

DataSpeak

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

November 15, 2011

Michael Kogan - Director of the Maternal and Child Health Bureau's Office of Epidemiology Policy and Evaluation

Good afternoon, everybody, and welcome to today's program. The Epidemiology of Autism Spectrum Disorders, New Approaches to Prevalence and Monitoring. I'm Michael Kogan and I'm the Director of the Maternal and Child Health Bureau's Office of Epidemiology Policy and Evaluation. The DataSpeak series is sponsored through the Office of Maternal and Child Health Information Resource Center. Autism Spectrum Disorders are a growing concern in the US today. As today's speakers will discuss, the number of diagnoses of these disorders has been rising. The most recent national estimates from the Maternal and Child's Health Bureau's National Survey of Children's Health and the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network have shown sharp increases in the prevalence of children with an Autism Spectrum Disorder in the US, approximately 1%.

Federal, state, and private stakeholders are working to discover the causes behind the rise in these disorders. In today's program, our speakers will discuss this increase, whether this increase is a result of improved identification of these disorders or if there's been a true increase in risk. Improved identification could include increased awareness among both providers and patients, and parents, increased availability of screening and services, and changes in diagnostic criteria. Data systems are needed to evaluate all of these multiple and overlapping factors. Today's speakers will also discuss the data systems and sources that researchers can use to look at Autism Spectrum Disorder prevalence including national data systems, state and local special education data, and projects like the Interactive Autism Network. True prevalence estimates are important for identifying the factors that put children at risk for developing appropriate policy responses and for directing services to areas of need.

Autism research and intervention is a priority of the Maternal and Child Health Bureau. The Bureau supports two research networks investigating physical and behavioral health interventions, research on evidence-based practices, and state demonstration projects to improve services for children with Autism Spectrum Disorders among other projects. Today's program will bring the focus to epidemiology and the efforts of both public and private stakeholders to develop new approaches to monitoring ASDs.

We're very excited to have four great presenters with us today. Our first speaker today will be Dr. Catherine Rice who is an Epidemiologist at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. She'll discuss the latest information on ASD prevalence.

Our second speaker will be Dr. Laura Schieve, also an Epidemiologist at the National Center on Birth Defects and Developmental Disabilities who will look at the possible contributions of risk factors to the rise in ASD prevalence.

Our third speaker, Dr. Matthew Maenner is a Postdoctoral Trainee in Developmental Disabilities Research at the Waisman Center at the University of Wisconsin-Madison. His presentation will review some of the ways special education data have been used to evaluate trends in the number of children with an autism classification.

Our final speaker will be Dr. Paul Law the Director of the Department of Medical Informatics at the Kennedy Krieger Institute. He will give an overview of the data collected by the Interactive Autism Network and its uses.

Now, before I begin, I'd like to introduce Sarah Lifsey - Altarum Institute, the moderator for today's program. Sarah?

Sarah Lifsey - Altarum Institute

Thank you, Michael. First, I'd like to welcome our presenters and everyone who's in the audience today. Thank you for joining us. Before we begin our presentations, I just had a few pieces of brief technical guidance for you all. First, I'd like to call your attention to the DataSpeak website, which we hope you will visit after today's program. There you'll find resources on today's topic including some that our speakers will highlight in their presentations. On the website you will also find archives of all of the DataSpeak programs going back to 2000. The slide on your screen shows some of the most recent programs that are available and the address you can use to access them. I'd also would like to point out that you are able to download today's PowerPoint presentations and some additional resources directly from the screen that you're seeing right now. On the left-hand side of the screen, in the box that says downloads, you can click on the item that you are interested in to highlight it, click save to my computer and follow the simple instructions on the screen.

Finally, please know that your phone line will be muted during the presentations. At the completion of the program we'll be having a question and answer session and we will provide instructions for asking questions over the telephone at that time. If you'd like to pose the question online you can do so at any time during the program using the questions box on the lower right-hand side of your screen, just type your question in the box next to the arrow and hit enter. Now I would like to turn to our first speaker, Dr. Catherine Rice who will discuss the increase in the prevalence of children with Autism Spectrum Disorders. Dr Rice?

Dr. Catherine Rice - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention

Thank you, Michael and Sarah. Today I'd like to talk about prevalence of autism and give a general overview of what we know at this point. So certainly, many of you who are on this call and have been part of the community who has been concerned about the numbers of children who've been identified with a Autism Spectrum Disorder in the last 15 or so years and it's very clear that there are more children receiving services under a classification of autism than in the past, or children have been diagnosed increasingly in a medical or clinical setting with an Autism Spectrum Disorder. On the slide there is some data being shown from the California Department of Developmental Services and the US Department of Education Special-Education that eligibility counts for autism that have been reported since the early 90s, and in both of these service-based systems we've seen significant increases in the number of children in particular who have been identified with autism.

Now, when we're talking about prevalence of autism we want to go beyond just those individuals who have been identified and classified as having autism for a service reason and look in the population to say who else may have the constellation of developmental history and

behaviors that go along with an Autism Spectrum Disorder. As we know autism, at this point there's no biological or medical test and it's diagnosed by looking carefully at developmental history and a range of social communication and behavioral features. Putting that together and looking across individuals in the population, prevalence studies have tried to come up with a more complete estimate of both who has already been diagnosed and who else may have that constellation of features.

Most of the studies on prevalence of autism and Autism Spectrum Disorders have been done in high resource countries. And the first studies have been done, started in the 1960s and since that time there have been multiple studies. There is a figure on the slide that shows just in terms of points on the figure the prevalence estimate in terms of numbers of children per 1000 children who have autism or an Autism Spectrum Disorder. Now we see overtime, particularly in more recent studies, increases and much larger estimates from earlier on and summarizing across these studies. Prior to the early 1990s the average across these different studies can be summarized to be about 1 in 2000 children. That focused primarily on more classic autism or Autistic Disorder and also found that co-occurring conditions of intellectual disability was present in about 75% of children with autism.

Since that time, we have had significant changes in terms of the diagnostic classification and studies that were reported around the mid 90s and then in the past decades changed from about 1 in 500 to 1 in 150 to the most recent studies, closer to about 1 in 100 children with autism and that's mainly looking at the Autism Spectrum Disorders including Autistic Disorder, Pervasive Development Disorder, not otherwise specified and Asperger's Disorder. So in about 1% of children the co-occurring intellectual disability has also changed to be about 40-50% of children in the spectrum.

This slide shows a range of studies that have been done and reported since 2009. Now, because autism is a behaviorally defined condition, although we try to summarize what is the prevalence of autism in a single number, we're probably always going to find some range in terms of those estimates and these studies have found from 1 in 213 children with an Autism Spectrum Disorder to 1 in 38 children with a recent study both in South Korea and the Netherlands showing over 2% of children having an Autism Spectrum Disorder. This is much higher than we had seen in other studies. Now, averaging across all of the studies that have been reported in the last few years the average is about 1.2% of children affected with an Autism Spectrum Disorder.

