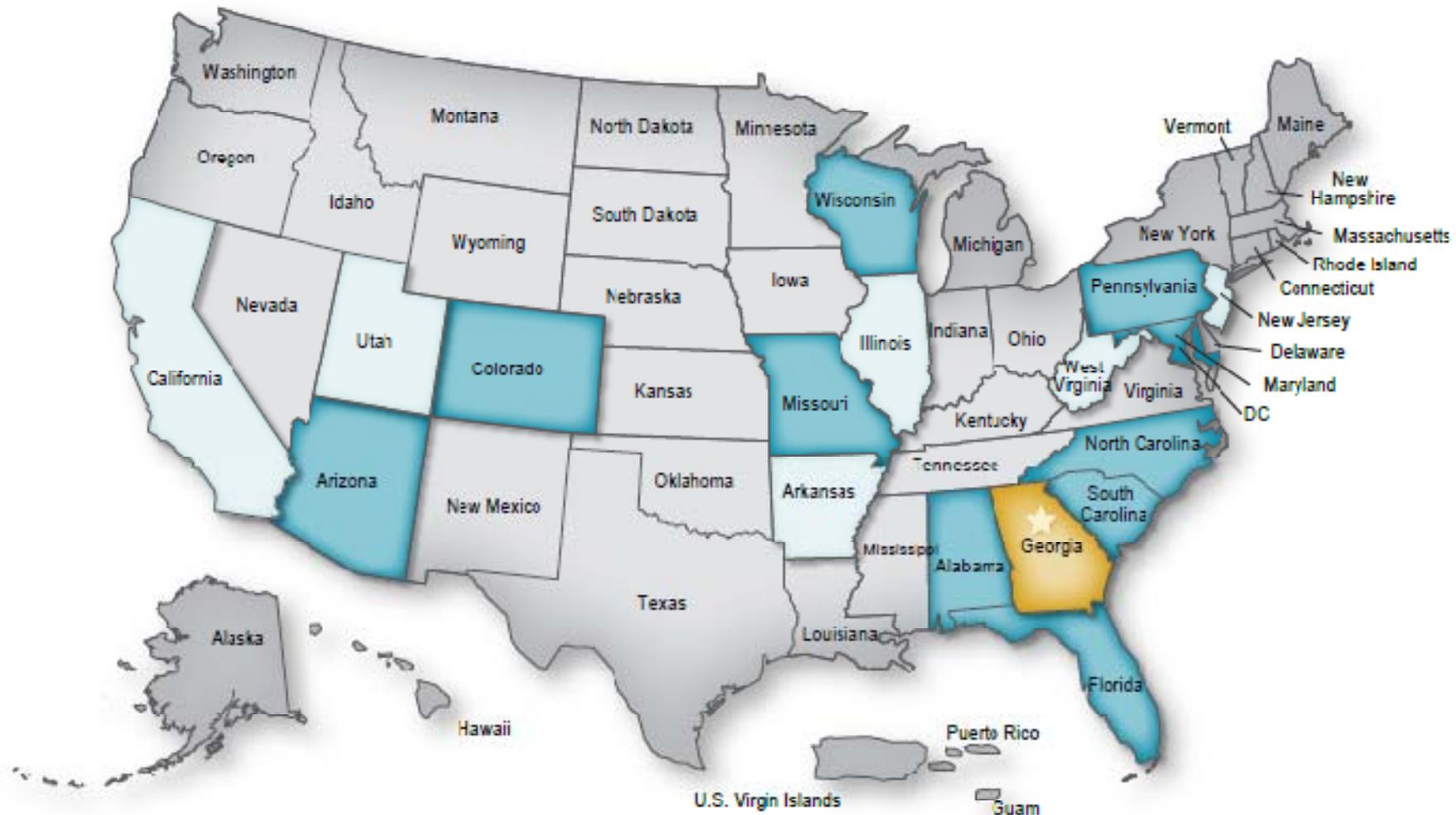
Autism and Developmental Disabilities Monitoring (ADDM) Network

- ◆ Collaborative effort to estimate prevalence of ASDs in multiple areas of US



- ◆ Provide data to
 - ★ Characterize the ASD population
 - ★ Describe variation by subgroups and over time
 - ★ Evaluate methodologic factors which may influence estimates
 - ★ Inform hypotheses on potential risk factors

