



# Workshop on U.S. Data to Evaluate Changes in the Prevalence of Autism Spectrum Disorders (ASDs)

## Executive Summary



**Tuesday, February 1, 2011**

**Centers for Disease Control and Prevention**

**Tom Harkin Global Communications Center | 1600 Clifton Road, N.E. | Atlanta, Georgia**



# Acknowledgement

## Co-Sponsored by the National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC) and Autism Speaks

*Panel members\* were representatives from:*

Autism Science Foundation  
 Autism Society of America (invited)  
 Colorado Department of Health  
 Columbia University  
 Drexel University  
 George Washington University  
 Health Resources and Services Administration (HRSA)  
 Johns Hopkins University  
 Kaiser Permanente®, California  
 Medical University of South Carolina  
 National Institutes of Health (NIEHS, NIMH)  
 Parkinson’s Institute  
 SafeMinds  
 Parents of children with an Autism Spectrum Disorder  
 Persons with an Autism Spectrum Disorder  
 University of Alabama at Birmingham  
 University of Arizona, Tucson  
 University of Arkansas  
 University of California, Davis – MIND Institute  
 University of North Carolina, Chapel Hill  
 University of Pennsylvania  
 University of South Florida  
 University of Southern California, Marshall  
 University of Utah  
 Washington University in Saint Louis  
 University of Washington  
 University of Wisconsin, Madison  
 Yale University

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*\*Refer to Appendix B in full workshop summary for biographies of panel members*

*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 (CDC). This summary report reflects statements made by individuals attending the workshop and does not constitute consensus recommendations made to the CDC.*

# Workshop Summary

## PURPOSE

Autism spectrum disorders (ASDs) are estimated to occur among about 1% of children in the U.S. This is in line with estimates from other industrialized countries. However, the identified prevalence of ASDs has increased significantly in a short time period based on data from multiple studies including the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network (<http://www.cdc.gov/ncbddd/autism/addm.html>). Whether increases in ASD prevalence are partly attributable to a true increase in the risk of developing ASD symptoms or solely to changes in community awareness and identification patterns is not known. It is clear that more children are identified with an ASD now than in the past and the impact on individuals, families, and communities is significant. However, disentangling the many potential reasons for ASD prevalence increases has been challenging. Understanding the relative contribution of multiple factors such as variation in study methods, changes in diagnostic and community identification, and potential changes in risk factors is an important priority for the ADDM Network and for CDC. This workshop was co-sponsored by CDC and Autism Speaks as a forum for sharing knowledge and opinions of a diverse range of stakeholders about changes in ASD prevalence. This summary report reflects statements made by individuals at the forum and discussions that were held among the attendees, and does not constitute formal consensus recommendations to CDC. The information, research, and opinions shared during this workshop add to the knowledge base about ASD prevalence in an effort to stimulate further work to understand the multiple reasons behind increasing ASD prevalence in the U.S.

## FRAMEWORK

The workshop brought together epidemiologic prevalence and surveillance experts in ASDs and other conditions as well as representatives from autism organizations, parents of children with ASDs, adults with an ASD, and other stakeholders. A total of 342 people registered to attend the workshop (143 in person and 199 via webinar).

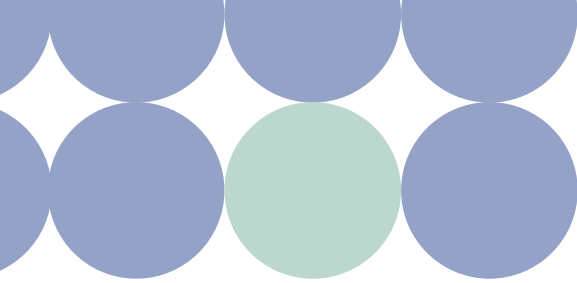
Prior to the meeting, the panel members met via teleconference and were asked to submit at least two publications that they viewed as important background reading for understanding ASD prevalence trends. Panel members were provided with the compiled reference list (Appendix C) and articles and were asked to review, at a minimum, the priority readings prior to the workshop.

Presentations during the morning of the workshop summarized current knowledge and issues related to ASD prevalence and provided perspectives from subject matter experts in cancer, Parkinson disease, asthma, schizophrenia, and analytic modeling of prevalence changes.

Following the morning's presentations, the public was invited to provide statements, and there was an open invitation to provide written comments before and after the workshop. Workshop organizers, panelists, and stakeholders were asked to consider these comments when expressing their opinions on priorities for evaluating changes in ASD prevalence.