Now that summary of studies includes the Centers for Disease Control and Prevention's efforts to identify, monitor, and track prevalence of autism and describe the characteristics of children with autism in multiple areas of the United States over time. And this project is called the Autism and Developmental Disabilities Monitoring Network or the ADDM Network. I want to talk a little bit about the ADDM network, the findings that we have to date and where we're going in the future.

So the ADDM Network method, it's an active case finding surveillance system based on information that's documented in evaluation records. So there is some level of risk in terms of the population being screened, that these are children who have been evaluated either at a community provider such as a developmental pediatrician or a psychologist, or a neurologist, or through the school system in some sites with concerns about development impacting their education, but this could have been for a range of conditions, potentially a concern about autism or intellectual disability, or language disorder for instance.

We look at children who are age 8 because we found an earlier study that we identify the most children at age 8. At that point because we still are seeing delays in early identification of autism, by the time children are 8 years of age we find that more children have been evaluated for developmental concerns and have that information documented in their records. We collect as much information we can on each child and we have a clinician expert team that goes through and looks at all of the developmental history on that child and applies the DSM or the Diagnostic and Statistical Manual of the American Psychiatric Association the criteria for autism, Asperger's Disorder and PDD-NOS.

So the last report from the ADDM Network was published in 2009. We are in the midst of preparing our next report and should have updated data in early 2012. But I'll talk a little bit about the current data that are out there. This represents 11 sites with children who were age 8 in 2006, born in 1998. We found across the sites a range of prevalence from a low of 4.2 per 1000 to a high of 12.1 per 1000. So between 1 in 80 and 1 in 240 children with an Autism Spectrum Disorder. The average was 1 in 110 children or about 1% of 8-year-old children. Very similar to what has been found in other studies we found about 4-5 boys for every girl identified, this is a very common feature of autism, which at this point still does not have a very good explanation as to why boys are more often affected than girls. We also found differences by race and ethnicity with highest prevalence among White, Non-Hispanic children. Now in a little bit I'll show you some data about changes in prevalence over time. And over time we've seen these differences in prevalence decrease somewhat, giving us some indication that some of these differences may be due more to identification factors than to true etiologic factors. But this is where having an ongoing surveillance system where we will be able to track this data overtime will be very helpful to determine if we're talking about identification or etiologic differences there.

Some of the other information that we have looked at in the population was when our people first concerned about the development of the children that are identified with autism? And we found that for the majority of children, who at age 8 we identified with an Autism Spectrum Disorder, that somebody had a development of concern before the age of 2 years of age in about 70- 95% of the children. And also, there was about 13-30% report of developmental regression by the age of 2. Despite these early concerns, we found the average age of the earliest diagnosis for autism was 4 years, 6 months, and that ranged depending on the site but quite a delay from those early concerns to autism actually being diagnosed.

Some of the other things that we've been able to characterize in the population is about 77% of the kids have a documented ASD classification on record. So somebody had diagnosed that individual as having an Autism Spectrum Disorder or they were receiving services for autism in special education. So that means 23% of the children we identified had a very clear and consistent developmental pattern associated with an Autism Spectrum Disorder but they didn't have an actual diagnosis on record. We also found that the majority of children were receiving some special education support but it really varied in terms of whether those children were classified as having autism for the reason as their special education support. In terms of the subtype, 47% of the children were ever diagnosed with Autistic Disorder and an average of 41% of the children also had a co-occurring intellectual disability. So this is very different from, as I mentioned earlier, about three quarters of children with autism having an intellectual disability.

This slide shows changes in prevalence in specific sites in the ADDM Network over time. So overall, we're seeing a general trend towards increasing prevalence over time in terms of Autism Spectrum Disorders. The magnitude of that increase really varies by specific site. Overall,

looking at the changes within a 4 year time period from children identified in 2002 to those identified in 2006, that includes children born in 1994 and those born in 1998, we saw consistent trends in terms of increases in Autism Spectrum Disorders. Overall we saw a 57% increase in ASD prevalence, we saw consistent increases among boys across all of the sites. In terms of girls, we saw an overall increase of 48%, but that varied by site. We also saw increases across the different racial and ethnic groups. However, the greatest increase was among Hispanic children. We also saw increases across the range of intellectual functioning so if you look at children who have cognitive impairment, those that have a borderline IQ, and those that are in the average to above average range. We saw increases across all of those groups but with the greatest increases in the borderline and average to above average groups.

So what is happening? What are some of the reasons for increasing ASD prevalence? A challenge we have is that there's no single reason for it. And it's very challenging because we've had quite a few things changing within the last decade or two that have impacted autism prevalence estimates. So some of these changes go under the category of identification issues such as the changes in the diagnostic criteria from the concept of autism of what was a much more severe disorder to incorporating a very wide spectrum of individuals. Also, we've had a great amount of increased awareness in the community, changes in availability of services, we've also had an increased recognition that autism can occur across the range of intellectual functioning and can co-occur with a range of other conditions as well. We've also had improved identification across certain groups, I've mentioned in terms of Hispanic children or children who have borderline, or average to above average IQ. In addition, we've had improved early identification. Overall though, it's hard to quantify each of these and to say all of this truly accounts for the increases in Autism Spectrum Disorders. So a true increase in risk is also possible.

So where are we with trying to understand the relative contribution of these factors? Primarily the debate has been sort of dichotomized to be an either/or, that people want to understand that this is all identification that is explaining the increase in autism prevalence or it's all increased risk, that something has changed in an exposure in our environment, in the susceptibility of individual fetuses or children that is increasing the actual occurrence of the symptoms of autism. And I think we've simplified this debate a little bit too much and really what we need to do is to look at all of these factors together. It is clear that some of the increase is related to identification factors, both identification in terms of improved seeking out and surveillance systems, and being complete in terms of our methodology of identifying children with autism, but also because of increased community awareness and identification as well. But it's very hard to actually prove the other aspects, which is a true increase in symptoms. It can't be ruled out but it's very hard to actually prove.

So how do we evaluate the multiple overlapping factors? How do we improve how we can quantify these identification factors and the potential risk factors that have been involved in changing autism prevalence? There's been some recent efforts to be specific in evaluating reasons for ASD prevalence increases and this chart summarizes some of the studies that have been published in the last few years, trying to look at specific factors whether they be identification factors or particular risk factors. So identification factors for instance, a study done by King and Bearman looking at the change in the identification of how mental retardation is identified or intellectual disability as we use the term today, has been identified in relation to autism, and in their analysis they indicated that over a quarter of the increase in the California Department of Developmental Services data could be attributed to this change in the use of intellectual disability and identification of that condition as well.

