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HEALTHY COMMUNITIES

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IS AUTISM ON YOUR RADAR SCREEN?

ISSUES IN EPIDEMIOLOGY, SURVEILLANCE, DIAGNOSIS,

INTERVENTIONS AND ACCESS

RUSSELL KIRBY: My name is Russell Kirby, and I'm a professor of Maternal and Child Health at the University of Alabama at Birmingham, and I am not Judy Zimmerman.

UNIDENTIFIED SPEAKER: Russ, we can't hear you.

RUSSELL KIRBY: I thought he turned it on. I mean, I'm talking right into the mic. Maybe I need to talk louder. I'll talk louder. Anyway, I'm not Judy Zimmerman from the University of Utah, and I'm not Barbara Becker Cattrall from Marshall University in West Virginia either. But, I am a Russell Kirby. And, it's been an interesting conference for me because everything that I've done has been without my collaborators, the whole conference. And so this session is the same. I do have their materials, however, and will integrate them into the presentation. But what we're going to do is talk about autism, look at the epidemiology, look at some of the issues with diagnosis, a little bit on treatment. Talk about some of the public health issues and why public health professionals

should be concerned about autism. And if I get through all these slides quickly, we have a little fun exercise we'll do at the end of the session, okay. So, we might as well get started. You know, being an educator, we always have educational objectives. And so these are some of the things that I hope to accomplish in our next hour and a half or so. Look at some of the demographic characteristics of autism and autistic spectrum disorders, utilizes some of the statistics to look at some of the controversies around the trends in the prevalence of ASD, look at how we might improve the current system-- and system is probably a euphemistic word here—for diagnosis and referral for children in early childhood who might have developmental disability-like systems, identify new opportunities to improve developmental and educational outcomes for children with ASD, and then, maybe at the end, little self-evaluation of how much we've learned. So I'd like to start talking about developmental disabilities by asking some questions that all seem to me and have for 25 years to be things that we ought to know the answers to. So just as for example, can anybody tell me accurately what the prevalence of cerebral palsy is in your state? See a lot of people shaking their head. Do you know whether there's more children with developmental disabilities today than 10 years ago? It seems like there might be, but we don't actually know that. What we know is that there is more children in programs where they're getting services, but we don't know for sure if the numbers increased. Or how about Neural Tube Defects? You know, has the prevalence of Neural Tube Defects declined in your state since folic acid fortification? Well, some, we kind of think that's happened, but there are still 10 or

12 states that don't have comprehensive birth defects surveillance programs, so we don't really know for sure everywhere. Or for that matter, you know, are children with autism or ASD being diagnosed earlier? Again, we don't really know that. So, the answer is no, or at best, sort of. And one of the things that we really lack in this country are population-based surveillance programs for developmental disabilities. We really don't have these anywhere. We have a few programs that look at specific conditions, but we really don't have disability surveillance anywhere in the United States. We also, despite a lot of effort, probably made by a lot of you, we've got a lot of work to do in terms of improving our program data for children with special health care needs as well, and particularly how that relates with some of the educational data systems as well. So we have a lot of work that we need to do, and just a quote from James Thurber, it's better to ask some of the questions than to know all the answers, and I hope, you know, before my career is over, we will actually be able to answer some of the questions as well. I just put this slide in just to remind you that there are a lot of resources that you can go to, and this is from the MCH library. It's a knowledge path on autistic spectrum disorder, and hopefully you all know about this particular resource. And they've got many of the pages, and quite a lot of information pulled together, focused specifically for maternal and child health professionals. Just very briefly, you know, we're all public health people. I frequently talk to audiences that are much more diverse than this, and like to put in something about why we do these kinds of things. But really, in terms of surveillance, from a public health point of view, what we're trying to do is

to describe the health status of a population by determining the rate or frequency of a disease or health condition, and then to try and understand what's responsible for it, what are the risk factors, what are the characteristics associated with it, ultimately to be able to pick the future of the disease, and as public health professionals, our hope is there'll be less in the future, maybe even none. And then of course, to use the information both to prevent disease, to reduce severity, to diagnose earlier, and lead to better outcomes for those individuals who may have a particular disease. So, you might ask, well, why is everybody so interested about autism and autistic spectrum disorders? And there's a number of reasons why that might be so. You know, they're very definitely is public concern that the prevalence of ASD is rising. We see that all the time in the media. There are fears about certain kinds of exposure, especially certain kinds of vaccines. The MMR notably. There are newer diagnostic tools, and newer approaches that can potentially make a diagnosis for ASD earlier than we used to be able to 10 or 15 or 20 years ago. Another reason is that the federal department of education modified the exceptionality categories for special education in the early-1990s, so that now there's a specific category for autism, and as you know, nothing will increase the prevalence of a condition more than having specific programs that people are eligible for if they have that condition. You know, I don't know whether that's, you know, directly a cause of the increase, but it's certainly something that happened. Then there's a lot of political pressure that was put on Congress first to fund a study in a community in New Jersey called Brick Township. And more recently, for funding for a more