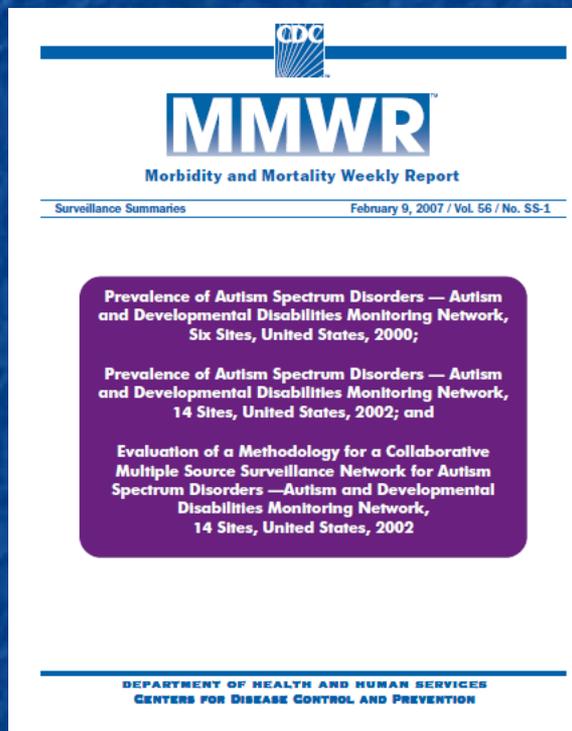
Autism and Developmental Disabilities Monitoring (ADDM) Network



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



How many children have an ASD? According to CDC...



- February 2007, the first ADDM Network report
 - **Between 1 in 100 to 1 in 300 - with an average of 1 in 150 children with ASD** (retrospective view of years 2000 and 2002).
- December 2009 – 2nd report
 - Retrospective view of 2006 (born 1998) for 11 sites
 - 2004 (born 1996) optional year for 8 sites
 - Prevalence changes in 10 ADDM sites from the years 2002 to 2006

Authors: Autism and Developmental Disabilities Monitoring (ADDM) Network Principal Investigators

ADDM 2006 Site	Area	8-year-olds in Population in 2006
1. Alabama	32 counties	35,126
2. Florida	1 county	27,615
3. Missouri	5 counties	26,533
4. Pennsylvania	1 county	17,886
5. Wisconsin	10 counties	34,058
6. Arizona	1 county	41,650
7. Colorado	1 county	7,184
8. Georgia	5 counties	46,621
9. Maryland	6 counties	26,489
10. North Carolina	10 counties	22,195
11. South Carolina	23 counties	22,681
11 site total		308,038; ~8% of US 8-year-olds

ADDM Network Overall



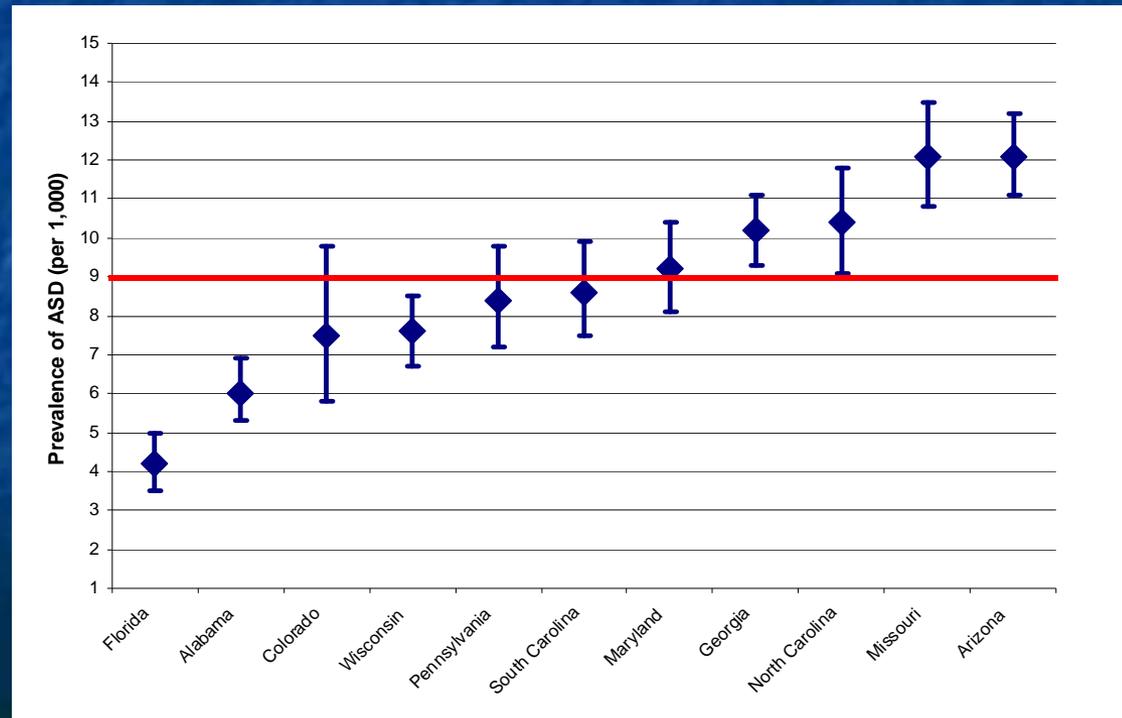
ASD Prevalence Estimates, 2000-2006

Surv Year	Birth Year	# sites	8-year-old Population	8-year-old children with an ASD	Average Prev / 1,000 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	308,038	2,759	9.0 4.2-12.1
2008	2000	11(14)		In process	

