

Transcript Details

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Why Has the Prevalence Rate of Autism Tripled in Recent Years?

Mr. Rokuskie:

In a 10-year period of time, the national prevalence rate for autism spectrum disorder has nearly tripled, going from 1 in 166 to 1 in 59. This new diagnosis rate means that 2% of the US population under the age of 18 carries a diagnosis of autism spectrum disorder. This dramatic change in the prevalence rate not only has an impact on society but has a significant economic impact on the US medical system and the families caring for those with ASD.

You're listening to ReachMD. I am your host, Paul Rokuskie, and with me today is Dr. Stuart Shapira, Associate Director for Science at CDC's National Center on Birth Defects and Developmental Disabilities. Welcome, Dr. Shapira.

Dr. Shapira:

Yes, wonderful, thank you.

Mr. Rokuskie:

So, Dr. Shapira, can you tell us a little bit about your professional background?

Dr. Shapira:

Well, first, Paul, let me say it's a pleasure having this opportunity to speak with you today about this important topic. With regard to my background, I'm trained as a medical doctor, a pediatrician and a clinical geneticist, and I'm also laboratory trained as a molecular geneticist, and after training I worked a number of years as a pediatrician and a geneticist taking care of children, including children with ASD, or Autism Spectrum Disorder. And in 2005, I joined the CDC where I have worked in the National Center on Birth Defects and Developmental Disabilities.

Currently, I'm the Associate Director for Science in the National Center, and my connection with ASD is that I work on a CDC study called The Study to Explore Early Development, or SEED, which is examining potential factors that might increase the risk for ASD, and I also represent the CDC on the Interagency Autism Coordinating Committee, which is a federal committee that is tasked with coordinating research efforts for ASD and improving services for individuals and families living with ASD.

Mr. Rokuskie:

Can you go into that a little bit more, Dr. Shapira? Where was this study conducted and with whom?

Dr. Shapira:

So the study that you are referring to is conducted through the CDC by the Autism and Developmental Disabilities Monitoring Network, or the ADDM, ADDM Network. The most recent report from this study was just published in April of 2018, and in that report the study was being conducted in 11 communities across the United States, and those communities or study sites are in Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee and Wisconsin. The staff at each of the study sites go to clinics and hospitals in their respective communities to look through health records of 8-year-old children who potentially have ASD based on diagnosis and billing codes, and the study staff abstract information from the health records that describes behaviors and characteristics that can occur in children with ASD. And in addition, the staff at most of the study sites go to schools in their respective communities and look through education records of 8-year-olds based on particular special education designations known as exceptionalities, and the staff abstract information from the education records, including the behaviors, the characteristics, and the results of developmental evaluations.

Now, all of the abstracted information for a child, whether from health sources, education sources or both, is combined into 1 record, and that record is reviewed by study staff who are skilled clinicians, and the clinicians code the information according to a surveillance

case definition for ASD that's based on the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, or the DSM, and those 8-year-old children who fit the case definition are identified as having ASD.

Now, in the recent ADDM Network report, it focused on children who were 8 years old in 2014, and more than 300,000 8-year-old children were living in the 11 ADDM Network communities at that time, and the study found that among those children, 1.7%, or 1 in 59, had ASD.

Mr. Rokuskie:

So, why does the ADDM Network focus on aged 8-year-old children?

Dr. Shapira:

Well, in 1996, the CDC conducted surveillance for ASD within 5 central counties of metropolitan Atlanta. This study used the methods that I described, but the study staff looked at children between age 3 and age 10, and one conclusion from the study was that the optimal age for determining the prevalence of ASD in school-aged children was age 8. Therefore, since 2000, the ADDM Network study has focused on 8-year-olds.

Mr. Rokuskie:

So, when my oldest son was originally diagnosed with autism spectrum disorder back in 2005, the national prevalence rate was 1 in 66 then. Based off your most recent study, it's 1 in 59, and that's a 15% increase over the previous prevalent rates, which was only reported 2 years ago. Can you discuss these findings and why we're seeing this increase keep going in the wrong direction?

Dr. Shapira:

Well, first, let me point out that the prevalence of ASD reported by the ADDM Network is not a national prevalence. It's actually a combined prevalence from the communities that participated in the ADDM Network in a particular study cycle, which occurs every 2 years. So every 2 years there can be changes in the number and the locations of the ADDM Network sites, which have been as few as 6 sites that looked at children who were age 8 in 2000 to 14 sites that looked at children who were age 8 in 2008. The first ADDM Network report which looked at 8-year-olds in 2000 found a prevalence of ASD of 1 in 150, and the prevalence has gotten higher over the years such that it was 1 in 68 for 8-year-olds in 2012 and 1 in 59 for 8-year-olds in the recent ADDM Network report for children in 2014. And in addition to the differences in the makeup of the ADDM Network sites from report to report, there have been changes in the proportion of sites that have access to education records in their communities. It's clear that sites with access to education records identify more children with ASD and thus tend to find a higher prevalence than sites that have access only to health records.