comprehensive public health surveillance and epidemiology program at CDC, and even more recently, there's a lot of activism right now on Capitol Hill to do something vastly more comprehensive that will include, you know, basic science and, you know, NIH kind of funding, as well as more funding for the public health activities. So, in terms of the reported prevalence of autism from the 1980s to now, I'd like to mention these three early studies, you know, that identified the prevalence of autistic disorders as being around .3 or .4 per thousand in part because I'm the first author of one of these three studies. And, we did a study looking at the prevalence of developmental disorders in children under the age of four in an area in Arkansas. We didn't access any psychology, psychiatry clinic records. You know, we basically got all our data from health sources. And not surprisingly, we didn't find very much autism in our study. And there were two other studies that were similar in terms of that. There were other studies being done in the 1990s, particularly in Western Europe. Scandinavia, France, England among others, that were finding a prevalence that was quite a bit higher. And for, you know, classic autism as much as one per thousand and for the whole spectrum of autistic spectrum disorders, you know, perhaps four to five per thousand. That was going on in the 1990s. And so, when CDC did the Brick Township study, which was done in 1998, they did a very comprehensive study. And they actually tried to identify all cases by doing an initial evaluation of all the children, and then having those children who met certain criteria actually evaluated by a multidisciplinary team of specialists. So they did very comprehensive assessment. Not the kind of thing that we typically are able to do

in a public health setting. And in this particular study, they found the prevalence of autistic disorder at four per thousand and of autistic spectrum disorder at 6.7 per thousand. Now if you do the math on that 6.7, you know, you'll get that number one in 166 that you frequently see in the media. What they forget of course is that there is a 95% confidence interval around that. Anyway, we have had a number of studies that have been looking at the prevalence of autism. I'm going to talk in a few minutes about the very recent publication, I only have one copy of it, but if you log onto the MMWR website for the morbidity and mortality weekly report surveillance summaries, this was published on February 9th, and has the results of our comprehensive surveillance in a number of sites around the United States. But I'll give you more details about that in a few minutes. But there definitely has been an upward trend in the number of children receiving services for autism in the United States. And I'll show you some data in just a minute. So, has autism always existed? It's always an interesting question. We don't really know. But probably it has. If you read the medical histories or, you know, text, you know, dating back to the 1800s, you will read descriptions of cases that sound sort of like it. But, again, they didn't do the kind of evaluations that we can do now, so we don't know. But the original characterization of autism was done by Dr. Leo Kanner in 1943, and the very next year, Dr. Hans Asperger identified the condition known as Asperger Syndrome, which we now think of as what you might call higher functioning autism, individuals who typically are of relatively normal intellect, but have, you know, severe social functioning problems. And people with Aspergers are frequently quite able to function within

society, once they have appropriate education. So, again, the concept of autistic spectrum disorders has been evolving over the past 30 years. There's a condition called Rett Syndrome, which is a genetic disorder, which affects almost exclusively girls. It's a neuro degenerative disorder, that used to be thought of as part of the autistic spectrum and now is not. Now it's thought of as being outside. But anyway, there's been evolution of these ways of thinking over time. And this is a graphic just to show in terms of data from the Federal Department of Education, in terms of numbers of children with an autism exceptionality and what's been happening with that over time. And if I've added the more recent data points, the trend line that would be pretty much going up at maybe not quite the same rate, but still rising in the last few years. So you're looking at basically approximately a 10-fold increase in the number of children in the school system with an autism exceptionality from the early 1990s to present. So it's a fairly dramatic thing.

But I'd like to show these graphs, which show this much more effectively. This is a series of graphs that were published by Craig Newschaffer in pediatrics about two years ago, and what he did in this particular study was to take the Federal Department of Education data. Now, how many of you are familiar with public education data systems? A few of you are. But, you know, there's something they call the December 1 count, which is kind of like a school census. And all school districts are required to report to their state, and then it all ends up eventually in a federal database. And there's reporting both for children in regular

schools as well as children in special education. And so what Craig did was to take those data for approximately 20 years, and put them together in a way that you can look at the relationship between age period and cohort. And so what these graphs do is they show by birth year, they show the trend in the prevalence of peer autism and then in subsequent graphs, some other conditions. So each of the color distributions is the cohort of children as they go through the educational system. And of course, what's interesting is that it's a pretty linear kind of a trend, as you go from basically the oldest children, who only have one data point in this data series, and then the youngest children are the ones up there, who only have one data point because they're just entering the school system. And you can see these things are all parallel. The slope's almost identical, meaning that as children age, the rate of increase in the prevalence of autism is not changing. But the overall prevalence is changing fairly dramatically, particularly when you reflect upon the fact that it's a logarithmic scale. So it's at least an order of magnitude increase over this approximately 17-year period. So that's what autism looks like. But if you look at some other, here's speech language impairment. And the lines are almost right on top of each other. So there's basically been no change in the overall prevalence, you know, by age across Brick cohorts for speech language impairment. Well, here's mental retardation. Again, you know, there is, it's a little, there's a little bit of a pattern that you see. But, if you look at the data really closely, the interesting thing is that it's actually gone down. These are older cohorts and these are more recent. And the prevalence of MR is going down and we don't know exactly what's going on