Other efforts have shown smaller impact. So for instance, a study led by Dr. Schieve, who will be talking to us about this in a just a few minutes, really showed a very minor impact of some of the perinatal risk factors and I will let her explain that more fully in just a few minutes. So, we have multiple areas where we need to look very systematically in good data sets, where we have done our best to identify all of the children with autism that we can find in the community and then to look at that data over time and look at the various identification risk factors that might be changing. So where we are now is trying to consider how to evaluate these multiple overlapping factors.

So, in conclusion, the recent prevalence estimates are about 1% of children. This represents the Autism Spectrum and is up from 1 in 2000 children, which represented more restricted autism. We need to better understand the multiple overlapping factors and there's not likely to be one reason for the change. We're not likely to find one particular risk factor, one particular change in identification that has accounted for the changes in Autism Spectrum Disorder prevalence, but I think no matter what the reason is, it's very important to take the fact that these are more individuals than were expected, that we take these estimates to plan more appropriately for policy and service needs, and that we address the needs of people with an Autism Spectrum Disorder across the lifespan. We talk a lot about children, but there is so much also that needs to be done to support adults on the spectrum. These data can also help identify promising clues for risk and provide some basic observations in the search for mechanisms but by themselves can't answer those causal questions about autism.

I think it's important that we do know enough at this point about autism in general that we don't need to prove that this is all identification or all risk to move forward with these studies that are being done to look at the complicated biologic and environmental factors that could be involved in autism. Thank you for your attention.

Sarah Lifsey - Altarum Institute

Great, thank you so much. As a reminder, if you have a question for our speakers, you can submit it online at anytime using the form on the lower right-hand side of your screen. Next I'd like to turn to Dr. Laura Schieve, who will discuss perinatal risk factors and Autism Spectrum Disorders.

Dr. Laura Schieve - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities

Thank you. I'd like to start by just acknowledging and thanking my collaborators on this project. So as we just have heard the prevalence of Autism Spectrum Disorders has increased markedly in recent decades and today I'd like to focus on the most recent data from the ADDM Network that indicates that ASD prevalence in the US increased 57% in a four-year time period, from 2002 to 2006, and that's an increase from 6.0 to 9.4 per 1000 children. There are three general explanations for the increase, intrinsic measurement changes, extrinsic identification effects, and the possibility of an increase in 1 or more ASD risk factors.

So this project was to consider how changes in a given risk factor might impact the ASD prevalence and we were specifically interested in that recent 57% increase in a four-year period because it is such a short time period and such a large increase. We formulated a mathematical model to estimate a risk factors likely impact on the ASD prevalence and then we applied that model to several prenatal and perinatal risk factors that have been previously found to be associated with ASD and have all been implicated as increasing at some point over the past decade, and these are preterm and very preterm delivery, low and very low birth weight,

multiple births, cesarean delivery, breech presentation at birth, and use of assisted reproductive technology or ART for conception.

So a given risk factors impact on ASD prevalence will depend on three things. The baseline prevalence of the risk factor or RFP, the change in that RFP overtime, and the estimated relative risk or the magnitude of the risk factor ASD Association. We started the project by modeling various combinations of these three risk factor characteristics and we used this kind of complicated equation shown here, I'm not going to go into that, but just to say that the three analytic steps in which we came to this equation are outlined further in the paper we just published, which I will give you the citation at the end of this talk.

But the model has several inherent assumptions, which I will discuss. First it assumes the magnitude of the risk factor ASD Association is constant from baseline to follow-up. Second, it assumes individuals having children at baseline and follow-up are similar in terms of their underlying genetic susceptibilities and that is that there are no drastic changes due to a substantial in or out migration. Both of those assumptions are generally reasonable if you're looking at short time frames. Third, because of a lag time between birth and the ASD diagnosis, the model assumes that migration into and out of a population between birth and ASD measurement is limited and will be not be differential by risk factor status, and that might be reasonable in a large geographic population such as the entire US, but it doesn't necessarily hold for all local populations, particularly if parents might selectively move based on access to and quality of services. And then finally for simplicity, this model is presented in terms of changes in a single risk factor, but we do know that risk factors often co-occur and the model is presented this way but the model can certainly be extended to consider risk factor combinations.

Okay, so here are some of the general findings. This table presents a range of hypothetical scenarios assuming uncommon risk factors, that is the baseline prevalence was assumed to be 1% or 5%, and that's shown in the first column. Then we considered 2 relative risk estimates, 1.5 and 2.5 and these are generally in the range of what's been seen in various autism etiologic studies. And then finally, we considered what would happen if these types of risk factors increased a moderate amount or 10% or a large amount or 50%. So the percentage change in ASD prevalence for each of the various scenarios is shown in the fourth column and the actual new ASD prevalence rate expected is in the last column and in calculating those estimates in the last column we assumed the baseline prevalence was 6.0 because that's in keeping with the recent ADDM trend data that we were interested in.

So if you just look down the 4th column you'll see that for most of the scenarios the expected ASD prevalence change is less than 1%. So for example in the very first row, we see the RFP is 1%. The RFP increases by 10% and the relative risk is 1.5. In that situation the baseline ASD prevalence of 6.0 would be expected to increase by only 0.05%, which is a negligible change. In the second scenario we assumed a stronger association that is the relative risk here was assumed to be 2.5, still that would result in only a 0.148% increase in ASD prevalence or a change from 6.0 to 6.01. Looking down the rows, in the very last row you see a slightly more extreme scenario and there you see the ASD prevalence would be expected to increase a bit more by 3.5% or an increase to 6.21.

Okay so this table is very similar to the one I previously presented and in fact columns 2 and 3 are exactly the same as what I just showed you. The difference here is the RFPs in the first column are higher at 10% and 20% to illustrate scenarios for common risk factors. So, and if you look down the 4th row now you will see greater impact on ASD prevalence, but still most of

these scenarios would be expected to result in an ASD increase that's less than 5%. Only one scenario, and that's the one in the very last row, where you have a 20% RFP, a 50% RFP change, and a relative risk of 2.5, that's the only scenario that results in and an ASD increase greater than 10%. So that scenario would result in an increase from 6.0 to about 6.7.

These are some of the same data that I just went over, but this time illustrated graphically because some people process it better that way. So just to orient you to this, these are the various scenarios with RFPs ranging from 1% to 20%. So these are indicated by the colored lines, the black line is 1%, up to 20% indicated by the purple line. Then we looked at various scenarios where the change in the risk factor prevalence ranged from 5% to 100% and that's shown along the x-axis. And then in every scenario on this graph the relative risk is assumed to be modest at 1.5. So what this illustrates is that for a risk factor with this type of relative risk, nearly all scenarios will have only a small impact on the ASD prevalence. So even when you have a common risk factor or the 20% RFP and you assume that that risk factor doubles or increases 100% during the timeframe of interest, the result is still less than 10% impact on the ASD prevalence.