Overall ASD Prevalence Estimates



- **11 Sites in 2006 (born 1998)**
- **From 4.2 to 12.1 per 1,000 8-year-old children**
 - = ~ 1 in 80 to 1 in 240 children
- **Average of 9.0 per 1,000,**
 - about 1% of 8-year-old children
 - = ~ 1 in 110 children



Prevalence by Sex, Race or Ethnicity

Males and Females

- Average 4.5 boys to every girl identified with ASD
 - Males = 14.5 per 1,000 (~ 1 in 70 boys)
 - Females = 3.2 per 1,000 (~ 1 in 315 girls)

Race/ethnicity

- White, non-Hispanic children with highest ASD prevalence, but variability across sites
 - White, non-Hispanic: average 9.9 per 1,000 (~ 1 in 100 children)
 - Black, non-Hispanic: average 7.2 per 1,000 (~ 1 in 140 children)
 - Hispanic: average 5.9 per 1,000 (~ 1 in 170 children)

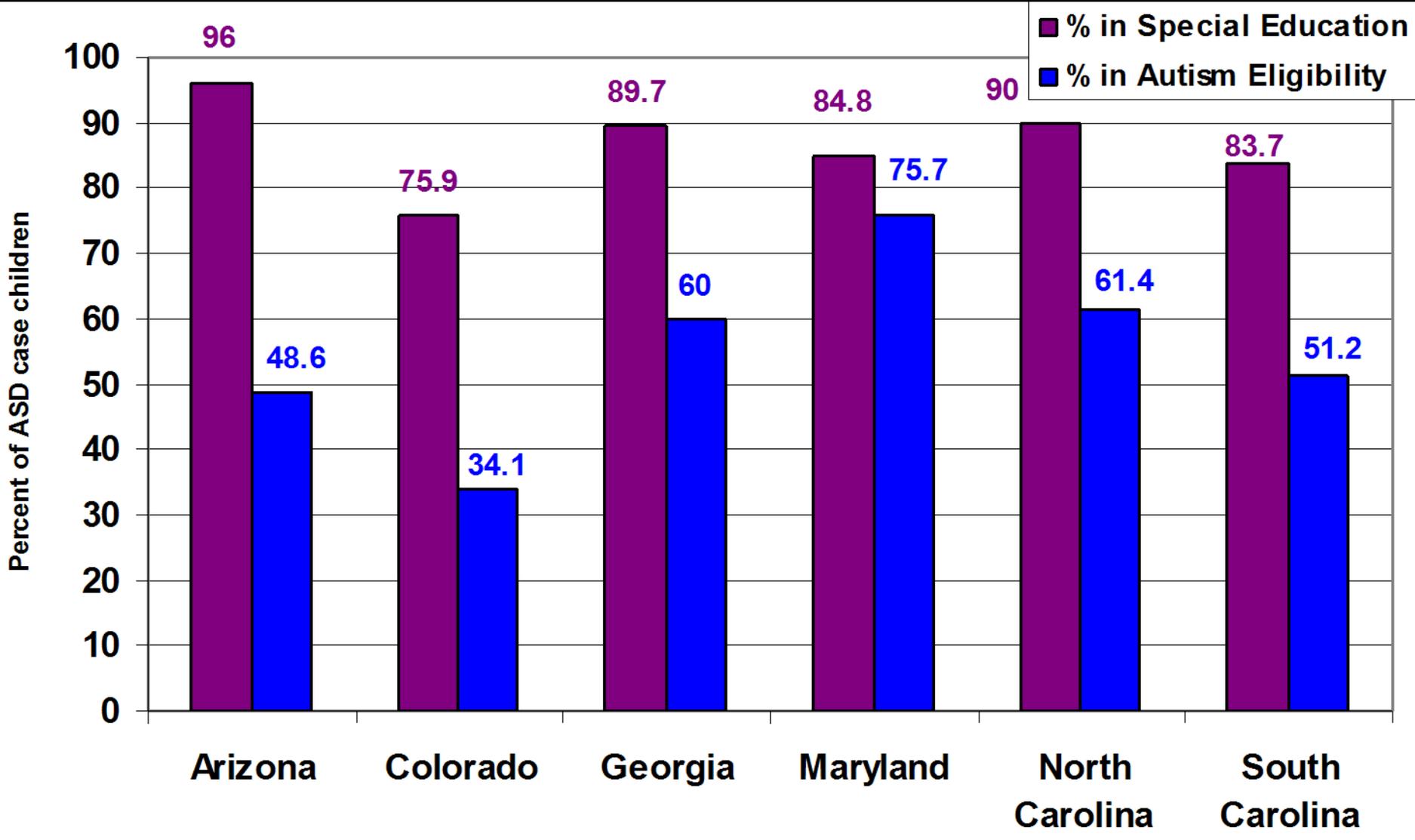
Developmental Concerns and Age of Earliest Documented ASD Diagnosis