with that. It's very possible that you could have some reclassification from MR into autism, might be part of a little bit of it, but overall it's not a huge difference that you are seeing across the nation. And then of course, some other health impairments. And this is, you know, there's all kinds of things included in this one. Oh, I wanted to mention one other thing with MR. It's a widely known pattern with MR that as children get older, the prevalence of MR declines. Okay, and you can see that here. You know, when you get up. It usually keeps on entering (inaudible) at 14 and then it declines a little bit. Not a lot, but a little bit. And that probably has to do with children dropping out of the school system or going into other kinds of programs and so on. Probably not really due to the actual prevalence of MR decline. When you work with these administrative data, you have to be very circumspect about how you interpret the information. But, you guys all know that because you work in public health, right? Yeah. So, anyway, other health impairments as a variety of things that are included in that category and, you know, it's an interesting category but it's hard to know exactly what it means because of the, you know, the diversity of conditions that are included in that category. And that dramatic brain injury, this one is, you know, I'm very, well, let's just say I don't have an explanation for why this last year is all of a sudden shooting across the whole age distribution for TBI. But it's not something I've specialized in, so I don't know if they might have possibly had a change in definition that just occurred in the most recent year and this data set that's causing that to happen, but I don't know for sure about that. Okay, so those are just a little bit of background in terms of what we know from administrative data

on the prevalence of ASD. So CDC has been involved in a variety of activities in recent years, starting with analyzing some of the national surveys. You know, the National Health Interview Survey for example. They've also done some work with the National Survey of Children's Health, and other representative sample surveys. They've done the Danish collaborations, they've did the Brick Township Study. They've been doing surveillance in Metropolitan Atlanta for a number of years. And they've recently funded a collaboration, which is the project that I and my two colleagues each were involved in, called the Autism and Developmental Disabilities Monitoring Network, or ADDM. And they also have been trying to get together a project to look at early ASD surveillance, looking particularly at children in early childhood. They have not secured sufficient funding to do that as well as they would like. So, if we look at data, you know, asking yourself the question of, you know, what kinds of major disabilities in childhood are more common, well, these are data from Metropolitan Atlanta, showing that among eight-year-olds in Metropolitan Atlanta with 1996, that, you know, autism is one of the more common of the major developmental disabilities, second to mental retardation. And it's possible, by the way, for some children to have multiple disabilities that you could occasionally see a child with cerebral palsy who also has autism, and more frequently, children with CP will have neurosensory impairments as well, and potentially MR as well. Okay, so anyway, the previously reported summary data, you know, prior to the Adam network suggested that the prevalence of autism was one in 166. And the more recent data, which is what was, I borrowed these slides from a CDC presentation on the day this was

announced, which is why it says the data reported today. It should say the data reported last month. Again, using the same kind of methods that Metropolitan Atlanta has used, the ADDM Network has a number of different sites that are all using the same methodology to identify cases of autism, ASD, and other developmental disabilities. And using comprehensive methodologies, it's a very rigorous approach that involves some identifying all potential, I'll go on to the next one 'cause it probably says some here. But it basically involves all of the potential places where diagnoses or evaluations of ASD might be made, reviewing the records, compiling them into a common database, and then having blinded of clinician reviewers review that material and make a determination of whether a particular child is classified as a case. And so it has a number of different features. You know, trying to come up with as complete a account as possible, to come up with comparable estimates so that we can compare across areas and try to find out whether there are socio-demographic or cultural other factors that might influence the prevalence of autism. Also to look over time by conducting the studies in the same jurisdictions at different time points. And then, also to improve the consistency of identification people with ASD's. And one of the things that most of the projects fund are train the trainer activities to teach people who work in developmental pediatrics, developmental psychology, and other settings where they do primary care for children, how to identify warning signs that that child might have a developmental delay. So anyway, the first phase of the ADDM Network had 16 sites, and looked at ASD MR, and a few of the sites, CP, among children who are eight years old. And then there were a

couple of other sites that used different kinds of methodologies which were evaluated in this phase. The new phase, which is just starting, will have 11 sites, again using the same methodologies so that we'll be able to compare data over time. So this just gives you a map that shows the areas where these programs are to be found. It is a little bit misleading in that very few of these programs are statewide programs. Metropolitan Atlanta is in five counties. The Arkansas program actually was in five counties. They were not one of the ones that was refunded. The Utah program was, I think it was in metropolitan Salt Lake, which has about 70% of the state's population. The West Virginia program was statewide. But most of them are looking at smaller regions. You might be wondering, well, why is it that so many of these programs are in the Southeast? Well, that's just because of who applied for the grants, and who, you know, they had a competitive review and that's just the way it happened. It would probably be nice to have a program in Michigan or New York, but, you know, that, that didn't happen. So, in terms of the methods that we have here, it has to do with identifying potential cases at multiple sites, both educational and health, and then screening source files for information that might indicate the possibility of a developmental disability, particularly that might indicate ASD or CP, and then looking for standardized test scores for intelligence tests to look for MR. And then when there are files that are found that have those triggers, the abstractors review those and put the data in the comprehensive database. And then as I mentioned, the clinician reviewers review the records to determine whether the case is a confirmed or not confirmed case.

