



# Prevalence of the Autism Spectrum Disorders (ASDs)

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

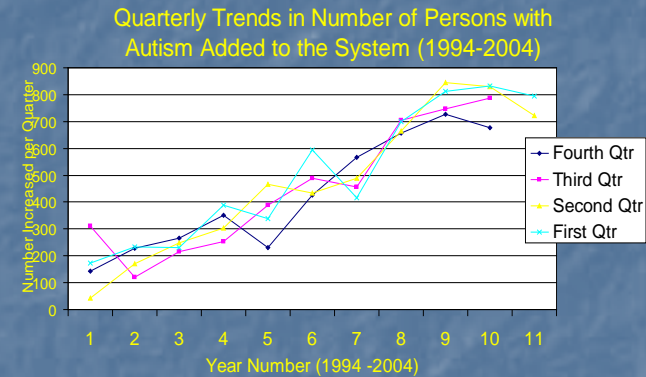


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**Centers for Disease Control and Prevention**

*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 autism

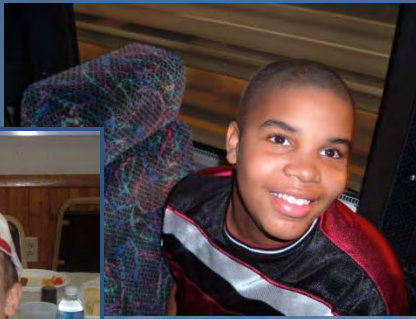
- It is clear that more children are identified with an Autism Spectrum Disorder (ASD) than in the past.
  - Children **receiving services** under a specific classification
  - Children **diagnosed** in a medical or clinical setting



- Who else may have an ASD?
  - Little **population-based** data of the features of ASDs
    - Behaviorally-defined
    - Prevalence studies involve **population screening**
      - Direct screening – access, participation
      - Records-based screening







## Prevalence Estimates

- 1960's – '80's: estimated **0.5 in 1,000** children with *autism*
- *Since 1994 DSM-IV and ICD-10 criteria - spectrum*
  - Average estimates: **6-7 per 1,000** children
  - Some studies showing around 10 per 1,000 children (1%) or more children with an ASD
    - Study from UK indicating 1% of adults with an ASD

# Autism and Developmental Disabilities Monitoring (ADDMM) 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

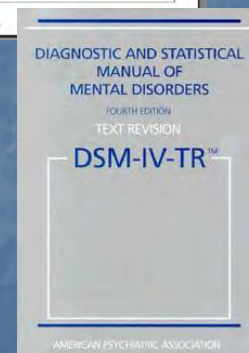




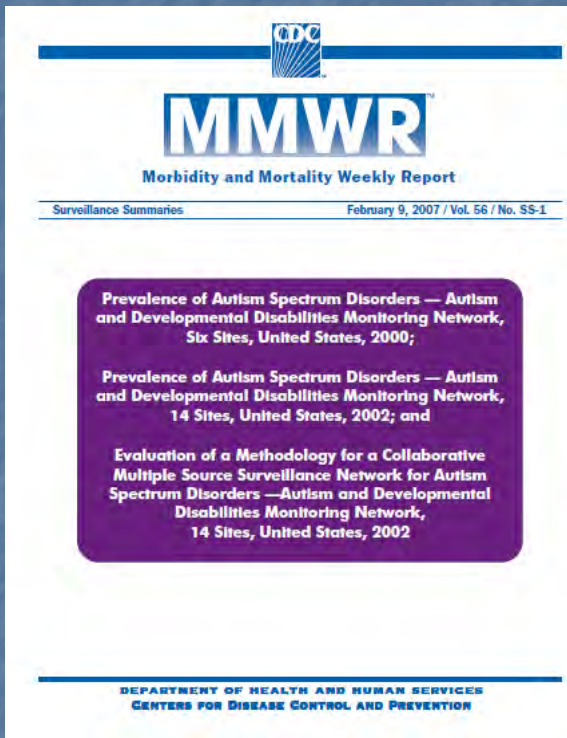


# ADDM Network Methods

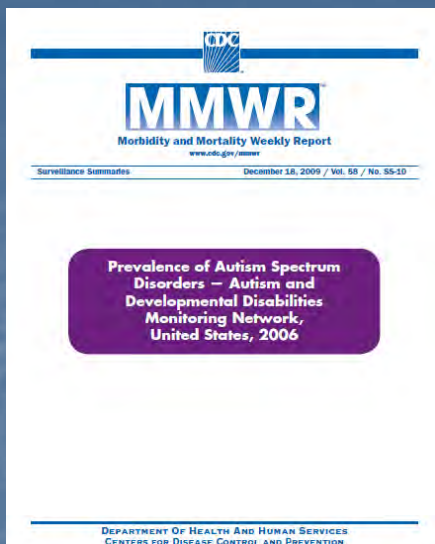
- **Active case-finding with retrospective records-based screening for ASD classifications or behaviors.**
- Children at **age 8 to identify peak** prevalence.
- **Multiple sources** of information.
- **Detailed** descriptive and testing information collected.
- Ongoing **quality control** within and across sites.
- Independent clinician confirmation of ASD case status based on **documentation of the DSM-IVTR criteria.**







- February 2007, the ADDMM 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.