- **70-95%** with a documented **developmental concern** before the age of **2 years**
- **13-30%** of children had a **reported developmental regression** by 2 years of age
- Average age of earliest ASD diagnosis was **4 years, 6 months**; ranging from 3 years, 6 months to 5 years



ADDM 2006: Special Education



76-96% receiving public special education services; 34-76% autism eligibility

Change in ASD Prevalence Estimates

- 10 sites
- 2002 to 2006
 - ◆ children born 1994 and 1998



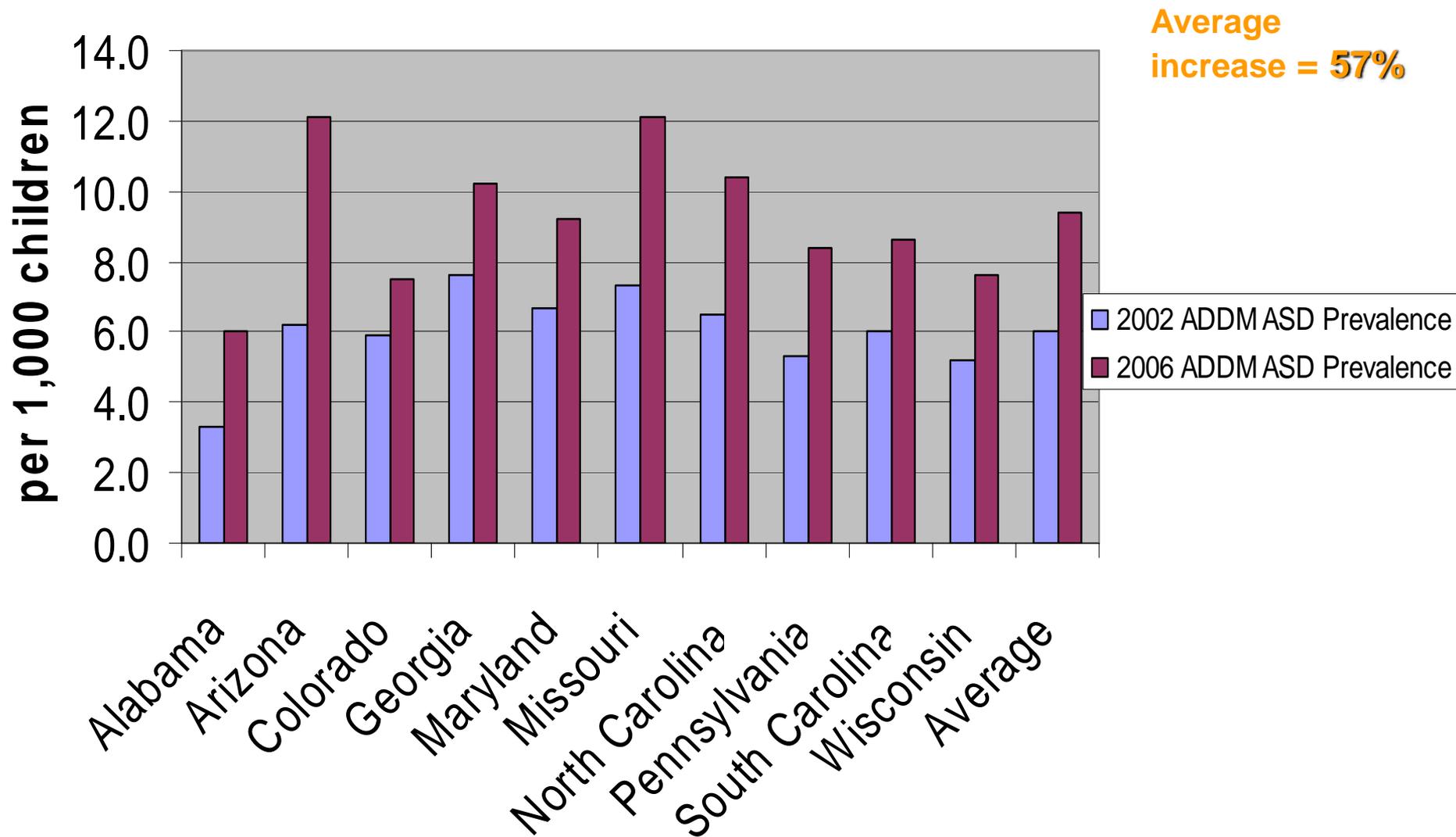


Change in ASD Prevalence Estimates from 2002 to 2006 by Total, Gender, & Race or Ethnicity