Okay, and again, this is a very similar graph. Everything is the same except this time the relative risk assumption is 2.5, and now we see that uncommon risk factors, those RFPs, 1% and 5%, the black and green lines, there is still little impact on ASD prevalence even if they increase by a large percentage. So when you get to more common risk factors, those that are 10% and 20%, you see that as the magnitude of the association gets stronger these types of risk factors could have a more meaningful impact on the ART rate but only still if they increase by a large percentage.

And then these are some extreme scenarios and this was just to answer the question "well, what would it take to have a very large increase on ASD prevalence?" I'm not going to go through all of these, but for example, in the very last row, which is you know, a very unlikely scenario, you would have a very ubiquitous risk factor at 40% RFP. You assume that it doubles in your timeframe of interest and that it has a very strong association with ASD or a relative risk of 5.0. If all of those conditions are met you would expect that ASD would increase by 64.5%.

Okay. So those are hypothetical scenarios and now I'm going to turn to our real world examples. We obtained estimates for the 1994 RFPs and the 1994 to 1998 cRFPs for several prenatal and perinatal factors and we used the US public natality files and the US national ART surveillance system for our estimates. We chose 1994 and 1998 birth years because these are consistent with the recent ADDM birth cohorts. Remember ADDM tracks 8 year old children so when they're looking at 8-year olds in 2002 and 2006 those correspond to children who were born in 1994 and 1998. Then we estimated relative risks for our risk factors of interest from systematic literature reviews, we searched English-language publications in '94 or later using various search terms and we also reviewed article citation lists. Altogether, we screened 266 articles and selected 40 that met our criteria for full abstraction.

Okay. So this table shows the three risk factors that we were interested in that had an RFP of greater than 5% and that's preterm, low birth weight, and cesarean delivery. For preterm and low birth weight the change in RFP was around 5% but actually during this time period the cRFP for cesarean was near zero. Looking at the third column, for all risk factors, both negative and positive studies have been reported for the risk factor ASD Association and among those positive studies relative risks were generally 3.0 or lower, but for preterm and low birthrate there were a few outliers. So given all of these indices, we looked at the likely ASD impact and found

that for any of these risk factors it's less than 1% or really zero in the case of C-section because you can't have an impact if you didn't increase.

Very preterm, very low birth weight and multiple births all had low RFPs and low to moderate cRFPs. For all factors, most association studies suggested low to moderate relative risks. However, for each factor outliers suggested the possibility of stronger associations. But even if we assume these most extreme relative risk assumptions the ASD prevalence impact would still be very small, less than 1%. Okay and then the story is similar for breech presentation and ART.

ART is actually an interesting case. There's been some speculation that this could be a key exposure to consider because it has increased dramatically and indeed the cRFP for ART use was 35% in just this small time period. There is very limited data on whether ART is associated with ASDs, however, even if we assume the most extreme estimates for relative risk, and these were based on very small sample sizes, but even if we assumed a very large relative risk the baseline RFP for ART is just too low currently and thus the estimated ASD impact is also estimated to be low.

We also just took a look at the RFPs and cRFPs for various risk factor combinations. As you'd expect, the RFPs are lower when you combine factors than when you look at each factor individually. The cRFPs are a little higher; they are in the 10-25% range. While we don't have good data on the relative risk, they're likely higher than the individual relative risk. But still, given this combination of RFPs and cRFPs, it's really hard to imagine a realistic scenario that makes a sizable impact on ASD prevalence.

And then finally, in the last row we considered whether a child had any of the perinatal risk factors. This time the RFP is high at 32% but the cRFP is less than 1%. So this assessment model can be extended to various types of risk factors or to assess identification related factors. But the take-home message is that for any factor to have a sizable impact you really need a large RFP, cRFP, and RR. And for the six risk factors that we assessed, the estimates for the 1994 RFP, the 94 to 98 cRFP, and the relative risks were insufficient to have contributed substantially to the recent ASD increase.

Okay. In assessing any risk factors it is important to consider the accuracy of the estimates, so we used some large population-based data sets and past studies indicate that our RFP and cRFP estimates are pretty accurate especially for some factors such as low birth weight, but they might be less accurate for other factors such as breech. But even if we assume a moderate degree of underreporting it wouldn't have impacted our findings for breech. Likewise, although there was a range of uncertainty for the relative risk estimates, there was a fair amount of consistency in estimates across studies. And again, when we considered that the outliers in relative risk were correct, that did not substantially impact our ASD impact measures.

Okay, so previous studies do indicate that preterm and low birth rate are risk factors for ASD and more limited studies do implicate multiple births, C-section, breech presentation and ART as possible risk factors. However, none of these contributed substantively to the recent observed ASD increase. So it's not that these are not important at an individual level, they are, but it's unlikely that any of these risk factors can explain the recent population prevalence increase. I'm going to end it there. But if you download the slides, this is the citation for this study, which was just recently published.

Sarah Lifsey - Altarum Institute

Great. Thank you so much. As a reminder, if you have a question for our speakers you can submit it online using the question form on the lower right-hand side of the screen and if you want to download the slides or the additional resources, as Laura mentioned, you can download them from the downloads area from the left-hand side of your screen. Now I'd like to turn to Dr. Matthew Maenner, who will discuss findings on autism prevalence using special-education data.

Dr. Matthew Maenner – T32 Postdoctoral Trainee in Developmental Disabilities Research at the Waisman Center at the University of Wisconsin-Madison

Thank you. I'm going to talk about special-education data, which is another data set that has been used to evaluate trends in autism. So if you are interested in a part of the country that might not have a CDC ADDM site, you might consider whether the special-education data are appropriate for your questions. Every year, public schools are required to report the number of children served in special-education programs by disability category and autism is one of these categories. For monitoring trends I think part of the appeal of the special-education data is their ubiquity. They are reported every year and for every school going 15 years back and a lot of the current data are publicly available. So perhaps because they're so available and so widespread these data have received a lot of attention over the years to the extent that if you look up autism in Wikipedia you see a figure based on national special-education counts.

But there are some important issues to consider when interpreting special-education counts. Schools are required to provide appropriate services for children with special needs but they do not necessarily have to classify children according to their medical disability. These criteria for autism classifications can differ from state to state and in practice the implementations probably vary quite a bit within any single state. Autism didn't even become a reporting category until around 1993 and these data are only available in aggregate, whether it's at the national, state, or school level.