**December 2009**

# Prevalence of Autism Spectrum Disorders (ASDs) –Autism and Developmental Disabilities Monitoring (ADDMM) Network, 2006

## 2006 Surveillance Year for 11 sites

- Prevalence changes in 10 ADDMM sites from the years 2002 to 2006
- 2004 Surveillance Year (optional year in appendix) for 8 sites



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



# ADDM Network Overall

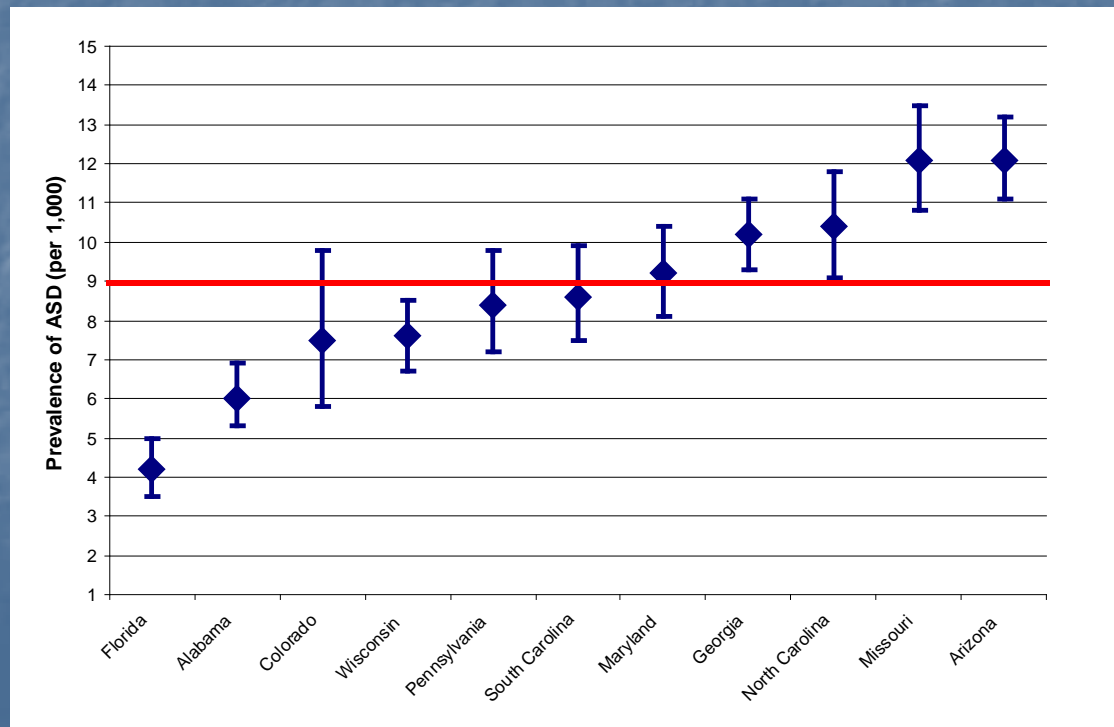


## ASD Prevalence Estimates, 2000-2006

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	



- 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)

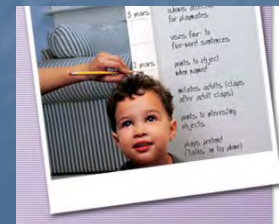
## Race/ethnicity

- 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)