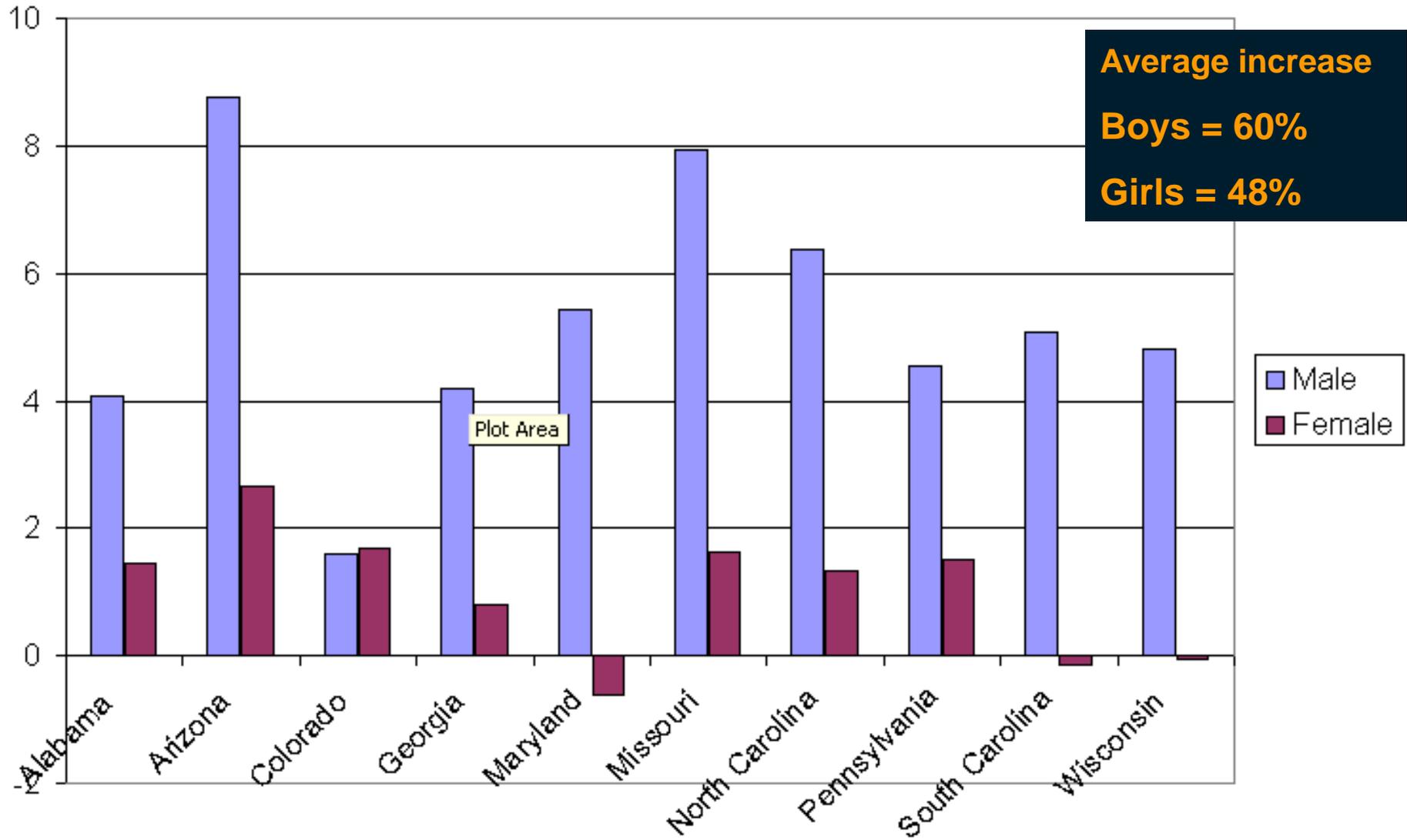
	Total	Males	Females	White non- Hispanic	Black non- Hispanic	Hispanic
% Change Average	57%	60%	48%	55%	41%	91%

- Overall trends consistent, but variation by site.

Change in identified prevalence of autism spectrum disorders (ASDs) among children aged 8 years, Autism and Developmental Disabilities Monitoring (ADDM) Network, 10 sites*, United States, 2002 to 2006