One of the common research uses of special-education data has been to examine trends in autism classification and this slide has a couple of good examples of studies that have done this in different ways. Craig Newschaffer and colleagues examined trends by both age and birth cohorts and found that younger birth cohorts tended to have higher prevalence of the autism category than older cohorts and then on the right side of the slide is Paul Shattuck's paper on diagnostic substitution and this received quite a bit of attention when it came out and was received as a little bit even controversial because Shattuck tried to determine whether the increase in the autism category was offset by decreases in other special-education categories, and so in the figure you can see that autism and the group of low prevalence classifications increased and intellectual disability and learning delays decreased over the time period. So this is consistent with the diagnostic substitution hypothesis, but because these data are at the national level we can't see that individual children are getting one to one substitutions of leaving one category and entering the autism category. But I think both of these papers are great places to start if you're interested in learning more about how these data have been used.

Other researchers have examined associations between the autism classification and other factors. On the left side of the slide, Mandell and Palmer found a positive correlation between state-level autism prevalence and increasing per pupil spending in schools. And there have also been a number of environmental studies using special-education data. These include proximity to coal power plants, average annual rainfall, and the distance or number of Superfund sites in an area. But because these associations are made at kind of an ecological level, like the state or county, or school district level, there's been some debate about how defining some of these studies should be interpreted.

In the paper three reasons not to believe in an autism epidemic Gernsbacher and colleagues made the argument that these increasing trends in autism in special-education might be due to incremental changes in awareness or how children are being classified and that really there could be many potential reasons as to why schools would be so slow or quick to utilize the autism category.

So how would we show whether there is evidence of this gradual and incremental process? We often report autism prevalence for very large regions. Many of the studies using special-education data look at trends at the state or national level. So we thought that we might be able to seize the evidence of these incremental changes if we considered changes at a much more local level and so to do this, we chose to look at school districts. And so you can see here we were able to get 7 years of publicly available special-education data from the Wisconsin Department of Public Instruction. The maps show elementary school prevalence by school district and the overall statewide prevalence is listed underneath each state for each year. And you can see that the red areas on the map are high autism prevalence and the blue areas are lower prevalence. And in any given year you can see that there is quite a bit of red and blue, although I think over time the state gets more and more red.

So our question was “what about the districts that already had high prevalence in 2002?” How did they change over time? We hypothesized that districts that started out with a high prevalence would show more stability in prevalence or at least smaller increases over time and that districts that began with a low prevalence would show greater gains over time. And our findings largely supported our hypothesis. In this figure the bars in the background are the statewide special-education autism prevalence and you can see it’s a pretty steadily increasing each year, but then we grouped school districts by the 2002 autism prevalence into 8 groups, so there’s roughly the same number of students in each group, and we followed those groups over time. And you can see that the districts that started out with the highest prevalence were pretty stable relative to the others and that districts that started out in the lowest prevalence group had the largest increases over this time span and contributed much more to the overall statewide increase. And also along the bottom of the figure are ratios between the high and low groups in any given year. And you can see that this gap decreases dramatically from over 24 in 2002 to 1.8 in 2008 and so can see that this gap is really closing both in relative and in absolute terms.

John Harrington wrote a really nice commentary on our article and he talked about how a school should really expect to have a certain amount of autism and if they identify less than this amount that might be indicative of may be less developed services for people with autism or that people were choosing to move to other schools for services. So to go back to this idea of incremental change at a local level, maybe these schools that started out with higher autism prevalence aren’t necessarily high risk, but could instead be characterized as early adopters of really making use of this category in their district, or I think this quote by William Gibson is fitting that the “future is already here, it’s just not very evenly distributed.”

I also wanted to talk briefly about how really anyone can get started using this data source and share some of my own experiences and sort of lessons learned from working with this data. You can get national or state level data from the Department of Education or I think also the National Center for Education Statistics. But for areas smaller than the states like the district levels that I’ve been working with, I’ve only seen these available on individual States Department of Education websites and each state often has different ways of distributing the data, some make it really easy to download and then just give you everything in a big spreadsheet, others present the data as part of reports that they have done with analysis of the

data and I think at least one state requires you to submit a proposal and get approval for your analysis and then sign a data use agreement before you can even use the data. So there's a lot of variability there. And another option, and this is something I haven't pursued, is to try to contact people working in these agencies that might be able to give you the data in the way that you want it.

And so I think one of the biggest challenges of working with this data is that it really wasn't collected for research or for us to analyze trends, it's part of the reporting responsibilities for the schools, and so when we try to use it in analysis it can be a bit messy because we're using it for a purpose other than the purpose that it was created for and intended to be used. And so districts can change from year to year and I had to reconcile those differences and there isn't necessarily a database where we can draw on, where we have all of our information all in one place, everything that we want in a data set we kind of have to stitch together and merge different data sets in different ways and they don't always align perfectly. So school districts don't necessarily overlap with census designations or county boundaries or other things in which other pieces of data that we might want to look together. So it can be a challenge to gather all the data in the way that you want it.

And then the special-education counts themselves can be organized in different ways. For example, the autism data might be available in terms of age, and then the overall student count might be grade level, so then you have to figure out what grade is an 8-year-old in or what age is a 3rd grader to try to make the two equivalent. So finally, I wanted to show just a quick real-world example of how we can take the data that's available and turn it into something that suits our purposes.

So in California, special-education data aren't available to download all at once in like a big spreadsheet file, at least that I was able to find, but they do give you the option to look up one year and one district at a time. So this picture shows us selecting the ABC Unified school District for 2010 and 2011 and then it produces a table, but with roughly 1100 district and 9 years of data, that's like 10,000 tables and web pages that you would have to go through and then you'd still have to put it all together. So one way to make this less cumbersome is to automate it. And I noticed that the school district and year information are contained in the web address that calls each table, so I wrote a program that cycles through each of the school districts and years, pulled up each table, scrapes the data off the page, and then it puts it into the file that I was kind of hoping for in the first place. So this is just one example to show you that these data exist and they might even be available to everyone, but it could take some creativity to turn the data into something that's useful for you. So I hope this gives you an idea of how special-education data have been used to examine trends in autism and special-education and also how you might get started if you wanted to answer a question using this data source. Thank you.

Sarah Lifsey - Altarum Institute

Great. Thank you so much. As a reminder, if you have a question for any of our speakers you can submit it online at any time using the question form on the lower right-hand side of your screen and we will be getting to the question and answer session pretty soon, but I would like to right now turn to our final speaker, Dr. Paul Law, who is going to give us an overview of the data in the Interactive Autism Network and its applications.

Dr. Paul Law - Director of the Department of Medical Informatics at the Kennedy Krieger Institute

Thank you, Sarah. So I really appreciate my colleagues educating us about epidemiology of autism in the United States and just really thoroughly enjoyed their talks. I get to talk about something other than epidemiology. And so I guess our host thought the IAN project was just so interesting that they had to invite me even though the topic isn't epidemiology. So hopefully that's the case. So also, this last talk is a little bit, I think you'll find it easy to listen to. It's about a partnership between families and researchers and it's a bit lighter on the numbers, so hopefully it will be a nice topic for us to end with.