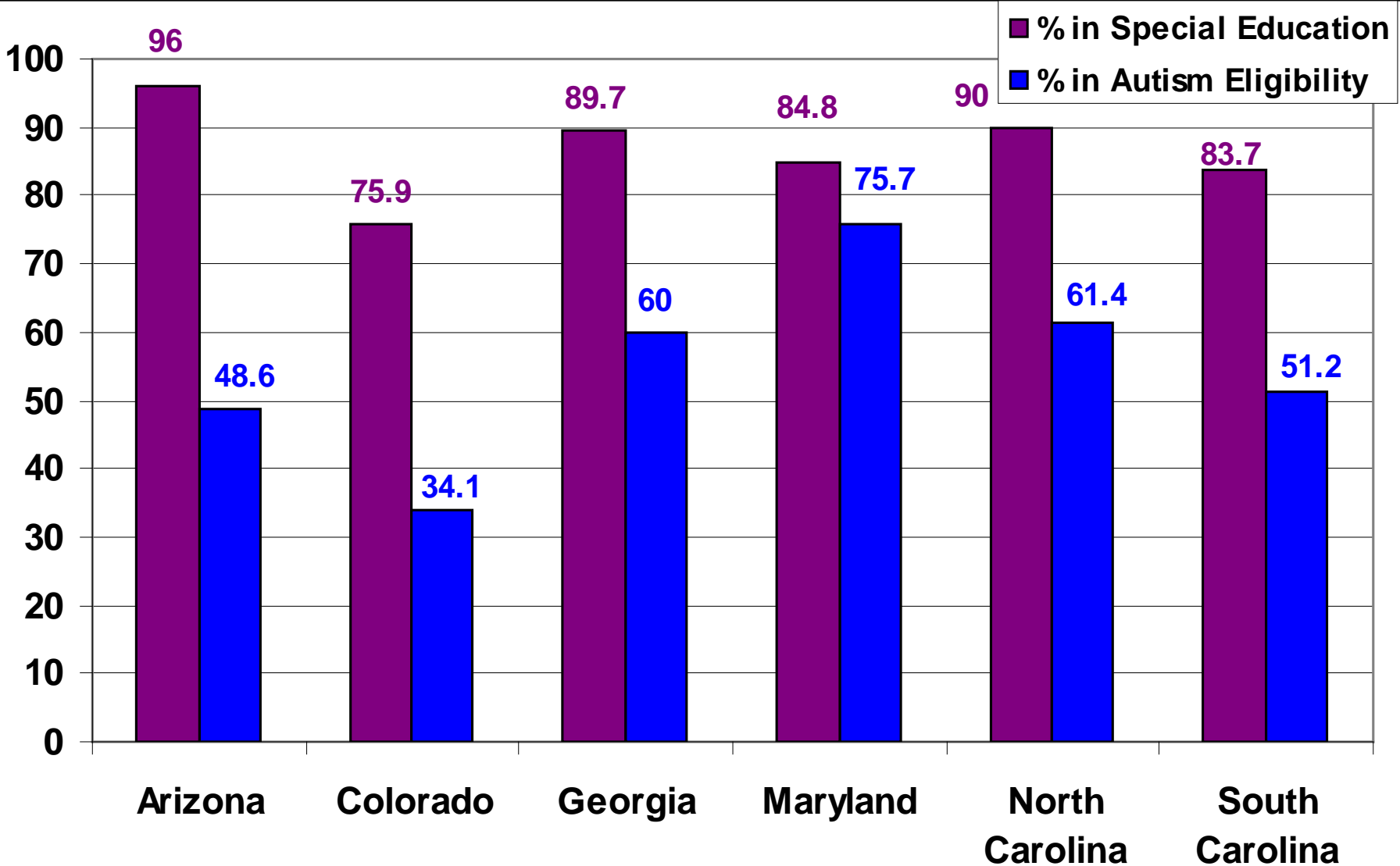


# Developmental Concerns and Age of Earliest Documented ASD Diagnosis

- **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



# ADDMM 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



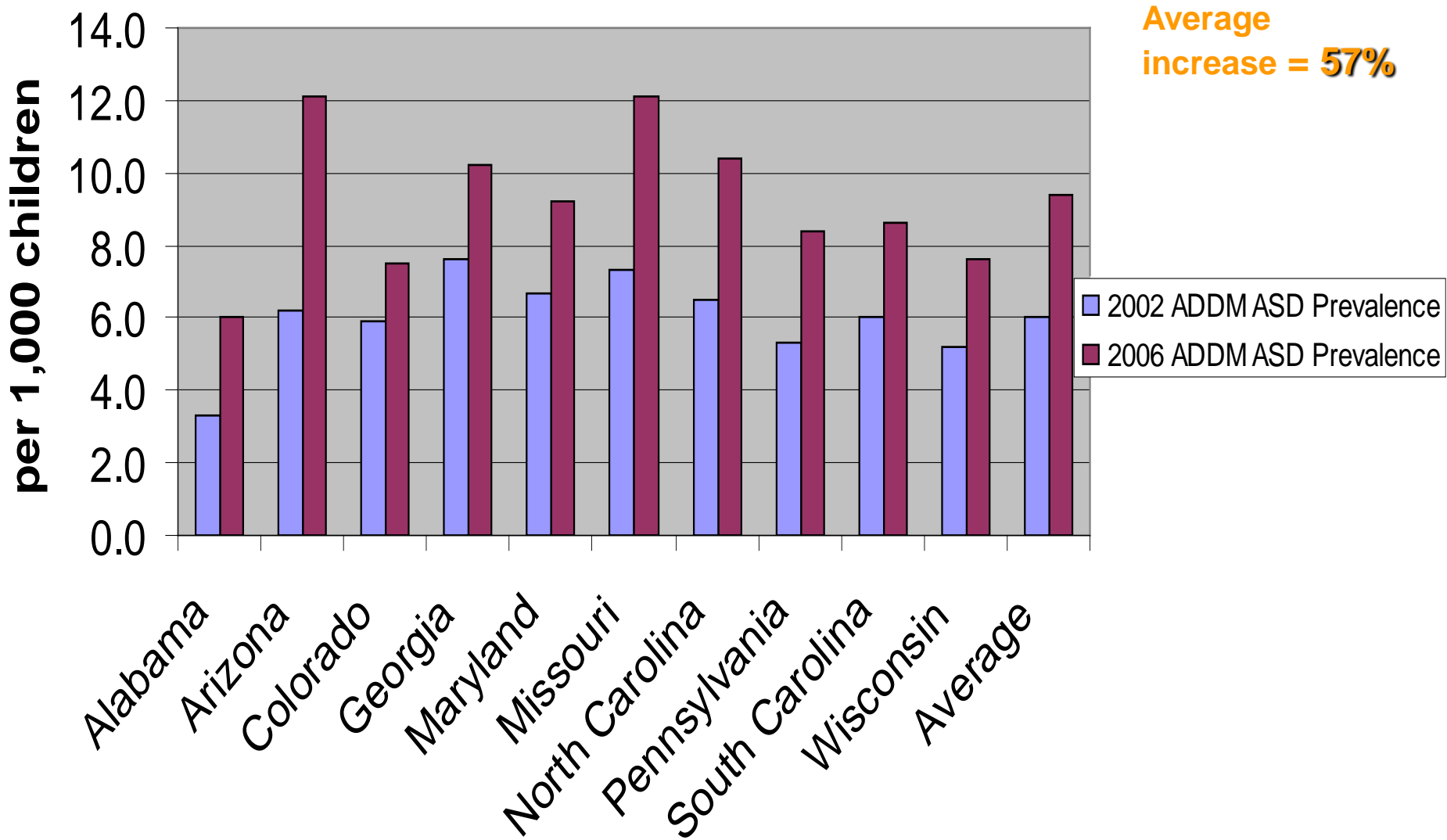
# Change in ASD Prevalence Estimates from 2002 to 2006 by Total, Gender, & Race or Ethnicity