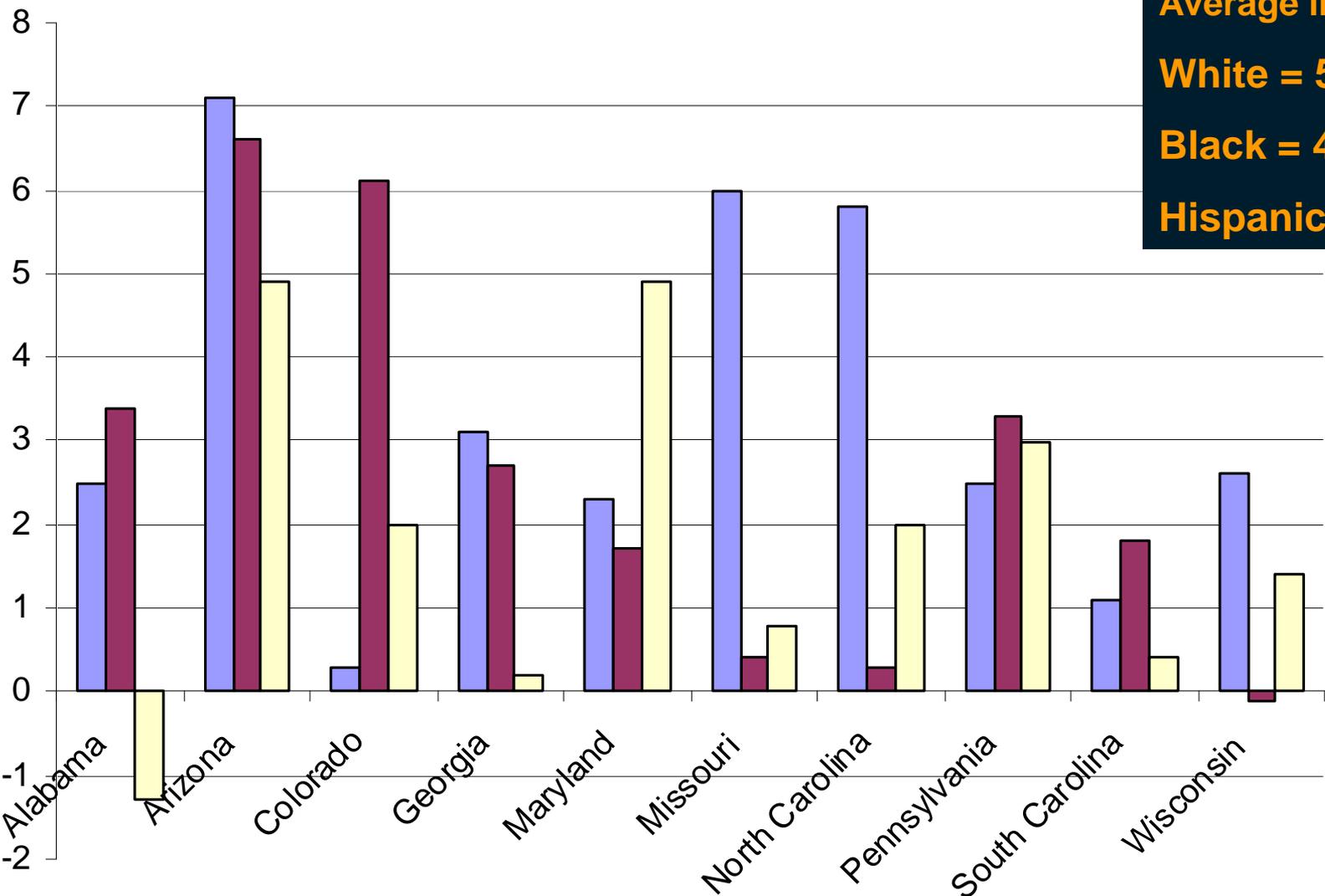


ADDM 2002-2006: Absolute change in ASD prevalence estimates in boys and girls





ADDM 2002-2006: Absolute change in ASD prevalence estimates by race or ethnicity



Average increase
White = 55%
Black = 41%
Hispanic = 91%

White
Black