So then, a little bit about some of the results. In the 2000 study year, this just tells you some of the areas that were included in the 2000 study year. So there were, you know, Arizona, Georgia, Maryland, predominantly the Baltimore region. New Jersey, a few counties in Northern New Jersey. About half of South Carolina and all of West Virginia. And, those areas, you know, included about four and a half percent of all eight-year-olds in the United States. So it's not a large proportion, but it's diverse in terms of the extent. And in that study, they found that the prevalence of ASD among eight-year-olds was a 6.7 per thousand. But that ranged across the six sites from 4.5 per thousand in West Virginia to 9.9 per thousand in New Jersey, with the others having rates that were more, you know, similar to the average. They also found a gender discordance, which is something that we've known about for a long time, that there is a much higher prevalence of ASD among males, generally thought to be around three to four fold, but sometimes higher, sometimes lower in different populations. And that was confirmed in this study as well. This is interesting. A sizable proportion of the cases identified in each of these sites had never had an actual clinical diagnosis of ASD. But by putting together the information from all of these different sources, with more detailed information than most clinicians see because they just do the one evaluation, the clinician reviewers were able to make a diagnosis in a sizable proportion. And, you know, in my study in Alabama, I didn't get funding to do the 2000, but I'm in the 2002 data. And it was about 20% of our cases that had never had a formal diagnoses. The problem is, it's a surveillance

project. We're not allowed to contact providers, we're not allowed to contact families, you know, because of, you know, the rules of surveillance. But it's an interesting thing that we probably need to find a way to do a better job of piecing together this information so that families can get the diagnostic information about their children. And then in terms of the proportion network, wherein special education across these different sites varies quite a bit. And the proportion that actually had an autism exceptionality, you know, the highest is about 60% in Georgia and the lowest is around 30%. So that means that, you know, the numbers we showed a few minutes ago looking at the trends in autism, that's just for the children who actually have the autism, you know, exceptionality. So most children who have, or most children that we identified as having autism based upon the more comprehensive review of evaluations don't have, are basically not getting special education services associated with their autism. That's not necessarily a good or a bad thing. It's just an observation about the data.

Now in the 2002 study year, we had a number of additional sites, including Alabama. And these four sites were, including mine unfortunately, were the sites that were not able to get a FERPA waiver, to enable us to look in the school records. So our data were only from the information that was identified in health or mental health sources. Ironically, in Alabama, I think it's ironic, and I don't want anybody to go calling anybody in Alabama and telling them this, but ironically, because our early intervention program is in the same agency that runs our Children with Special Healthcare Needs Program, we were able to review the

early intervention records because that was not in the Department of Education. But in terms of, you know, direct school-based things, we couldn't. And then this shows the other states that were included in the study. And CDC's goal is to have about a 30,000 population. Some of them are smaller and larger.

So then, this study had about 10% of the US population over eight years old. And, we found, you know, the overall prevalence was fairly similar to what we found in 2000. About 6.7 per thousand. And it ranged, if you exclude my study where I didn't have the special education records, and New Jersey, which was the highest, the other 12 are all in the range of 5.2 to 7.6 per thousand, which is fairly consistent with the earlier data that we've seen, both in the United States and elsewhere. Okay. And this graph—yeah, that actually did show up okay. You can see, this shows where the information was being obtained from and what the overall prevalence estimates were. You can see that there's a pretty wide variation across the sites in terms of how much of the diagnostic information they obtained from education sources, how much they got from health sources. And unfortunately, you know, it varies dramatically. We don't know exactly why. It probably has something to do with the historic organization of schools and how they interact with healthcare providers in different states. Probably has a lot to do with how much funding they have for special education in different states, you know, all those kinds of things. But we don't really know. But anyway, there is a wide, wide variation. I did an estimate for Alabama, assuming that we, you know, just hypothetically assuming that we would have found cases at about the

average rate of the other sites that did get information from educational sources. And my prevalent, my adjusted prevalence estimate was right in the midrange of the other sites. Somewhere in the range of, you know, 5.5 to 6.5. So, but I don't know what that would have done. And again, as we mentioned, you know, boys are more often affected than girls across these different sites, with between three and seven boys affected for every girl. So that's a pattern that we see. In terms of race and ethnicity, in most of the sites, at least in the 2000 data, there was fairly similar prevalence for white and black children. However, in Georgia, metropolitan Atlanta, they had a higher prevalence for white children than black children. And in the 2002 data, there was, again, several of the sites that had a higher prevalence for white children than to black children. But in many of the other sites, it was very similar in prevalence. And the prevalence varied widely for Hispanic children. We didn't really choose our sites with a view to having large populations of Hispanics. And so there's a lot of variability that you see there as well. In terms of cognitive impairment, early delays, and agent diagnosis, between a third and a little bit more than half of the children with ASD also had cognitive impairment, typically defined as an IQ of less than 70. And girls were more likely to be cognitively impaired with ASD than boys in most of the sites. Although that's an observation that we are actually doing a more comprehensive analysis on right now, which is not finished yet.

