

Summary of Workshop on Evaluating Change in ASD Prevalence, February 1, 2011

Catherine Rice, PhD

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

**IACC Meeting
April 11, 2011**



Current Issue

- **Identified prevalence of ASD has increased significantly in a short time period across multiple studies** including the US-based CDC Autism and Developmental Disabilities Monitoring (ADDMM) Network.



Workshop Co-Sponsored by NCBDDD / CDC and Autism Speaks

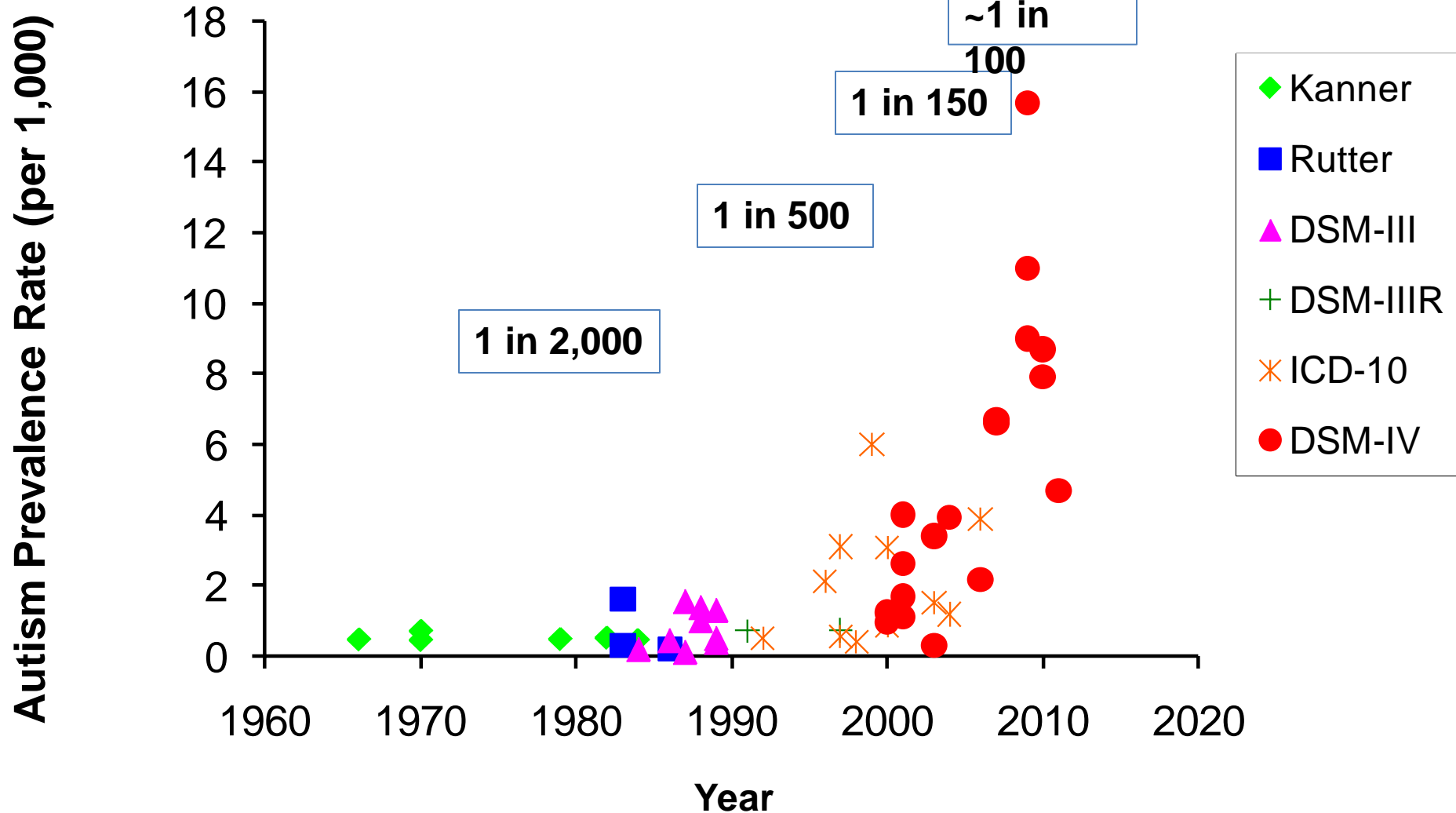
Planning Committee

- ❑ Carrie Arneson – **University of Wisconsin, Madison**
- ❑ Amanda Bakian – **University of Utah**
- ❑ Tom Bartenfeld – **NCBDDD, CDC**
- ❑ Julie Daniels - **University of North Carolina, Chapel Hill**
- ❑ Geri Dawson - **Autism Speaks**