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

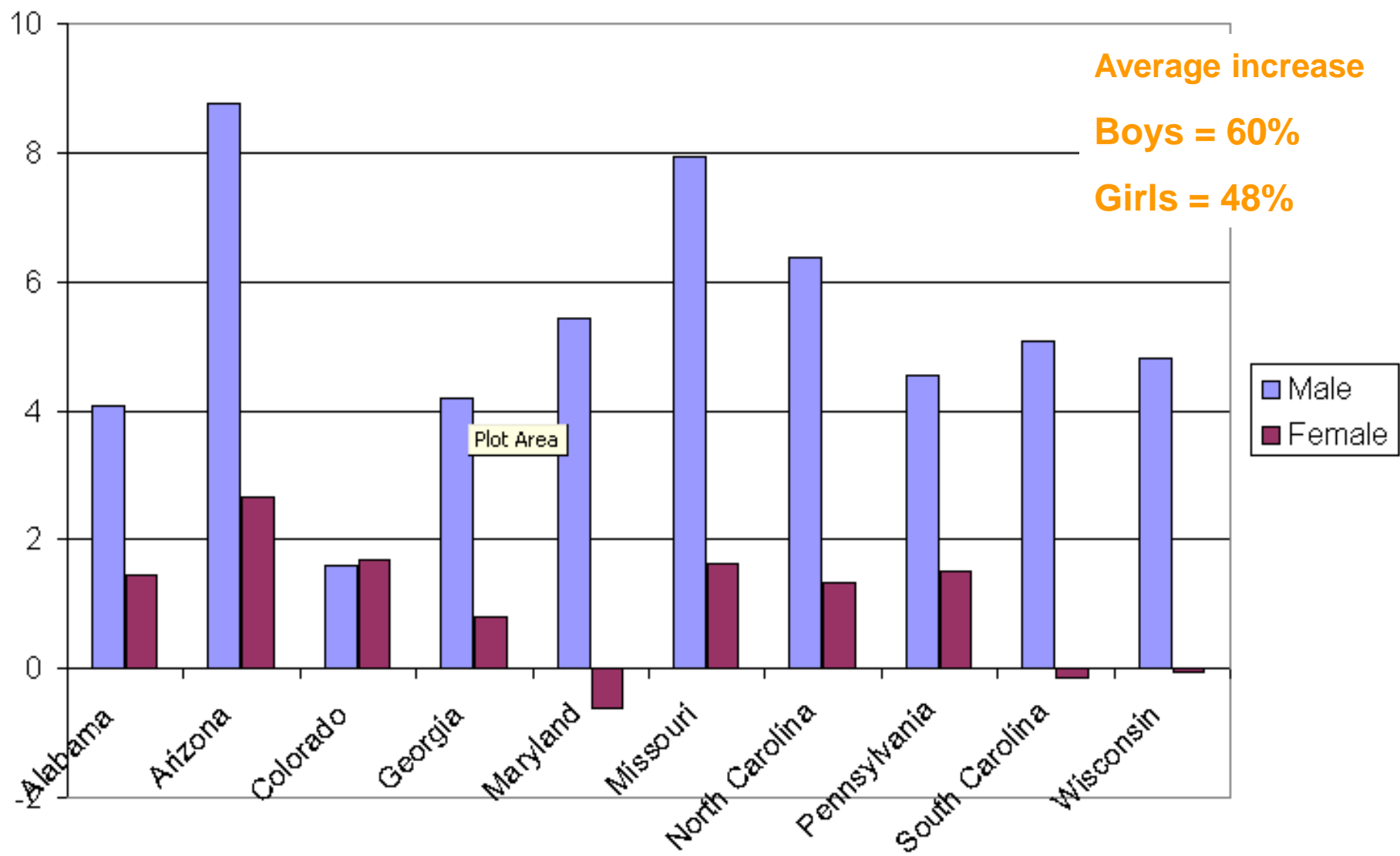
- Overall trends consistent, but variation by site.