After hearing open comments from the community, the workshop was divided into four panels:

- Panel 1 – Utility of ASD Prevalence Data
- Panel 2 – U.S.-Based ASD Service Data
- Panel 3 – Autism and Developmental Disabilities Monitoring (ADDM) Network Data
- Panel 4 – What Else Is Needed To Understand ASD Trends?



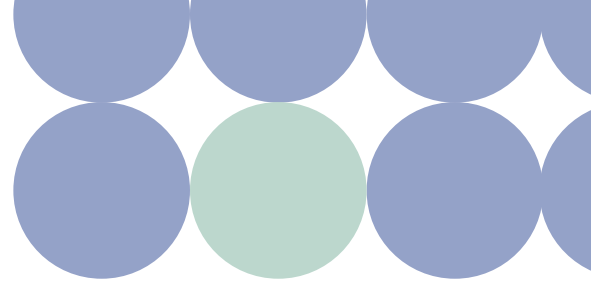
For the workshop panel sessions, members of each panel were asked to reflect on questions along the following themes to better understand ASD prevalence trends:

- What can we do now with existing data?
- What should we do next to build on existing data systems?
- What else is needed in terms of new analyses, data collection, or other efforts?

## SUMMARY POINTS

Panel members and attendees commented that the effort to increase transparency and expand the dialogue related to ASD prevalence change was appreciated and necessary to move the community forward around the issue of understanding ASD prevalence changes. Additional key points made during the workshop included:

- The identified prevalence of ASD has increased significantly in a short time period across multiple studies, including data from the CDC's U.S.-based Autism and Developmental Disabilities Monitoring (ADDM) Network.
- CDC is the source for ASD prevalence estimates in the U.S., but other data systems exist or could be developed to better understand trends in ASDs.
- ASDs are conditions estimated to occur among about 1% of children in the U.S. There is an urgent demand to address the many needs associated with ASDs. Prevalence estimates have, for example, fueled action by advocacy groups and the Interagency Autism Coordinating Committee (IACC) and driven the creation of legislation and presidential priority. However, individuals, families, and communities continue to struggle to address unmet needs across the lifespan of people with ASDs. ASD prevalence estimates are important to stakeholders for program planning and making policy changes, in addition to highlighting the need for research into causes and interventions.
- In terms of reasons for increased ASD prevalence, the debate has been dichotomized by researchers, advocacy groups, and the media to indicate that increases must be explained either by identification factors or by increased risk among the population. In reality, a more complex understanding is needed. It is clear that some of the increase has been related to intrinsic and extrinsic identification factors. However, although a true increase in ASD symptoms cannot be ruled out, such an increase has been difficult to prove. Panels discussed needing to identify and use methods to better understand the role of potential identification and risk factors in the changing prevalence of ASD.
- Some people expressed hope that understanding why ASD prevalence has increased may help identify modifiable risk factors. There was debate about the roles of prevalence and surveillance in answering questions about risk and causes of ASDs. Prevalence studies provide descriptive data on the number of people with a condition in a defined population. These types of studies are not sufficient to identify what causes ASDs. However, prevalence studies can be used as tools to examine variation in occurrence of ASDs across place, groups, time, and exposures, which may provide clues about groups who are at increased risk for ASDs. Other study designs would then be necessary to fully investigate the reasons behind observed variation in prevalence.
- There are likely multiple forms of ASDs with multiple causes that are poorly understood. It was noted that sufficient evidence exists that biologic and environmental factors, alone and in interaction, need to be considered as causes. It is not necessary to have confirmation that a portion of the increase in ASD prevalence is due to increased risk in the population to motivate the active pursuit of causes of ASDs. By better understanding what causes ASDs, maybe we can understand the increases in measured prevalence.



- A risk factor might be strongly associated with ASD and might be modifiable, but it might not have increased sufficiently in the population during the time frame of interest. Therefore, this risk factor might be related to an individual's risk for ASD but not related to the increase in population prevalence of ASD. The model demonstrated that for any factor to have made a noteworthy contribution to population changes in ASD prevalence during a short time period, three conditions must be met: the factor has to be fairly prevalent in the population, it has to have increased substantially, and it has to be strongly associated with diagnosed ASD.
- There was a shared recognition of the importance of, and commitment to, obtaining and using prevalence and epidemiologic information to improve the lives of people with ASDs.

## PANEL DISCUSSION SUMMARIES

The four panel chairs compiled main discussion points brought forth by their members for building on existing infrastructure and for developing new initiatives to better understand ASD trends. These discussion points are summarized below.