Hispanic

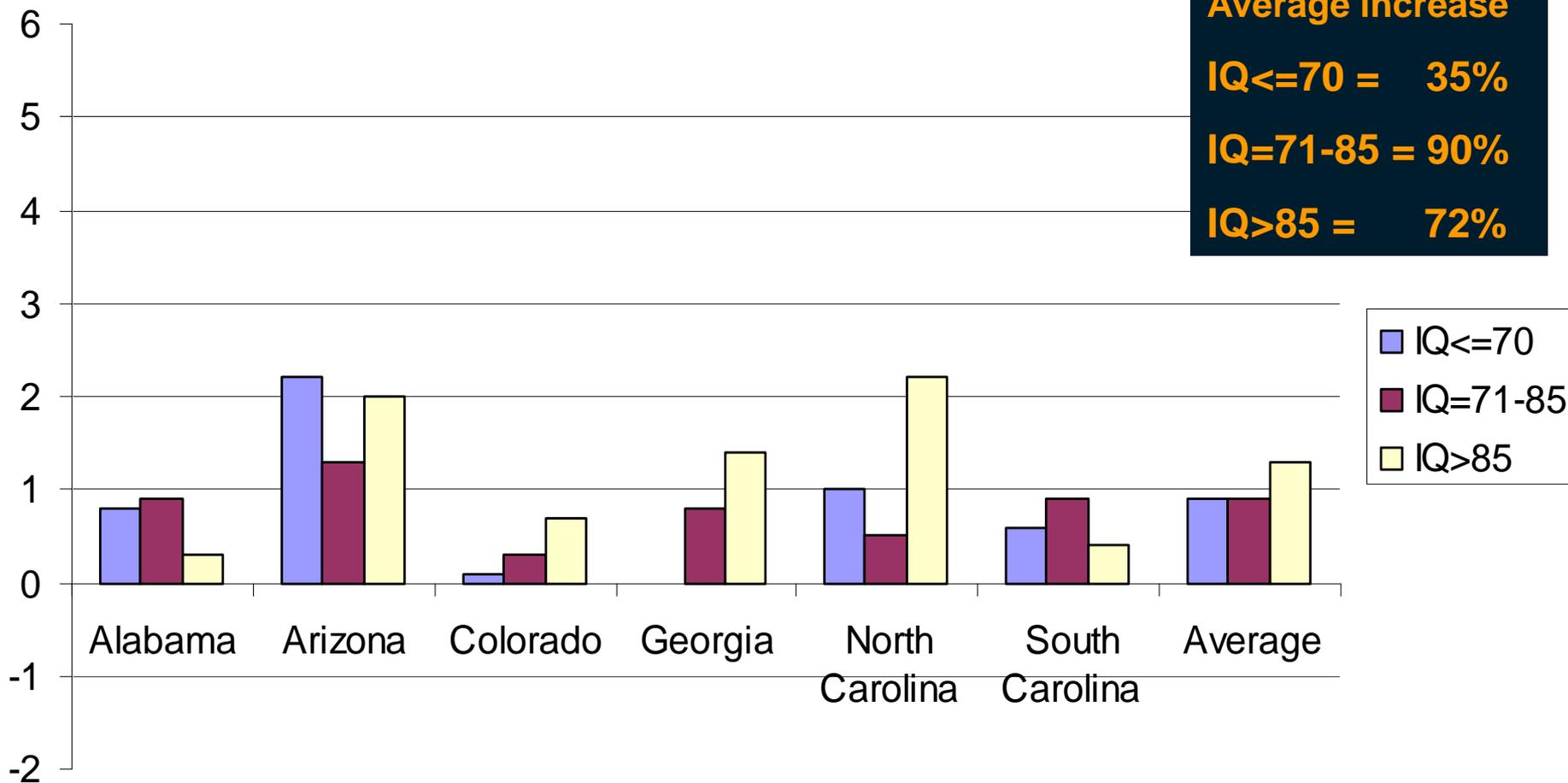


Change in ASD Prevalence from 2002 to 2006 by Cognitive Functioning Level

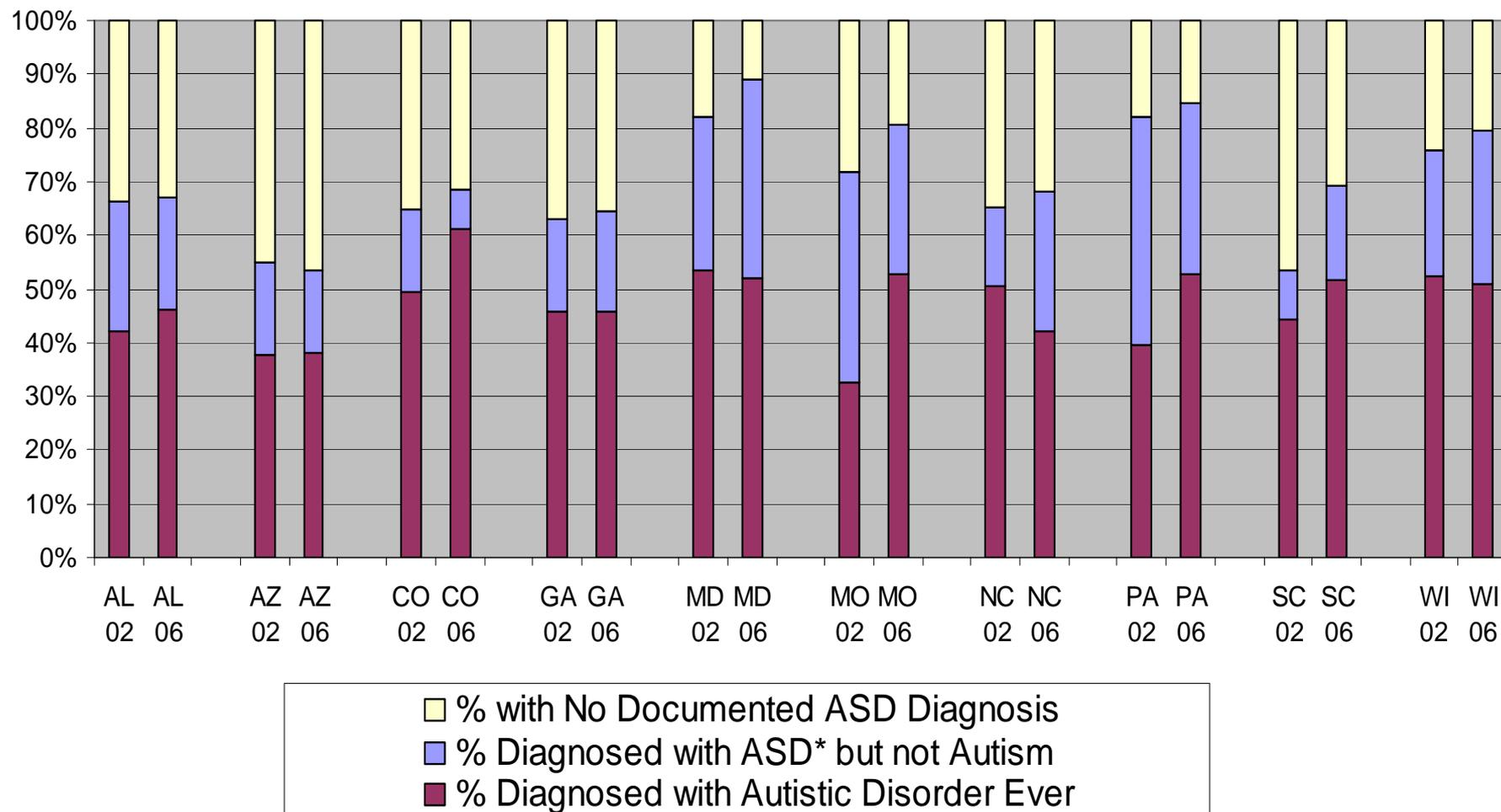
	Cognitive Impairment (IQ≤70)	Borderline (IQ=71-85)	Average to Above Average (IQ>85)
% Change, Average	35%	90%	72%