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

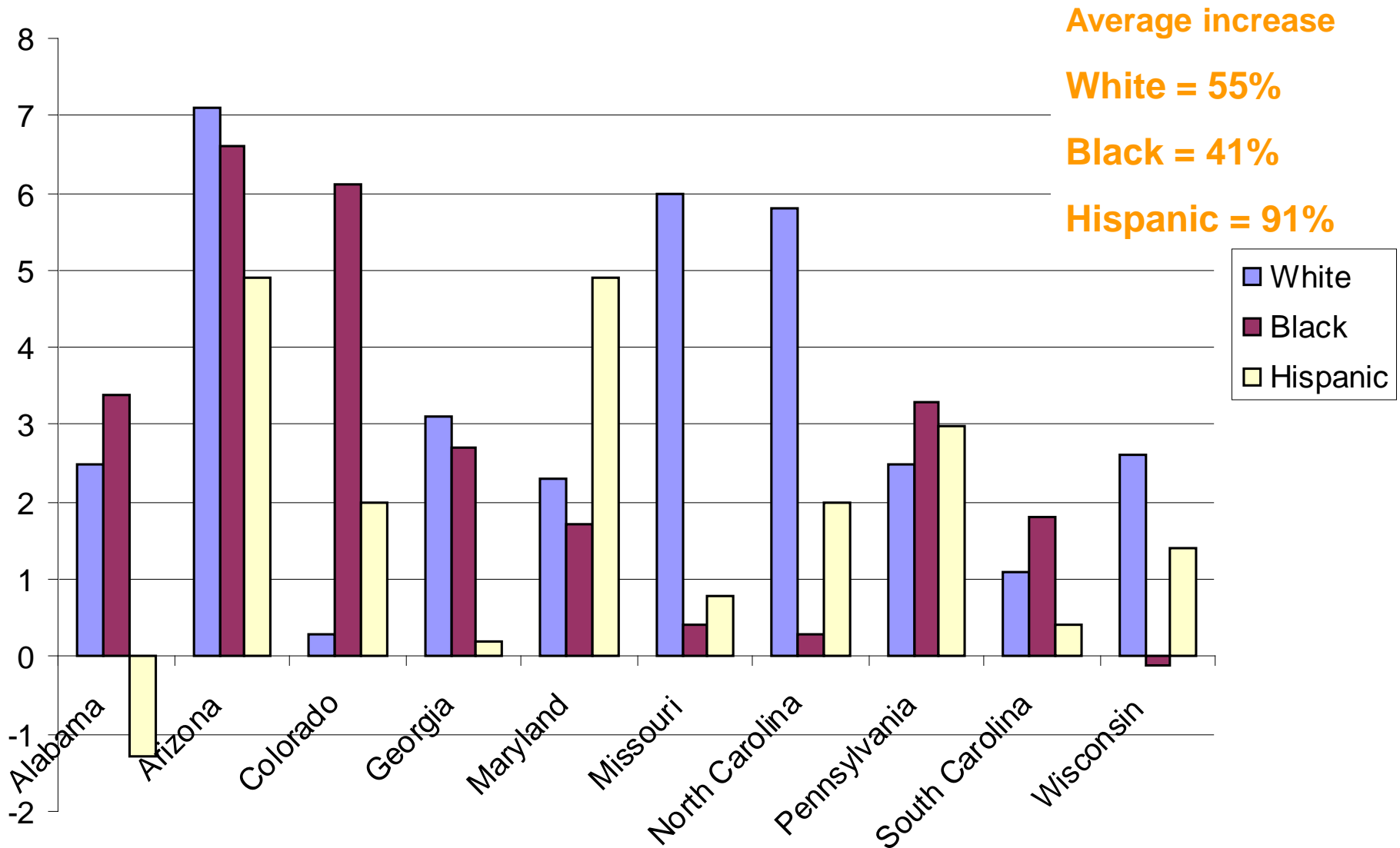


# ADDMM 2002-2006: Absolute change in ASD prevalence estimates in boys and girls





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