### Collaboration

The panels indicated that collaboration among professionals and stakeholders is important, and the following points were made to assist collaborative efforts among those interested in understanding ASDs and supporting the ASD community through science:

- » Continue efforts of this workshop to develop and enhance communication among families, individuals affected, researchers, service providers, advocates, and government entities about ASD prevalence, research, and service needs.
- » Seek public-private partnerships to support data collection, analyses, and usage.
- » Seek input from and collaboration with those in other fields, such as cancer epidemiology, to identify and utilize methodologies for evaluating changes in the prevalence of complex conditions.
- » Collaborate with other data systems, such as the Environmental Public Health Tracking Network, to improve access to population-level environmental data.

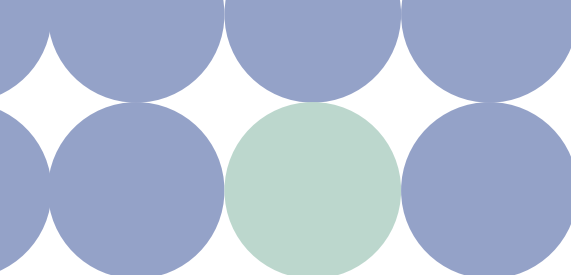
### Analytic Activities

Points were made on better utilizing existing data to understand ASD prevalence trends:

- » Provide funding opportunities to encourage analyses and dissemination of findings from existing datasets.
- » Link existing datasets identifying children with ASDs to other health, service, and research databases.
- » Conduct analyses that will help explain variations in ASD prevalence across subgroups (e.g., race and ethnicity, sex, diagnostic subtype, and geographic groups) and if variation persists over time.
- » Use complex modeling and multifactorial analyses to better understand variation in ASD prevalence such as by possible etiologic subgroups (e.g., specific genetic conditions and family history), geography, and sex, and by potentially harmful exposures among cohorts.
- » Conduct simulation studies to predict the anticipated course of ASD prevalence.

### Data Enhancements to Inform Practice

The panels discussed the importance of using data on the prevalence and characteristics of people with an ASD to better inform service and support efforts:

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- » In addition to prevalence estimates, provide more in-depth information on population characteristics of people with an ASD (such as functional level and impact of functional limitations, subtype, developmental characteristics, and associated conditions) to improve program planning and support needs.
  - » Examine data to better understand lags and disparities in ASD identification to, in turn, inform screening, identification, and program planning.
  - » Conduct analyses to provide better estimates of current and future needs of adults with an ASD.

## Additional Studies

Beyond enhancements to existing data systems and uses, the panels discussed new types of data collection and studies including:

- » Expand ASD prevalence efforts to include very young children and adults.
- » Examine prevalence over time among older children by following up with those identified in previous studies
- » Conduct additional validation studies at various ADDM Network sites and use the results to enhance estimates of ASD prevalence.
- » Conduct further studies to better understand who is identified and who is not identified in national parent report surveys and in service-based data such as special education child counts.
- » Develop ways of better capturing the heterogeneity of ASD phenotypes including the complexity of core and associated features that may present in different combinations for people with an ASD.
- » Improve tools for culturally sensitive screening and case confirmation among large populations.
- » Identify ways to measure and monitor the traits associated with ASDs among the general population to reflect various degrees (dimensional) rather than categorical (having an ASD or not having an ASD) case vs. not case) levels. This includes characterizing how these traits overlap with other conditions and typical development.
- » Conduct cross-sectional and longitudinal studies following cohorts over time. This could include examining trends in characteristics of the population, such as ASDs among specific subgroups (based on, for example, race and ethnicity, immigrant status, and socioeconomic status), age of identification, diagnoses, comorbidities, services use, and family characteristics.
- » Monitor trends in ASD prevalence prospectively to rule out identification factors by consistently conducting developmental and ASD screening at a given age with diagnostic follow-up and documentation of each step and outcome.
- » Conduct prospective studies that examine biology, phenotype, identification patterns, and service needs and use of people with an ASD.
- » Examine trends in other behaviorally defined conditions (e.g., attention-deficit/hyperactivity disorder, depression, and anxiety).

## NEXT STEPS

The workshop summary will be made freely available to the community through posting on the CDC's and Autism Speaks' websites. It is hoped that the information, research, and opinions shared during this workshop will add to the knowledge base about ASD prevalence and stimulate further work among public and private groups to understand the multiple reasons behind changes in identified ASD prevalence in the U.S.

Centers for Disease Control and Prevention

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