We also found that the majority of the children who are identified, there was documentation in the record that a parent or a professional was concerned, you

know, prior to the age of three. But the median age at earliest diagnosis was, you know, 4 and a half to 5 and a half years old. And we know that, you know, there are now diagnostic tools that can make a pretty good diagnosis at 18 or 36 months. But, you know, the take-home message about this is, you know, parents are the most knowledgeable usually about their children. And when parents have concerns, you know, their providers need to be paying attention and doing something about it. Because we also know that the earlier that you make a diagnosis and put the child, actually, you don't have to make the diagnosis to put the child into treatment, but the earlier that they get intervention, again, typically the better the long-term outcome would be.

Okay. And then this, just, because there is this concern about is the prevalence rising that compared for the six states that had data for both 2000 and 2002, and this is what you get for the comparison, basically, there is not compelling evidence that at least among eight-year-olds, that there's been an increase in the prevalence from 2000 to 2002. All of these rate ratios are hovering right around 1.0. The one for West Virginia is a little bit higher. But even that, you know, could very well again have to do with the fact that in West Virginia, they have a Center for autism that was just gearing up, and, you know, potentially was, was doing good work. Possibly. But anyway, there's not compelling evidence that the prevalence increase from 2000 to 2002 among children who are eight years old. Okay, and that says what we just said. So we'll continue on. Actually, I think I'm going to just continue along with that. Just a couple of summary things. And then

I have some information from, from some of the, you know, particularly from Utah and a little bit from West Virginia that I'll share. We don't know the causes of ASD's. Firstly, it very well is potentially a multitude of disorders that are still being clumped together as one. We don't really know that. It might be one. But, you know, we don't have specific evidence about that. It's probably due to multiple complex genetic and environmental interactions. There have been a few very specific genes and the wheels that have been identified that people think are associated with autism and they've been able to find linkages. But nothing that gets anywhere close to even 1% of cases. You know, it's still a very big black box in terms of what the potential role of genetics is. What we do know however is that the recurrence risk for ASD, you know, in a family, defining a family as a mother and father who have multiple children together, the recurrence risks in the studies that we have ranged from three to eight percent. And so if you think about an overall population risk that's somewhere in the range of six to seven per thousand, well, three to eight percent would be in the range of 30 to 80 per thousand. So it's probably somewhere's in the range of a five to 10-fold greater risk of recurrence. So that again is pointing toward something having to do with genetics. But again, it's still something we don't know a lot about. What we do know is that this is a scenario that we probably need to pay more attention to, we probably need to do more comprehensive research, particularly being able to understand the impact of perinatal and environmental factors as well. And hopefully, the research will continue. And I do applaud the funding for basic science research as well, because that's where we're really going to eventually

tease out the contributions of genes and environment. It's probably going to require more of a genomic epidemiology perspective. It's not going to be single genes. It's going to be probably a very complex set of interactions that are involved.

Okay. And I think that said just about everything else there. Another thing, you know, I have some data from Utah where they make some estimates of how much it costs to do the surveillance that we're doing. One of the reasons why we probably don't have as many of these projects as we might is because it's very expensive. And I can tell you, just from my own project in Alabama, looking at the northern half of Alabama, my grant's about \$350,000. I think it's 340 the current year. We get cut back just like everybody else does, you know. And, you know, for our 2002 study year, we found 116 confirmed cases. And we spent that, in the first three years, we had probably about \$950,000. See, and plus we also were looking at CP, and we found, you know, 130-odd cases of CP in that time as well. But if you think about that on a per case basis, that's quite a lot. If you think of it on a per berth in the study area, it's not so much. You know, maybe \$30 per case. But if you think about it in terms of per case actually identified, it's quite a lot. So again, don't go calling up your congressman and telling them how much it costs to find cases of autism. Tell him instead that we desperately need to find the causes and we need more funding to do this kind of research. So some of the things that are positives about the ADDM approach, you know, it's a collaborative multi-site surveillance system. We've got pretty much all of the top pediatric