- In 2006, between 29-51% of children classified with cognitive impairment (average 41%) (44% in 2002).

ADDM 2002-2006: Absolute change in ASD prevalence estimates by cognitive functioning estimate



ASD Subtype as Identified by a Community Professional



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

Why did ASD prevalence estimates increase from 2002 to 2006 in ADDM?



■ What can we measure? 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
- had a more stable population
- decrease in age of diagnosis
- better identification of Hispanic children
- more identification of children without cognitive impairment



■ No single explanation - multiple factors at play

- ◆ Could be additional ascertainment issues
- ◆ True increase in risk possible

ADDM Network Strengths



- Collaborative, multi-site surveillance system
- Record review methodology allows application to large populations (8% of US 8 year-olds)
- Confirmation of documented ASD symptoms using *DSM-IVTR* criteria
- Multiple-sources of information
- Quality control
- Expansion to other DDs at some ADDM sites
 - Intellectual Disability, Cerebral Palsy, ASD and Epilepsy
- Creation of multi-year population-based dataset for further analyses (examples: parental age, multiple births...)

ADDM Network Challenges



- **Maintenance of the network of sites over time—resources and competitive process**
- **Site-specific differences in methodology**
 - Access to education records
 - Quality of information in records
 - Requesting additional codes for monitoring other DDs
- **Timeliness – intensive, collaborative process and retrospective review**

Van Naarden Braun K, et al. 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. *MMWR SS*; February 9, 2007; 56(1):29-40

ADDM Network Overall Findings

- **Average prevalence of ASD about 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, including Kogan et al., from NSCH.
- **Prevalence increased 57% between 2002 and 2006**
- **Methodological factors cannot completely account for changes in ASD prevalence estimates**
 - *Some* increases due to better identification through records
- **Despite slight improvements in age of diagnosis significant delays persisted**



What we know for sure - more children with ASD identified and the impact on individuals, families and communities is significant.

Implications



- Prevalence estimates can be used to plan policy and service needs for persons with ASDs.
- Highlight the need for a coordinated, collaborative, and multi-prong approach to:
 - Intensify search for 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.



CDC Public Health Actions



■ Surveillance:

- ◆ Document and understand changes in prevalence over time

■ 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

■ Build on ADDM infrastructure to

- ◆ Estimate prevalence in the same populations over time
- ◆ Evaluate measurable identification and risk factors

■ Expand scope of surveillance to

- ◆ Complementary data from national surveys
- ◆ Increase types of data collected
- ◆ Other neurodevelopmental disorders
- ◆ Younger and older age groups
- ◆ Provide technical assistance
- ◆ International settings

www.iacc.hhs.gov



Principal investigators and Project Coordinators:



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For more information

ADDM Reports in CDC's *MMWR Surveillance Summaries*

www.cdc.gov/mmwr

CDC autism website

www.cdc.gov/autism





Q&A Session

Please submit the evaluation immediately following this webcast.