So what is the IAN project? Well primarily it's important to understand our goals, which are to improve the lives of individuals with autism, a goal that hopefully we share with everybody else working in the field. And we aim to do that by accelerating meaningful autism research and by engaging families as partners in the research process to know their viewpoints and to engender their participation. We wanted to improve the return on investment or ROI of other autism research projects working in the area and to kind of vicariously live off of their successes. We want to contribute directly to scientific knowledge, meaning mainly publications that are useful to this field, but also to facilitate distribution of information to the public that doesn't necessarily come in the form of formal publications.

IAN is a multi-faceted internet mediated research initiative open to all individuals with ASD and their immediate family members. We've been in the US only for a while, but actually a couple weeks ago IAN opened up to anybody in the world who wants to participate and it is a partnership between families and researchers. So, again, kind of going back up to the first point on this slide. Most of it happens online. It's an informatics infrastructure for ASD research. So a couple of the key things that we provide to researchers and we're very valued for is subject recruitment services, so about 80% of research studies are significantly delayed in autism because of difficulties connecting with families and so we have helped over 400 different research projects to connect with families.

And then we also collect data from families that we then use ourselves but also is distributed freely to researchers. There are more than 40,000 subjects that are actively participating in IAN. And I said earlier that it's now international. The data is either provided by the parent or by the adult individual with autism themselves and the diagnosis that they provide is validated, and I'll give you a couple slides about that in just a second.

We consist of two online components and this is what our homepages looks like. IAN research, which is over to the right, is where families join an online research project and participate in an online research protocol which consists mainly of forms that we ask them to fill out a variety of topics. And then IAN community is where we meet the public, if you will, and provide information to everybody in the autism community, but especially the participating families and individuals.

So we use a lot of different ways to invite families to participate, everything from word-of-mouth, advertising, to Facebook, willing families, once they've heard about the project, come to www.IANresearch.org and sign up and consent online. The eligibility at this point is it's gotten simpler since we launched and basically now it's simply any individual with a professional diagnosis of ASD is eligible anywhere in the world. My son loves aliens, we didn't actually limit it necessarily to just the earth, but, and then there's also certain family members, so IAN is not just an individual registry, it's a family registry and the parents and the siblings are invited to participate and their information is often just as useful as the data from the affected individual.

And we're international, based on characteristics of the individuals as they are registering, they get led through a distinct research protocol that's just built for them based on their level of affection, you know, how severe their autism is or what their age is, or their gender, or what have you. This is what a typical question looks like within our interface. And this is the homepage, if you will, for usually the parent or the individual with autism to organize their work. So they would click on one of these individuals names, this is actual our family profile, who are also participants, and fill out forms that are incomplete and it looks like down here at the bottom, under Isaac, there's one that's incomplete, but everything else is up-to-date.

And so what types of data do we collect? We collect obviously the child's diagnosis and developmental history, treatments that the family is using, the impact that it's having on the family, information about the siblings, and the child's educational placements, and we use standardized measures that are designed for parent self-report, like the social responsiveness scale by Dr. Constantino at Washington University and the social communication questionnaire which is kind of like the autism diagnostic interview and designed by Dr. Cathy Lord. And this is not intended for you to actually to be able to see much of, but suffice it to say there's a lot of forms and there's a lot of data collected on most of those forms and this is actually old, going back to last year, but we have well over 8 million data points within the IAN database at this point in time.

One of the key questions that comes up is "well how do you know that these individuals actually have autism?" So the research we are doing is based on a validity of that information and at first we started off with the assumption that families would provide very good information and we could rely on that and we could also use the online assessment tools that we had, like the social communication questionnaire to help confirm the diagnosis, but it wasn't until a little bit later that we actually went back recruited some of our participants and validated that there reported diagnosis in IAN was indeed accurate. And so in two different studies that were done in different ways 98% of the time the diagnosis reported by the parent concurred with a professional assessment of the individual.

IAN started off being mainly about our relationship with families and the data that we could collect with them online, however, it's grown to be a bit more than that over time as we've added on other projects. So IAN core is sort of how we began and what I've just described to this point, but now there is something called IAN genetics, where we're working with Dr. Sam Nelson at UCLA and inviting families from all across the country to participate in the genetics which basically means they go and have their blood drawn at a local commercial lab called LabCorp and they can participate in the genetic study and then researchers can come back to them and if they need more clinical data and we want to recruit them into clinical centers they can do that, but it's sort of a quick way, a very fast way to get genetics research going.

NDAR is a key collaboration we have to provide parent provided data to the National Database for Autism Research, which is an initiative of the National Institute of Mental Health. So families can opt in to having all their data from IAN contributed to this national database. We're also doing an online randomized controlled clinical trial. So online clinical trials have been done in schizophrenia and other disorders and basically whenever you have an intervention that is extremely safe, and you have outcomes that can be measured by parent or teacher report in our case, then it's possible to design a clinical trial that really has very little direct clinical involvement. So we do have study physicians and they will talk to the parents, but the families actually won't go in to a clinic to be assessed, and within weeks we should have a reasonable answer as to whether or not Omega-3 fatty acids works for the hyperactivity symptoms of

autism, which is something that many families are already treating their children with and also there is some scientific basis for being legitimate.

And then the last thing is the SSC at IAN project, I'm sure some of you heard of the Simons Simplex Collection it's the largest genetic project to date, and they couldn't see closing up the project without sort of allowing their families to be engaged long-term from a central location, so this was a project that was across 14 different sites and they basically just said, hey, could you work with us to engage our families and to re-contact them about future studies to help to re-contact them about research results that pertain to their own personal health and to do surveys and whatnot with this group of 2700 families. So we are doing that now.

Data sharing, so basically IAN data is shared with any researcher who wants it in a simple format that's all organized and hopefully wouldn't have to go through and do a lot of gymnastics to use it as our previous speaker was talking about.

And then we support the use of our data with an interactive code book where a researcher can come in and make decisions about how they would like to see basic descriptive statistics of the data. They can choose to see the entire skip patterns that are involved with each survey instrument or each online instrument and they can see all of the validation roles. So they check all of the boxes like this person did over here, it's probably going to be too much information most of the time, but every last little bit of how our surveys are executed online is available to the researchers to see and that does become important for certain types of data analysis and nice pie charts are presented in each case. And this is totally available to the public. There's no reason to make this private. If you go to our homepage you can see this tool it's called data explorer.