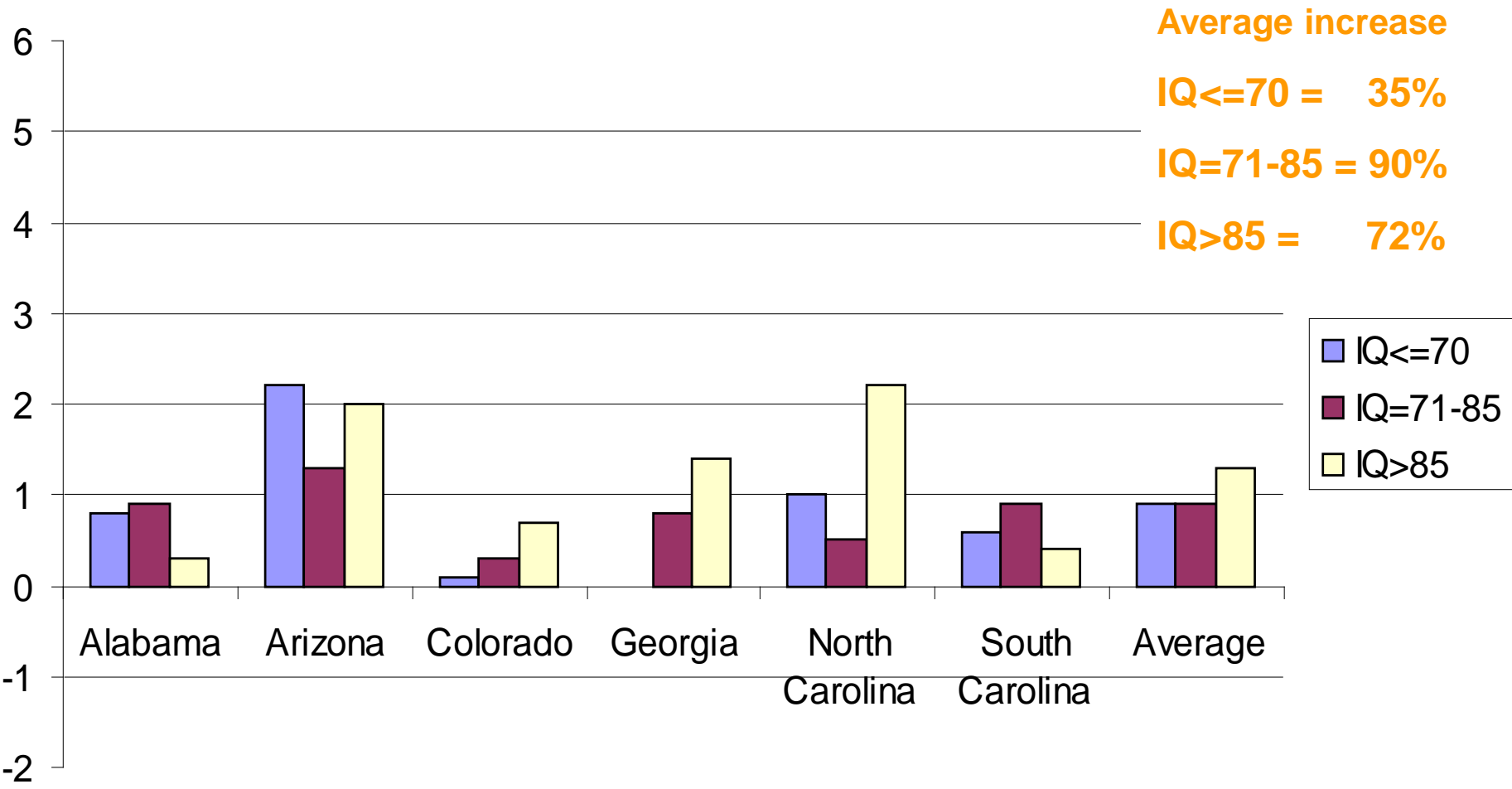
# Change in ASD Prevalence from 2002 to 2006 by Cognitive Functioning Level

	<b>Cognitive Impairment (IQ≤70)</b>	<b>Borderline (IQ=71-85)</b>	
<b>% Change, Average</b>	<b>35%</b>	<b>90%</b>	