- ❑ Keydra Phillips - **NCBDDD, CDC**
- ❑ Catherine Rice – **NCBDDD, CDC**
- ❑ Michael Rosanoff – **Autism Speaks**
- ❑ Anita Washington – **Research Triangle Institute**
- ❑ Martha Wingate – **University of Alabama, Birmingham**
- ❑ Marshalyn Yeargin-Allsopp - **NCBDDD, CDC**

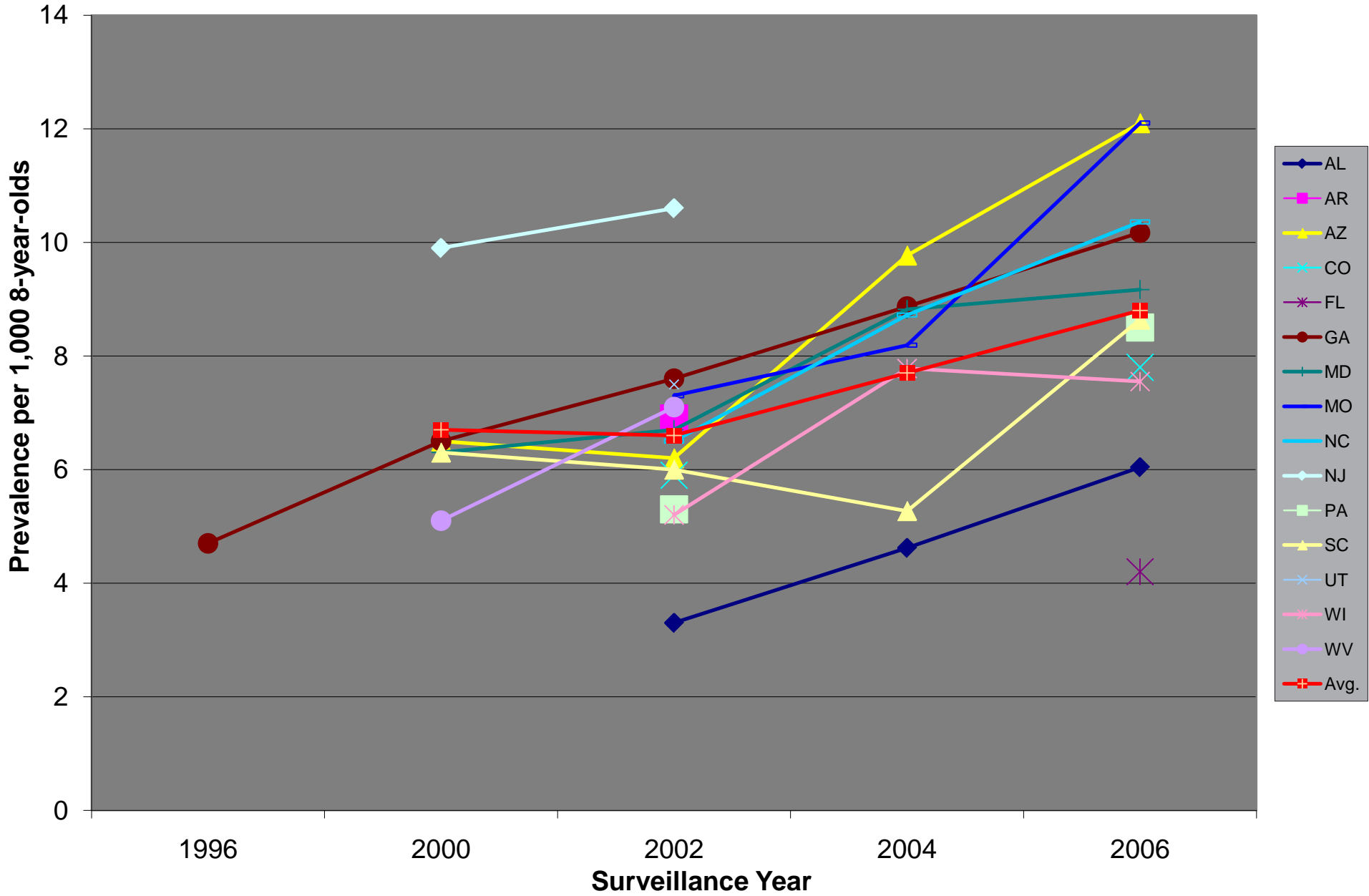
Purpose of February 1st Workshop

- Bring together epidemiologic prevalence/surveillance expertise in ASD and other conditions and stakeholders to:
 1. Summarize where we are with understanding reasons for ASD trends;
 2. Learn from prevalence / surveillance of other complex conditions;
 3. Identify priorities
 - *What can we do now with existing data?*
 - *What can be done to build on existing data systems?*
 - *What else is needed (data collection, analyses)?*