epidemiologists who are interested in the epidemiology of autism in our group. And the ones that we don't have, we have found ways to bring in as consultants. You know, people like Eric Fombone and Cathy Lord, and people like that. And so, it's a very strong research group that we have. We have a methodology that can be applied to large populations. It's a multi-source case ascertainment approach. It has a very rigorous quality control at a number of levels. I had to let one of my abstractors go because she couldn't meet the CDC expectations in terms of the quality of her abstracting. And those books, and we've had some issues with some of our clinician reviewers too in terms of that. So it's very rigorous at all levels. It has the potential to be expanded to other developmental disabilities, and in many of the sites they're looking at mental retardation. Several of the sites are looking at cerebral palsy. And one of the sites is looking at epilepsy in early childhood as well as ASD. And we have dedicated teams that work closely with partners. We do definitely have challenges. And being able to access education records is a huge problem. I personally think that, you know, in public health, that we should be doing a great deal more partnering with education on a number of different levels. And I've got some slides about that that we'll maybe get to later. But, you know, all, education and health are one and the same thing when we're talking about children. And to divide that up artificially and not think that it's something that we should be concerned about in maternal and child health is going to be missing a lot in terms of, you know, the positive outcomes that we're hoping for for our children. Again, we have a network of sites with funding and competitor process. We also have very ability in

accessing and the quality of the information that we find in the different sources. You would think that there would be standards in terms of how clinicians do evaluations for developmental disabilities. And there are sort of, but there's quite a lot of variation in how complete and detailed the records might be. You know, when our abstractors go to the Sparks clinics at the Civitan Center at UAB, you know, the files are like, (laughs) you know, huge, with all kinds of details. And other places, they might be just a few pages. We also have issues with, you know, the fact that we're looking at data for one calendar year in the study. We're not able, for example, to assess, you know, the impact of an additional year doing a prospective study. It's done as a series of cross-sectional studies. And that would certainly be helpful to improve on. And then again, it's also a study that takes a bit of time. We're just publishing our data for 2000 and 2002 last month. When you look at the calendar, it's 2007. And, you know, one would like to be able to do that more quickly. But it is very difficult to get the information compiled more rapidly. And then again, we need to continue to validate the methodology. And we actually do have an evaluation paper, you know, included in the surveillance summary report. They've also funded centers for autism and developmental disabilities research and epidemiology. And that project has a case cohort study that they've been looking at, which hopefully we'll have some results fairly soon as well. And then as I mentioned, you know, learning the signs and acting early, which is obviously one of the most important—we didn't have to do our study to be able to say this, but it's nice to be able to validate that we need to do significantly better in terms of making sure that children get routine and

comprehensive developmental assessments, and that when there are problems identified that we are able to refer them to appropriate specialists where they get the services that they need. Okay. I think there is a booth about Act Early that you can go and look at if you want to. Okay. So ASD, again, it's an urgent public health issue that affects children. And it's something that we are really just beginning to get a handle on, and have a lot of additional work. I wanted to just tell you a little bit about some of the more details from our Alabama project, beginning with, it's not the whole state, but I have pretty much the northern half of the state. Again, if you want to call up a congressman and ask him to give me another \$300,000, I'd be happy to do the rest of the state. But, and people in Alabama would be very happy if I could, because, you know, particularly down in Mobile Bay, there's a lot of concerns about environmental issues and concerns that they might be associated with ASD that I can't really address. Again, so our goals are consistent with what are for the national project. We use the CDC design data abstraction protocol. It's very comprehensive from Microsoft access, database, called Archie. It's now Archie V 3.1, I think it is. You know, they keep coming up with new versions of it. We also have funded several conferences where we've brought in the trainers for First Signs and tried to educate pediatricians and other providers of pediatric primary care as well. We're looking at children born in 1994 residing in this 32-County area. In terms of some of the things that we've found, just give you an idea of some of the numbers, this actually isn't the absolute final number. Our final number of confirmed cases is actually 116. But what you can see too is that for every case that we confirmed to

this process, there was another case that was a suspected case that for one reason or another didn't quite meet the case definition. All of those children who are suspected cases have other significant developmental problems, but they didn't meet the case definition for ASD. You can also see for CP, the cases that we identified that really looked like they might be cases are much more likely to be confirmed cases for CP than they are for autism. Ironically, with the, you know, our prevalence of autism was much lower than the other sites in the study. Our prevalence of CP was dead on with the other sites in the study. You know, very similar in the range of three to 3.3 per thousand. So, we think that if we could access school records, we'd be able to come up with a similar level. We interacted with, you know, the Alabama Chapter of the American Academy of Pediatrics to provide them trainings and seminars. We worked with the Alabama chapter of the Autism Society of America. We actually fund one of their staff persons about 25%. We pay for their newsletter and use that as a vehicle for communicating with the families and members of the community as well, and of course do a variety of presentations around the state. And hoping over time to be able to increase referrals for ASD to special education by interacting with preschool and schoolteachers. We haven't done as much with that as we had hoped.