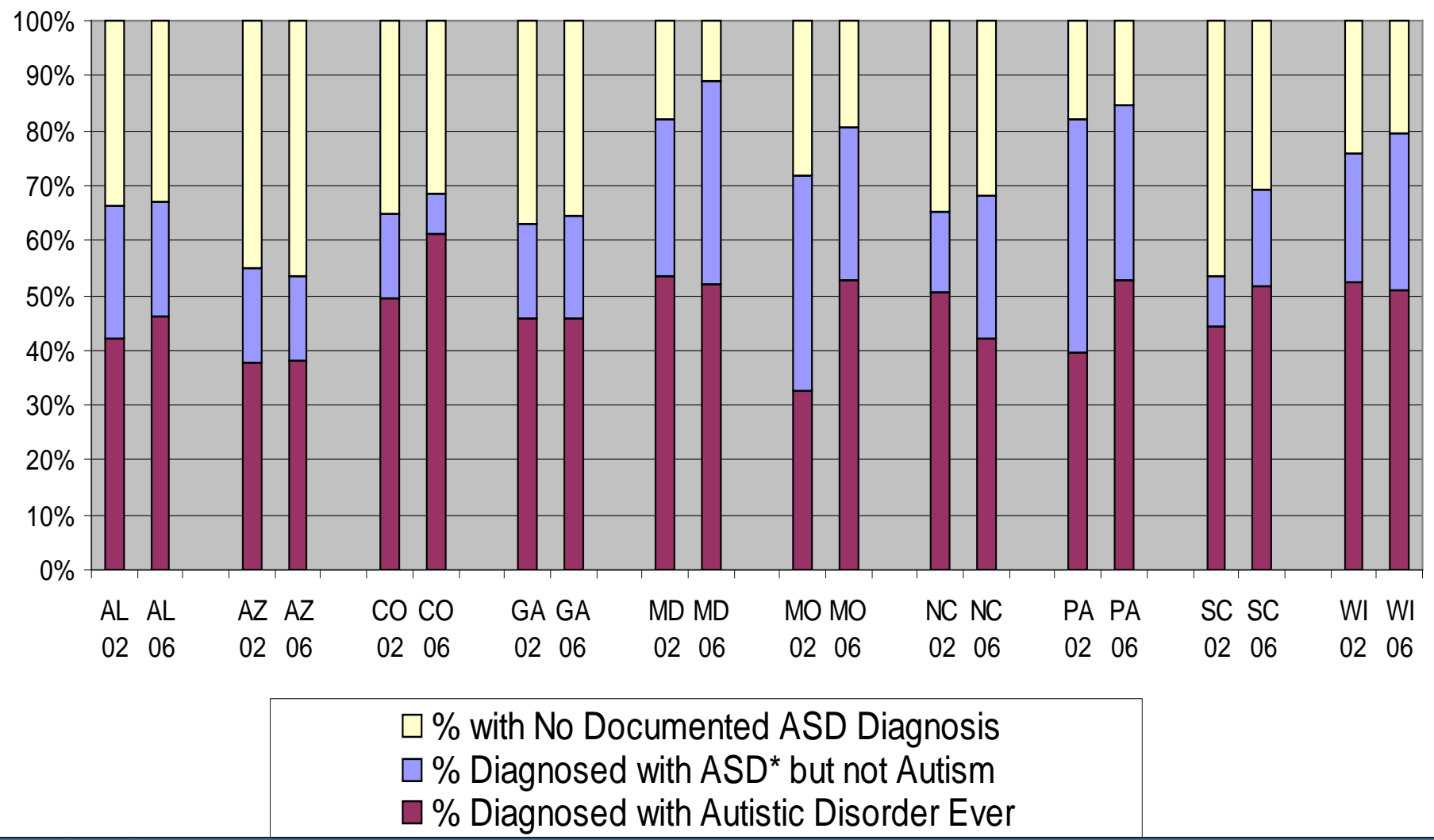
- In 2006, between 29-51% of children classified with cognitive impairment (average 41%)



# ADDMM 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...)**

# ADDMM 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



# ADDMM 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
- **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.



- **Build on ADDM infrastructure to**
  - Estimate prevalence in the same populations over time
  - Evaluate measurable identification and risk factors
  
- **Expand scope of surveillance to**
  - Increase types of data collected
  - Other neurodevelopmental disorders
  - Younger and older age groups
  - Provide technical assistance
  - International settings







## Principal investigators and Project Coordinators:



- **CDC:** Catherine Rice, Jon Baio, Kim Van Naarden Braun, Marshalyn Yeargin-Allsopp, Susan Graham, and Anita Washington;
  - **Alabama:** Beverly Mulvihill, Martha Wingate, Russell S. Kirby, Meredith Hepburn, Neva Garner;
  - **Arizona:** Sydney Pettygrove, Chris Cunniff, F. John Meaney, Kristen Clancy Mancilla;
  - **Colorado:** Lisa Miller, Cordelia Robinson, Gina Quintana, Yolanda Castillo, and Andria Ratchford;
  - **Florida:** Marygrace Yale Kaiser and Claudia Rojas;
  - **Maryland:** Li-Ching Lee, Rebecca Landa, Craig Newschaffer, and Maria Kolotos;
  - **Missouri:** John Constantino and Robert Fitzgerald;
  - **North Carolina:** Julie Daniels and Paula Bell;
  - **Pennsylvania:** Ellen Giarelli, Jennifer Pinto-Martin, Susan E. Levy, and Rachel Meade Reiss;
  - **South Carolina:** Jane Charles, Joyce Nicholas, and Lydia King;
  - **Wisconsin:** Maureen Durkin, and Carrie Arneson.
- Additional assistance was provided by project staff including data abstractors, clinician reviewers, epidemiologists, and data management/programming support staff. Ongoing ADDM Network support was provided by CDC and contractors: Nancy Doernberg, Joanne Wojcik, Rita Lance, Lori Plummer, and Lekeisha Jones.