In the most recent ADDM Network report, all sites except 1 had access to education records in part or all of their communities, and 2 of the sites increased their access to education records since the previous report. Now, contrast this with, for example, the 2002 surveillance year in which the reported prevalence was 1 in 150, but only 10 of the 14 ADDM sites had access to education records in at least part of their communities, so a higher prevalence goes along with more sites with access to education records.

Mr. Rokuskie:

So, essentially, the prevalence rate was probably higher back when those statistical analyses were done, but because the data was not completely accessible at that time, like it is now, or more accessible, that the number is actually becoming more to the norm of what we would be seeing in society.

Dr. Shapira:

Yes, we believe that's correct, and that's based on looking at other characteristics of 8-year-old children with ASD and how those characteristics have changed from the earlier ADDM Network reports to the more recent ADDM Network reports. So the ADDM study looks at characteristics such as demographics and intellectual disability among children with ASD and the age of developmental concern, the age of comprehensive developmental evaluation, the age of ASD diagnosis and the educational services received.

The most recent ADDM Network report found that there is a higher proportion of boys with ASD than girls, about 8 boys to 2 girls, and this gap has narrowed slightly since in previous reports the proportion was about 9 boys to 2 girls. And all ADDM Network reports have found a higher prevalence of ASD among white children compared to other groups, such as blacks or Hispanics. However, there's really no biological reason to think that ASD should be more prevalent in 1 racial or ethnic group compared with another. And in fact, the recent ADDM Network report bears this out. In the report 2 years ago, the prevalence of ASD was 20% higher in whites compared to blacks, but in the current report it's less than 10% higher. And similarly, in the report 2 years ago, the prevalence of ASD was 50% higher in whites compared to Hispanics, but in the current report, it's only 20% higher, so the gap between white and black and between white and Hispanic is narrowing. And in some of the ADDM Network sites, there was no difference in the prevalence between whites, blacks and Hispanics. So, why is the gap narrowing? It may be due in part to more effective outreach directed to blacks and Hispanics in communities as well as efforts to have all children screened for ASD.

And one other important characteristic that has been examined in the ADDM reports is also affecting prevalence is the proportion of children with intellectual disability. In the first ADDM Network report, more than half of the identified children with ASD had intellectual disability, and this is in contrast to the current ADDM Network report where only 1/3 of children identified with ASD had intellectual disability. The lower proportion of children with intellectual disability goes along with many more children with milder ASD now being identified and receiving services.

Mr. Rokuskie:

Also, part of it could be also when people are diagnosed. I know my oldest son was diagnosed at 4 years of age with autism but didn't get an intellectual disability diagnosis until he was 9 or 10 years old, so there is definitely a differentiation where you wouldn't see that in the data, and as more doctors and educators become more knowledgeable about the subject, that diagnoses are happening sometimes a little bit later as well.

Dr. Shapira:

Right, that's absolutely correct.

Mr. Rokuskie:

So you also saw differences in your sites when looking at diagnosis. Is that due to the information that you're receiving, that like Arkansas was different than New Jersey, and by a pretty wide margin looking at the data from the statistical analysis?

Dr. Shapira:

Yes, you're correct. The prevalence of 8-year-old children with ASD varied between the ADDM Network sites, and the recent report it varied from 1 in 34 children living in parts of New Jersey to 1 in 77 children in Arkansas, which is over a 2-fold difference in prevalence between these two ADDM Network sites. Some of the difference is due to factors I mentioned a few minutes ago, such as access to education records. Some of the difference could be due to how children with ASD are identified and served in their local communities. For example, communities that are more urban are likely to have greater access to services for children and families with ASD compared with communities that are more rural. Additionally, lower socioeconomic communities may have less access to services. So it's not surprising that there are differences in prevalence found in the different ADDM Network sites.

Mr. Rokuskie:

So, Dr. Shapira, do you have any final thoughts?

Dr. Shapira:

Well, I would like to go back to the discussion of factors that could be affecting the prevalence of ASD, and I've already mentioned some of them, and some of the change that has been observed in prevalence is due to a narrowing of the gap in prevalence between white and black or Hispanic children, and some of the change is due to more children with mild ASD being identified, and some of the change may be due to improved awareness of ASD and improvements in the way children are identified and diagnosed and served in their communities, as well as broader implementation of policies that improve access to services for children with ASD, and some of the change is due to a broader access to education records by the ADDM Network. Now, we cannot rule out the possibility that part of the change in prevalence over time is due to a true prevalent increase, but most indicators point to improved awareness, identification, diagnosis, and access to services as being the real driving factors here.

The indicators show that we seem to be moving in the direction of better identification and improved identification and receipt of services, so there seems to be a direction that we're moving that mirrors other national surveys with regard to the number, this estimation of the prevalence of ASD.

Mr. Rokuskie:

My thanks again to my guest, Dr. Stuart Shapira, Associate Director for Science at CDC's National Center on Birth Defects and Developmental Disabilities.

Dr. Shapira:

Thank you. Yes, appreciate this and having the opportunity to chat about this very important topic.

Mr. Rokuskie:

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I've been your host, Paul Rokuskie. Thank you for listening.