Let's see, is there anything here we haven't talked about? Okay, we talked about the sex ratio. We talked about that we haven't found major disparities by race or ethnicity. There are a few identified, but it's really not convincing. Higher

functioning autism, as it's euphemistically called, tends to be diagnosed at later ages. So, in our Alabama study, the fact that our median age at first diagnosis was about five and a half years, well, it's very likely that we missed a disproportionate share of the children who are at the higher end of the spectrum. And those again are more likely to be diagnosed at later ages. So our median age of diagnosis is definitely higher than five and a half, if we had had all the data. And then in terms of common comorbidities, you know, mental retardation is the most common comorbidity with ASD. But, many children who are on the spectrum do have other disabilities as well. And then I mentioned the recurrence risk is in the range of three to eight percent. And then of course since you all work in public health, you know that as soon as one problem is solved, another rears its ugly head. You know that. And, you know that we, so we've been able to improve these surveillance of ASD, but the next step really is to figure out how to crack this nut of improving early diagnosis. And that's really one of our key challenges. And we have diagnostic tools. I'm not going to say that they're perfect, or that they would be able to diagnose every child who really is on the spectrum in this timeframe. But we could certainly improve dramatically what we're doing.

So you have to ask yourself, "Well, what's the problem?" Well, you know, we've had years and years of advocacy, from many organizations, including AMCHP, trying to improve the usage of developmental assessments. I was looking at one of the reports that was available out in the hall, about EPSDT, and comparing

states and their EPSDT programs, and the thing I noticed about it is that there weren't actually any data on how many children actually had EPSDT screens in relation to the number of children who were in Medicaid or eligible to have them, or for that matter what happened on the basis of that. And, it's great to promote eligibility for services. But we also have to find a way to make sure that they get the services and that things happen as a result. And we've got a lot of work to do. And again, First Signs is a very useful tool. It's not exactly free. It would be really nice, you know, if MCHB had funded the development of First Signs so that it could be available, you know, in the public domain. But it's not. But still, it's a useful approach that could be used. And again, another thing that we really need to do is to get into the curriculum of medical schools, of residency programs, and really, I mean, what's the deal here with training pediatricians about acute and chronic disease that requires hospital treatment, when that 98% of what they're going to do is really working with children in the community. We need to do a lot more with training physicians about that. And the importance of developmental assessment is just part of a larger problem. But we definitely need to work on that. And one of the things that we've learned from trying to get the pediatricians to come to our First Signs trainings, no matter how attractive we make them, it's hard to get them to come, that maybe a train the trainer approach, where we train specific staff from large clinics, and have them work with their colleagues, might be a more effective approach. I don't know for sure. Again, who makes the diagnosis? Well, it's a fairly specialized diagnosis, and it's typically going to be made by a developmental pediatrician or a clinical psychologist. It's not the thing

that just any pediatrician is typically going to feel comfortable making this kind of assessment. So then you ask, well, okay, how many developmental pediatricians, you know, UAB is a really big university. You know, we're one of the biggest medical centers in the entire southeast. We have one developmental pediatrician. And she's able to do an autism clinic—you know, unless she's on vacation—for four hours every week. And she's got a waiting list that's six to nine months long. You know, so that's, that's one of the issues that we definitely have to deal with, is improving the number of trained providers who can make these diagnoses. And then we have to look at the other side and make sure that there are, you know, programs for the kids so that they actually get effective interventions as well. So you have to think about that, and, you know, as you're thinking about autism where you're from, you know, think about how many providers are there and what might you be able to do from a public health infrastructure point of view to improve that situation, 'cause it probably is a problem in most communities across the United States. And then again, you know, lag times for appointments and so on. So then I ask the question, how might we integrate disability surveillance into Maternal and Child Health. And some of you guys know me. I'm the guy who has all these crazy diagrams. And, you know, this is my diagram for how to integrate perinatal data sources. And everything I can think of, you know, in terms of potentially population-based data that you might put together, and how you might link those things in with other kinds of sources. I don't want you to spend a lot of time looking at this. I'll just make the point that everything that's on this diagram is being done in at least one

state, or was being done in at least one state. Some of the programs are not still in existence. But there's no state that's doing all of these things by any means.

But what I wanted you to look at is this diagram, which is my evolving diagram for looking at how we might put things together to look at Child health growth and development. Okay? And I've got the box up there for developmental disability surveillance. It has a link, the orange arrows that are actually coming from the first chart go back to birth defect surveillance, that we need to be able to integrate birth defect surveillance with developmental disability surveillance.

There is a huge overlap, depending on, you know, for specific developmental disabilities, there can be as much as a 40 to 60% overlap with birth defects. And we need to think of those together. But really what we need to be doing is to be thinking about Child health on a population basis. And it's wonderful that we have national surveys like the National Survey of Children's Health and the National Survey of Children with Special Healthcare Needs that give us a broad picture, give us a lot of information about family contacts and social demographics. We also need the surveillance system so that we can put together what's going on a population basis, and be able to link that back to specific communities. And the way to do that is by having a common database that basically records all the children in our jurisdiction. And the reason this is called the KMF or Kirby Master File, it goes back to a meeting that I had about 1987 when I worked in the Wisconsin Division of Health, and our administrator had called us all together to talk about how to link databases. And I opined that there should be a master file.

