

The Epidemiology of Autism Spectrum Disorders: New Approaches to Prevalence and Monitoring

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2:00 –3:30 p.m. ET

Questions and Answers

Q: Please explain how "at an individual level, having one or more perinatal risk factors might convey a moderate or strong risk for ASD, these factors are unlikely to explain the population increase in ASD prevalence."

A: (Laura Schieve) In order to influence a change in the ASD prevalence rate, a perinatal factor has to not only be associated with an individual's risk for ASD, but that risk factor also has to have increased during the time period of interest. Moreover, for a factor to have a substantive increase it needs to be a fairly common factor, it needs to have increased by a fairly large amount, and it needs to have a strong association with ASD.

None of the factors we assessed (preterm, very preterm, low birth weight, very low birth weight, multiple birth, cesarean delivery, breech presentation, or use of assisted reproductive technology) met all of these criteria and thus, we estimated that changes in these factors only made a negligible contribution to the most recently reported 57% increase in ASD prevalence during a 4 year time period.

For example, the 1994 US population prevalence of preterm delivery was around 11.01%. This increased by 5% to 11.59% in 1998. Most studies estimate the preterm-ASD relative risk is between 1.5 and 2.5, but outliers have been reported with relative risks approaching 5.0. Applying these data to the model we developed for this project, we estimate that the 5% increase in preterm most likely resulted in a <1% change in ASD prevalence. Even if we were to assume the outlier relative risk value of 5.0 represented the "true risk", the model only estimates a 1.5% change in ASD prevalence.

Preterm only increased a small amount in the 4-year time period of interest. Other risk factors increased more. For example the multiple birth rate increased by 17%. However, multiple birth is a much less prevalent factor – the 1994 prevalence was 2.57% and 1998 prevalence was 3.00%. Relative risk estimates are similar to those reported for preterm. Applying these data to the model, we again estimate that the 17% increase in multiple birth most likely resulted in a <1% change in ASD prevalence.

However, even though neither of these factors contributed to the ASD prevalence change, does not mean these are not important risk factors. At an individual level, studies document that a child born preterm will have a greater risk of subsequently being diagnosed with an ASD than a child born at term. Likewise, several studies suggest that children born in a multiple birth have a greater ASD risk than singleton children.

Q: When looking at the effect of multiple risk factors, did you make any assumptions for the model (additive or multiplicative model)?

A: (Laura Schieve) We assessed the percentage of children born with more than one risk factor (various combinations of risk factors were assessed) and we looked at how those percentages increased between 1994 to 1998. Although we did not have data on the ASD risks associated with having more than one risk factor, even if we assume they were fairly high, (relative risks of 3.0 or 4.0), the percentage of children with more than one factor was low (5% or less depending on the risk factor combination). Given these low percentages, the increases observed between 1994 and 1998 were not great enough to have affected a meaningful ASD change.

Q: In layman's terms, what is the bottom line regarding the increase in the numbers of children labeled as being on the autism spectrum?

A: (Matthew Maenner) A number of studies have suggested that changes in “awareness”, or how ASD is diagnosed, have contributed to increasing prevalence of ASD. Whether these factors account for all of the observed increase is unclear. Dr. Schieve's paper presents a model that shows “what it would take” for a risk factor to be responsible for the increase, and the conditions needed to cause an increase are much more extreme than many of the autism risk factors we usually study (such as parental age or low birth weight).

Q: Autism really is a spectrum. There are big differences between the 1% of children (or adults) who are the most autistic and the 3% (or 5%) who are less intensely autistic. Given the subjectivity of diagnosis (especially for those with mild ASD), it seems critical that publications provide detailed, standardized, consensus diagnoses for the patients in their studies. Methods, Methods, Methods. There is no “correct” prevalence: the prevalence you find is a function of your methods.

A: (Matthew Maenner) It's true that there could be large differences between any two people “on the spectrum”, and methodological and diagnostic differences could contribute to different estimates of ASD “prevalence”. Others have proposed using methods that are most meaningful for a particular purpose or question; for example, diagnostic criteria for a research study would not need to be the same as criteria for receiving respite services for autism. In any case, it seems everyone agrees that it is critical for studies to explicitly describe how ASD is measured.

Q: Are there any studies that evaluate the frequency of Autism Spectrum Disorders in individuals with chromosomal disorders, more specifically Down syndrome?

A: (Matthew Maenner) I am not well-versed in the Down syndrome & autism literature, but several studies suggest ASD is more common among individuals with Down syndrome. Lowenthal et al (2007) reported 16% of individuals with Down syndrome had PDD and 6% had autism, and that previous studies had noted between 1-11% had co-occurring PDD. It seems that many chromosomal disorders that often result in intellectual disability are also at increased risk for co-occurring autism (such as fragile X).

Q: Are there any areas with decreasing trend of prevalence of ASD?

A: (Matthew Maenner) Not that I am aware--most studies report prevalence for relatively large areas (states, regions, countries). It's possible that these larger regions contain smaller areas that have decreasing prevalence, but usually the overall trend is of increasing prevalence. Hagberg and Jick reported a very interesting finding in the UK, showing a plateau in prevalence over the 5 most recent birth cohorts that they observed. (http://journals.lww.com/epidem/Fulltext/2010/05000/Autism_in_the_UK_for_Birth_Cohorts_1988_2001.24.aspx)

(Catherine Rice) To date, there are no reports of an area with a decreasing trend in ASD prevalence. One site (SC) in the Autism and Developmental Disabilities Monitoring (ADDM) Network reported a decrease and then an increase in ASD prevalence when looking at changes from 2000, 2002 and 2004. (Rice CE, Nicholas J, Baio, J, Pettygrove S, Lee LC, Van Naarden Braun K, Doernberg N, Cunniff C, Newschaffer C, Meaney FJ, Charles J, Washington A, King L, Kolotos M, Mancilla K, Mervis CA, Carpenter L, Yeargin-Allsopp M. Changes in autism spectrum disorder prevalence in 4 areas of the United States. Disability and Health Journal 2010;3:186-201)

Q: What effect will up-coming DSM V diagnostic criteria for ASD have on prevalence measures?

A: (Matthew Manner) The new criteria could have important implications for how we perceive the frequency and determinants of ASD, and also how we provide services and interventions. We are in the process of examining how the DSM V criteria may influence autism prevalence and other associations previously noted in epidemiological studies.

(Catherine Rice) It is impossible to know what the impact of the changing diagnostic criteria for DSM 5 on ASD prevalence estimates. For the CDC studies of autism prevalence, we collect information in a way where we can apply both the DSM IV and 5 criteria so that we can evaluate the impact on prevalence once the criteria are finalized.

About the MCHIRC

The Maternal and Child Health Information Resource Center (MCHIRC) is dedicated to the goal of helping MCH practitioners on the Federal, State, and local levels to improve their capacity to gather, analyze, and use data for planning and policymaking.

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This question and answer sheet was created by moderator Sarah Lifsey.

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