We had a partnership with the State of Missouri where they wanted to create a dashboard of information that was relevant to their policy makers and they wanted to include a quarterly report to their governor comparing Missouri to national statistics. So we embarked on this project with them called StateStats and you can see this view which I'm not showing you today but you can go online and look at all this information, some of it has to do with age of first diagnosis and just gender distribution, basic things like that and treatments. And this can also be customized. So if you're just interested in looking at treatments and you just want to have a graph, which is what is selected here, you can set that all up, choose your state, which in this case is Alabama, fire it off, and then you get this information for Alabama. And this was interesting because one of our publications was on treatment patterns across the United States and we found that in rural places there was actually a much greater use overall of psychotropic medications because of the relative lack of availability of speech language and behavioral interventions and so forth. So Alabama is a very rural state and fits that profile perfectly because you see whole lot more medication use versus what this is pointing at and then up above it you see speech and language therapy and occupational therapy, and other ABA are all more common in the US as a whole rather than in the State of Alabama. So these are the kinds of things that you can query with the database with StateStats.

We did a project called access to care again with the State of Missouri, they have been a tremendous partner with us and they received HRSA funding to develop a survey on children's access to the medical system and so we did this with them, they oversampled within Missouri so they could have enough participants within that state, but then it was just sort of a random sample of individuals across the rest of the United States. So we can do all kinds of sampling methods within our population so we don't expose everybody to every survey so we get the answers we need.

And so there's two papers that have now been submitted for publication on that data. The Elopement Survey was particularly interesting because this was a pressing policy question that came up, a lot of parent advocacy groups were very concerned about children being at risk, running off, drowning, getting into a car, getting run over by cars, there was some evidence that was a significant increased mortality rates from elopement and so we were asked to do a survey. So the advocacy group, mainly the NAA, presented in October of 2010, very quickly they got together, four different groups, one was a coalition and approached us to do a survey so we began to design the survey just a couple months later it was done. We administered the survey in March; the data was reported back within less than a month to the public and then the information was used in part, really a lot of effort was by the CDC to institute a medical code that would cover children with autism. So that was a demonstration on how quickly we can act when asked to by the autism community.

And so that brings us to this slide, which is how you can help us or partner with us to advance what we're doing, and one is just to tell researchers about the resource, make sure they understand if they're doing a project they can use this for recruitment and there is data that is readily available. And tell your colleagues if you're not into research per se but more of an advocate, tell your state level colleagues about the resources that are online, and we have brochures that we can send you, we have other ways that we can, if you are interested in helping us engage more families in the network we are very interested in that. And perhaps looks at our websites and bookmark them. And I guess that's it. Thank you very much.

Sarah Lifsey - Altarum Institute

Great. Thank you so much and thanks again to everyone who has presented today. It's been a very engaging program and we already have some questions coming in. As I mentioned at the beginning we'll be taking questions both online and on the telephone. To post a question online just enter your question in the field at the bottom of the questions box and hit enter. And to ask a question on the phone just press *1 to indicate that you have a question, the operator will let us know that there is a question, and we'll indicate to you when to ask your question. So while folks on the phone are joining the queue I'm going to start with a few of the online questions that have come in.

The first question I have is from Penny, I think it's for Dr. Rice. For prevalence by groups are there any data on kind of ethnic subgroups like Somali or any Asian or Southeast Asian data?

Dr. Catherine Rice - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention

That's a very important question on additional racial and ethnic subgroups. In the ADDM Network we do have some data but the populations that have been surveyed are relatively small. So those estimates are pretty wide. The confidence intervals that go along with them are pretty wide indicating that they're not the great assessments that we have. So really that is something that is lacking that we need larger populations within the US and as we continue to look over time and can combine multiple surveillance years we'll have better data. There's also a need in terms of outside of the US of some of the prevalent studies that I mentioned have been done in other countries. So for instance there was a study published in South Korea that showed a relatively high prevalence and we don't have any indication of how that compares to other areas of South Korea or North Korea for instance, or for instance Korean individuals who live in the US or other countries that really are, there's a big need for data. There is an effort right now to look at the prevalence of children of Somali origin in the Minneapolis area and that project is ongoing.

Sarah Lifsey - Altarum Institute

Okay. All right I have another couple of questions. I believe these are for Dr. Schieve, asking about other factors that might have an impact on the prevalence of Autism Spectrum Disorders including the age of the father and non-genetic prenatal conditions.

Dr. Laura Schieve - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities

Sure, yeah and we picked out the ones that we evaluated in the talk I gave as examples, they've all been associated, but certainly advanced maternal and paternal age have been shown in many studies to be associated with higher risk for Autism Spectrum Disorders and the exact mechanism of that is unknown so while some of that could be due to environmental effects there's also thinking that could be partially related to things such as identification, if you are older you might be more established and have more resources for diagnoses. And that's something the ADDM Network has looked at as well, there's been one study out and there's another study going on right now that is also going to look at the effects on the population.

In terms of the other prenatal risk factors there's a number of studies underway on the individual relative risk for several risk factors including a study we are conducting here, the study to explore early development, where we are looking at things like hormonal exposures in addition to just ART, other infertility treatments, and infertility conditions, and also looking at things like maternal infection in pregnancy, there's been several suggestions that this might be an important area to look at further. The one problem with applying it to whether that's related to the increase is you need to get some data on the population-based prevalence or the RFP and cRFP illustrated in the model and you can make assumptions about that but for most perinatal risk factors when you get factors that aren't collected on the birth certificate and/or that might be not always diagnosed or might be subclinical in some women, it's harder to get those prevalence estimates, but you certainly could review the literature and come up with maybe a range of estimates and see how that might affect it.

Sarah Lifsey - Altarum Institute

Okay. The next question I have is another online question from Sue and I think it's addressed to all four of our speakers. What are some of the practical ways that the information presented today is useful to those who are in the field working with individuals with autism?

Dr. Catherine Rice - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention

This is Cathy; I'll go ahead and start. I think this may be a very basic answer but I think we've really underestimated the service needs for people with autism. So looking at prevalence estimates and trying to see who you might be expecting to be serving in your community and who you are actually serving might give you an indication of what's to come or some of the unmet needs that are out there, I think Matt Maenner made that point very well about education needs and how the various ways we classify individuals may or may not actually characterize the services that you're providing and so these estimates can be used to get a better indication of the service needs.

Sarah Lifsey - Altarum Institute

Okay. Does anybody else want to jump in on that?

Dr. Paul Law - Director of the Department of Medical Informatics at the Kennedy Krieger Institute

This is Paul. So I mean, most of the data that we wind up collecting and reporting on tends to be driven by people who are very action oriented. So in the case of the Elopement Data a lot was done with that, we are still just beginning to look at it. I got calls from many different projects that are first responders across the country, so this is just an example of a project lifesaver which is a large project that deals with children who go out of their house in an unsafe way and so they were looking for input and interest and were looking at our data, which has not been published yet. And you know, Dr. Farmer's work in Missouri on access to care, all that, that survey was driven by a need to collect information and identify why it is that individuals with autism aren't receiving the kind of care within an appropriate medical home that they need, and all of that is being used to influence care patterns within the state of Missouri.