Comparison of Autism Prevalence



ADDM Network ASD Prevalence - All Sites



Possible Explanations for Increasing ASD Prevalence

1. Intrinsic Identification Factors (internal methodology or measurement)

- Variation in methodology (service data, survey, screening)
- Improved ascertainment

2. Extrinsic Identification Factors (external identification and awareness)

- Changes in diagnostic criteria over time
 - From a severe disorder to a wide spectrum
- Recognition that ASDs can occur across the spectrum of intellectual functioning, and with other conditions
- Improved early identification
- Improved identification among some groups (Asperger disorder, PDD-NOS, girls, Hispanic children...)
- Increased awareness in the community
- Changes in availability of services



3. Change in underlying risk

- Possible etiologic - true change in ASD symptoms in population in relation to single or combined genetic, biologic and/or environmental factors
- Is there a modifiable risk factor?

Where are we in Understanding ASD Prevalence trends?

- The impact on individuals, families, and communities is significant.
- Debate has been EITHER/OR Identification vs. Risk.
- Some of the increase is related to intrinsic and extrinsic identification factors.
- A true increase in symptoms cannot be ruled out, but is hard to “prove”.
- How to evaluate multiple, over-lapping factors?
 - Improve specificity in quantifying and qualifying the multiple, potential identification and risk factors involved.



Recent efforts to be specific in evaluating reasons for ASD prevalence increases

Variables	% of increase attributed	Reference
<ul style="list-style-type: none"> •Decrease in age of diagnosis •Inclusion of more mild cases 	12% 56%	Hertz-Picciotto and Delwiche, 2009
<ul style="list-style-type: none"> •Change in use of Mental Retardation – substitution and accretion 	26.4%	King and Bearman, 2009
<ul style="list-style-type: none"> •Increase in parental age 	4.6%	Shelton et al., 2010
<ul style="list-style-type: none"> •Social influence improving diagnosis 	16%	Liu et al., 2010
<ul style="list-style-type: none"> •Improved ability to locate records 	<5%	CDC, 2009

- Examines one or two factors at a time in specific datasets
- Need for replication

Next...

- How much can be “explained”?
- How to consider, multiple, overlapping variables?

	Utility of prev data US Service Data		ADDM Network	What else?
	Panel 1	Panel 2	Panel 3	Panel 4
Chair	Alison Singer	Lisa Croen	Geri Dawson	Maureen Durkin
Recorder	Carrie Arneson	Lydia King	Keydra Phillips	Rob Fitzgerald
	Chris Cunniff	Paul Shattuck	Sandro Galea	Krista Crider
	Walter Zahorodny	Peter Bearman	Gerald McGwin	Ezra Susser
	Russ Kirby	Michael Kogan	Owen Devine	Cindy Lawler
	Maya Lopez	Sue Visser	Adolfo Correa	Carlie Tanner
	Richard Grinker	Irva Hertz-Piciotto	Mathew Zack	Michael King
	David Mandell	Lisa Miller	Paula Yoon	Stuart Shapira
	Lee Grossman*	Amanda Bakian	Matt Maenner	Diana Schendel
	Wolf Dunaway	Kim Van Naarden Braun	Julie Daniels	Joyce Nicholas
	Michael Rosanoff	Li-Ching Lee	Laura Schieve	Bill McMahon
	Judy Zimmerman	Thaer Baroud	Sydney Pettygrove	John Constantino
	Beverly Mulvihill	Peter Bell	Martha Wingate	Craig Newschaffer
	Jane Charles	Ruth Etzioni	John Elder Robison	Lars Perner
		Young-Shin Kim	Prisca Chen Marvin	Mark Blaxill
				Eric London
				Gayle Windham
	*invited			Kathleen Merikangas

Panel Discussions

- ❑ **Can the “Why” of ASD prevalence changes be answered?**
 - There was debate among panel members
 - Quantifying reasons behind trends is the wrong question - of course there’s a “true” increase because there’s an increase in cases.
 - Use prevalence to focus on services and helping families.
 - Research still needed on underlying causes and risk factors.
 - Most agreed there are multiple identification and potential risk factors involved.
 - Clear agreement that ASDs are a very important public health issue.
 - Many individuals, families, and communities are affected.
 - Prevalence data important for informing service needs and supports.