# For more information

## ADDM Reports in CDC's *MMWR Surveillance Summaries*

[www.cdc.gov/mmwr](http://www.cdc.gov/mmwr)



Updated autism website

[www.cdc.gov/autism](http://www.cdc.gov/autism)

# Additional informational slides



# 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



## 2008 Autism Spectrum Disorder (ASD) Research Funding by Funding Agency/Organization

Funding Agency/Organization*	Number of Projects	Average Funding Per Project	Total Funding
National Institutes of Health	422	\$279,803	\$118,076,888
Simons Foundation	77	\$558,256	\$42,985,684
Autism Speaks	203	\$152,539	\$30,965,449
Centers for Disease Control and Prevention	27	\$682,855	\$15,022,812
Health Resources and Services Administration	3	\$2,030,264	\$6,090,792
Department of Education	7	\$491,292	\$3,439,047
Autism Consortium	22	\$100,683	\$2,215,017
Department of Defense	8	\$147,223	\$1,177,781
Center for Autism and Related Disorders	26	\$31,369	\$815,581
Organization for Autism Research	16	\$45,625	\$730,000
Autism Research Institute	13	\$40,085	\$521,099
Southwest Autism Research & Resource Center	5	\$79,000	\$395,000
Centers for Medicare and Medicaid Services	1	\$24,643	\$24,643
<b>Grand Total</b>	<b>830</b>	<b>\$269,648</b>	<b>\$222,459,793</b>

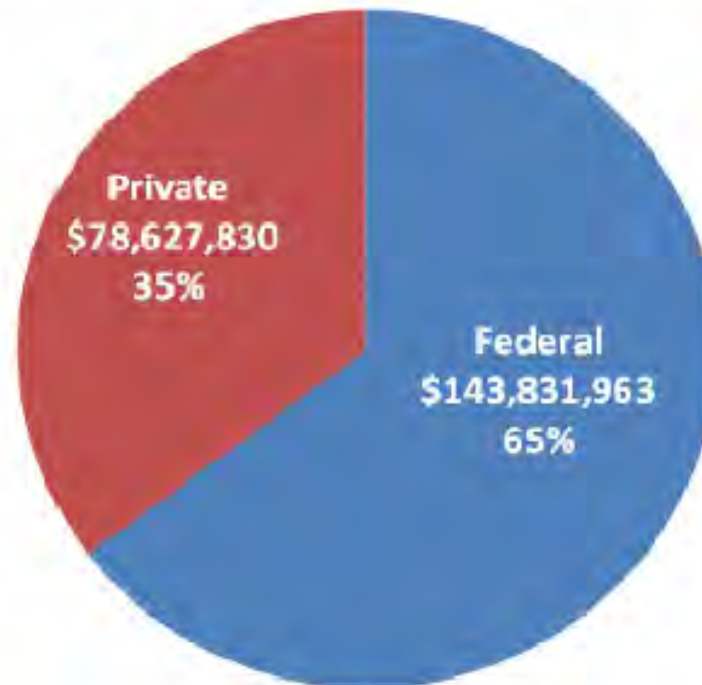
\*Includes Federal and private funders who responded to an April 2009 request from the IACC to provide a comprehensive listing of autism spectrum disorder (ASD) research projects funded (i.e., paid) in the most recent 12 months for which data were available. The IACC received responses from all of the 19 agencies/organizations contacted. Thirteen provided data and six reported that they did not fund ASD research in 2008 (the Administration for Children and Families, the Agency for Healthcare Research and Quality, the Doug Flutie Jr. Foundation for Autism, the Substance Abuse and Mental Health Services Administration, the U.S. Department of Housing and Urban Development, and the U.S. Social Security Administration.)

These slides do not reflect decisions of the IACC. They are for discussion purposes only.



## 2008 Autism Spectrum Disorder (ASD) Research Funding\* by Type of Agency/Organization: Federal versus Private (Total = \$222,459,793)

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\* Reported by the Autism Consortium, the Autism Research Institute, Autism Speaks, the Center for Autism and Related Disorders, the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, the National Institutes of Health, the Organization for Autism Research, the Simons Foundation, the Southwest Autism Research & Resource Center, and the U.S. Departments of Defense and Education.

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