Sarah Lifsey - Altarum Institute

Great. Thank you. The next question I have is for Dr. Maenner, and it's from Roxanne. How did you tease out potential effects of kind of the political zeitgeist avoiding the stigma with choices of labels or hidden diagnoses such as a category like multiple disabilities?

Dr. Matthew Maenner – T32 Postdoctoral Trainee in Developmental Disabilities Research at the Waisman Center at the University of Wisconsin-Madison

Well, I mean, that's an excellent question and in the paper that I wrote, I didn't try to say that the patterns were really attributable to anything, I was just trying to see what they were and whether certain places might have taken to this category sooner than maybe other places and then what happens to those places that start out high versus start out low. I think that the question brings up some really important topics on sort of we encompassed in this thing that we often call awareness or better identification, there might be a lot of different reasons for why someone either does or doesn't want to use that label regardless of whether there's more of it or not more of it, I think that what we were looking at was really how it's used and how often it's used, but we aren't really able to say why with the special education data.

Sarah Lifsey - Altarum Institute

Okay. Thank you. I don't think we have any phone questions yet, so I'm going to continue with the questions we've got online. This next one is from Akiko, and it is, has anyone looked at prevalence of autism, autistic disorder versus the spectrum and has the prevalence of this narrower diagnosis gone up over time as well?

Dr. Catherine Rice - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention

Hi, this is Cathy. I will talk about that. There have been other groups that have looked at autism versus ASDs more broadly and it depends on the data set that you look at. In our data here and the ADDM Network one of the challenges that we have is the meaning of the subtypes. We find a lot of variability in the use of the subtypes and many children actually have multiple subtypes. So we found that about 47% of the kids were diagnosed with autistic disorder ever, but a reasonable percentage, and I don't have that off the tip of my tongue right now, have multiple diagnoses.

So one of the ways we've actually looked at it, and this is certainly not a perfect comparison, but is to look at the change in ASDs by intellectual disability, thinking that those individuals who have autism intellectual disability may be more like the classic autism and what autism that was identified more commonly in the past, and we find increases among children who have intellectual disability and those who have borderline or average to above average intelligence as

well, but the greatest increases are among those children who have the borderline or average to above average intellectual functioning, so indicating that there is some increased identification among those more mildly affected individuals, but that increases occur across all levels of the disorder. We are doing some additional analyses to look at shifts in subtype and so hopefully we'll have more information about that in the future.

Sarah Lifsey - Altarum Institute

Okay. I have a related question from Mary. Autistic characteristics and behaviors may vary in both degree and intensity. How is a definitive diagnosis determined and by whom for these databases?

Dr. Catherine Rice - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention

So again, this is Cathy. I'll just start, but I think this could apply to several folks because it depends what is meant by "these databases?" Education is certainly very different than say our surveillance system that looks at children who have been evaluated for a range of developmental concerns that could be associated with autism and we look for some kind of indication of concern about autism so maybe they have a diagnosis or they're getting services under an autism category, but we also look for descriptions of behaviors that could be associated with autism, like challenges with eye contact or interacting with other children for instance, or limited interest in interacting with other people, and we take all of the information we can find on that particular child and then use the DSM criteria to say, was there a developmental concern early in life? Were the type and number of social communication and behavioral concerns present over this child's life that doesn't seem to be explained by another disorder? So clinicians go through and evaluate the information we have on those children.

Dr. Laura Schieve - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities

And I just want to add that I think in clinical practice, among the tests used, there is not 100% concordance among any of even the gold standard tests. I mean, they come close, but I think that it's an important point that in all of the systems there's parent report of a past diagnosis, there's review of records for some development concern, there's an educational eligibility for autism noted. In all of those systems it depends on a child being identified by somebody in the community either in the education system or the health system and the way they get evaluated and the rigor of the evaluation that they receive is probably quite variable, and in fact there are several ongoing studies with the ADDM Network and with other databases with some of the HRSA data in the national surveys looking at differences by racial ethnic group, and it's believed that a lot of the rates of change in some of those ethnic groups are not all the same. So, as Cathy mentioned, the rate in Hispanics has been going up much faster than the rate in Non-Hispanic whites and a lot of that is believed because identification can be changing in those groups, which also means similar to what Matt was showing, was that groups that start out lower have more catch up to do in terms of identification and awareness, and as people understand autism better some of those groups may be becoming more proactive, and also others may be recognizing the symptoms better that come in contact with those children.

But I think it's a good point that we don't, in this country, have a system that's based on direct screening, where a random sample of kids is screened all using the same measure to calculate US prevalence. So I think Michael said at the beginning, the prevalence of diagnosed or recognized autism is certainly increasing, whether the total prevalence of autism that includes all of these subclinical cases or I should say unrecognized cases is also increasing and to what extent, it's really I think still a question mark.

Dr. Catherine Rice - Epidemiologist at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention

Yeah and I would just add those are great points. Another, I think a key challenge we have is where is the line between what's an Autism Spectrum Disorder and what is having features or characteristics of autism as we broaden the view of what autism is, and certainly try to hear the voices of the many advocates who speak for themselves and look not just at deficits but look at strength associated with autism, it gets to be a little bit more challenging in terms of how do you actually measure an impairment that goes along with the disorder versus having some of the features and characteristics that may overlap with other conditions, or may be subclinical and not really rise to the level of saying this is an Autism Spectrum Disorder. I think we have a lot of work to do in terms of a clinical field in autism in terms of deciding how to evaluate that component and how to come to some kind of agreement on what that line may be.

Sarah Lifsey - Altarum Institute

All right. Well, thank you all for your answers and for your presentations. That is all the time we have for discussion today. Answers to those questions that we didn't get to during the Q&A session are going to be posted in writing along with the program archive in a couple of weeks. That website will be available on the DataSpeak website and you can access it at your convenience. If you think of more questions you can submit those to us via e-mail through the end of the week using this e-mail address, MCHIRC@altarum.org. Before you go we would like you to know that we will be broadcasting more DataSpeak programs in the coming months, announcements about the future DataSpeak programs will be sent out via e-mail to everyone who registered for today's program and the announcements will also be posted on the DataSpeak website.

Finally, before you log out we'd really appreciate you taking a moment to provide us with feedback on today's program. It's really important to us that we have your input on this session as well as your recommendations for future programs and future topics. To fill out this very short survey, simply click on the evaluation link on the screen now and the survey will pop open in a new window. Today's program is now complete. I want to say thanks again to everyone who attended and to all of our great speakers. Thank you for joining us and have a good afternoon.