- ❑ **Can we quantify different components’ contribution to increase?**
 - Multiple approaches needed to better evaluate and quantify the identification and risk factors influencing ASD prevalence.
 - However, several challenges, such as insurmountable measurement error, need for data on risk factors in population, and broadness of the phenotype.

Key Recommendations from Panels

1. What are the immediate priorities using existing prevalence / surveillance data to better understand reasons for trends?

- **Enhance utility** of current data for the community
 - More information on characteristics of people with ASD (e.g., functioning information)
 - Understand disparities in ASD identification to inform identification efforts
- **Expand Analyses**
 - Examine **factors influencing differences** among subgroups and across places
 - Use **complex modeling** and **multi-factorial analyses** for multiple id and risk factors
 - **Examine trends** in how the **ASD** population by characteristics (age of id, comorbidities)
 - **Examine trends** in other **behaviorally-defined conditions** (e.g., ADHD, depression, anxiety)
- **Partnerships and Collaboration**
 - Continue to collaborate with families, individuals affected, researchers, service providers
 - Seek **public-private partnerships** to support data collection, analyses, and usage
 - Seek input and **collaboration with other fields** who are evaluating changes in prevalence of complex conditions

Key Recommendations from Panels

2. What are the next priorities for using existing prevalence/surveillance data to better understand trends?

- Provide funding opportunities for **trend analyses** and dissemination from existing datasets.
- **Linking existing datasets** identifying children with ASDs to other health, service, and research databases
- **Leverage data systems** being developed (electronic health records)
- Include information on **service use and needs**.
- **Validation** (parent-reported diagnoses, service-based) and expanded validation (record-review method)
- **Follow-up** existing surveillance cohorts (ADDMM)
- **Evaluate** ASD prevalence **across age groups**, including adults

Key Recommendations from Panels

3. What else is needed to understand reasons for ASD trends?

- **Expand** coverage of prevalence projects
- **Supplement** quantitative data reports with
 - more **qualitative information** on characteristics and functioning to inform supports needed
 - Other forms of data collection such as biological measures and treatments
- Identify ways to measure and **monitor traits** associated with ASDs in the general population on more of a continuous dimension vs. only a categorical (case vs. not case) level.
- Conduct **longitudinal studies** following cohorts over time.

Where do we go from here?

□ ADDM Network

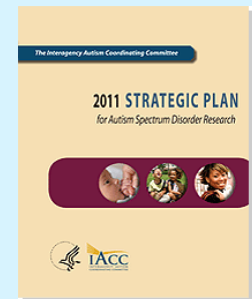


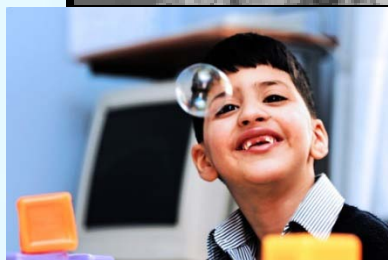
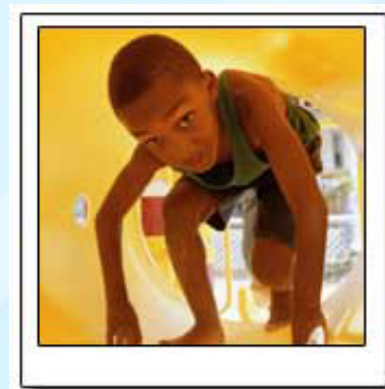
- Continue to build trend dataset and update prevalence
- Examples of analyses to examine trends
 - Impact of changing DSM criteria on prevalence
 - Trends in ASD prevalence by SES, parental age, age of diagnosis
 - Development of methods to link geographic analyses and other datasets
 - Development of simulation methods to model how changes in various risk factors and population demographics would impact ASD prevalence



□ Share summary report from Workshop

- Inform CDC's efforts
- Other investigators and funding agencies
- IACC Strategic Plan update, if applicable?





Thank you!
crice@cdc.gov

For more information:
www.cdc.gov/autism

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333

Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348

E-mail: cdcinfo@cdc.gov Web: www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.