Well, the idea with this is that it would start with the birth certificates. But you have to find a way that you can account for children who might be moving into the community, because the fact that they weren't born in your community doesn't mean that you shouldn't be concerned about the conditions that they have, and so you have to find a way to create some kind of a dummy record for that. Or you could do another one of my pet projects and, you know, the National Birth Index. Anybody heard of the National Birth Index? No? Didn't think so. It doesn't exist. (laughter) but it certainly makes a great deal of sense to me. You know, if we have a National Vital Statistics System, why couldn't we have a national repository of all of the births that occur in the United States that have the ability to be linked with other kinds of sources. There are some national security aspects to it that would be very beneficial as well. You know, fraudulent obtaining of vital records documents would be drastically reduced if we had a National Birth Index and that was the place that each state had to go to make sure that the person that was applying was, you know, was alive and appropriate and so on. Anyway, that's an aside. What we need to be doing though is to be thinking creatively about how to bring in our educational data sources into our thinking about public health. And one of my pet projects is to bring the United States into the 20th century, where all of the other Western countries have been for a long time, and actually have a mechanism for evaluating children's readiness to learn when they enter school. And that would be a data collection system that would evaluate a variety of domains of Child health, including, you know, health status, immunizations, and those sorts of things. But also on, you know, parental

assessments of the child's health status, information about whatever specific kinds of health disabilities or impairments or issues they might have and, you know, just a few that come to mind are obviously things like asthma and other respiratory illnesses, potentially hearing impairment or other kinds of things like that. And also, some assessment of how likely the child is, really, to be ready to learn to their full potential when they enter school. And pretty much every other Western country has a similar kind of thing. In this country, you just have to show a potentially fraudulently completed card that shows that you've had immunizations, and that's all you need to do. And that's a problem. Likewise, we should be looking much more closely at special-education data much more so than the kind of things that I've shown you on these, you know, these global kinds of analyses. But, you know, we should, you know, special-education data is a very important source I think for looking at issues in the child health population. And then of course, bringing this back home, we need to be able to be building comprehensive children with special health care needs a databases, that allow us to look at the population that we're serving and evaluate, you know, what kinds of positive benefits are being achieved from participating in those kinds of programs.

And then, of course, other administrative data I have here, you know, it never made any sense to me that we stop linking death certificates when the children get to be one year old. You know, there's hardly any of them that died beyond the age of one. How easy would it be to link them up to the age of 10 or 14 and

so on. So then, new opportunities or perhaps, you know, old and new and borrowed and blue, we know what we need to do. You know, we need to have more provider education, have more providers, we need to have parents who are more aware, we need to promote early identification, we need more and wider availability of programs and services. We need to be able to offer things to parents when their child has one of these disabilities. We clearly need more research on effective intervention. You know, families are grasping for anything they can find, and there's a lot of quackery that's going on out there. And it would be nice to be able to offer parents alternatives that are really effective. And we need more research to learn what those are. We also need more research in epidemiology, basic and clinical research, and ultimately, leading not only to secondary prevention, but actually being able to prevent ASD from occurring at all. So this is, I've got more slides here, but if anybody does want to get in touch with me, I'll leave that up for just a minute. My e-mail address is there and I'm quite happy to talk with anybody who might have an interest. And then, I've had some things handed out from Utah and I've got some slides from Utah that look at some of the activities they been doing with their program, you know, specifically working with communities and working with providers and so on. And then I have also a little bit about West Virginia, where they've actually made ASD a reportable condition and some of the things about how they've gone about that and not so much on how it's working yet. It's only been a couple of years, but that's something that potentially could occur. Okay. Everybody who wanted to jot that down has it down? Okay. So, in terms of the Utah Registry of Autism and

Developmental Disabilities, again, in Utah, they have the same kind of pattern of increasing prevalence in the school data that we've seen elsewhere. This chart shows the trends in terms of prevalence across the 2002 sites. And you can see that Utah had one of the higher prevalences among all of the sites. They selected a few just to show the prevalence in males compared to females. And it turns out that in Utah, there is a sevenfold excess in males compared to females, you know, compared to other sites that are in the range of three to four. In terms of prevalence by race or ethnicity, you know, they actually found a higher prevalence among white non-Hispanics. Now, you have to remember in Utah, pretty much everybody is white and not Hispanic. You know, they're starting to get, some, you know, immigration of Hispanic families into the community. But it's a fairly homogeneous population. In terms of parents identifying developmental concerns prior to the age of two, they found 89% of the cases had that, and we had 91 in the Alabama data. So fairly high. But the median age of diagnosis, you know, in Alabama it was five and a half years. In Utah, it was four years and one month. And again, those are much higher than we would like to see. In terms of loss of skills and children who are regressing as they develop, 32%, about a third of the children in Utah have that as one of the features of their condition. And then, this is a summary slide that compares studies sequentially from 1966 up to the present in terms of the reported prevalence per-- this is prevalence per 10,000. And you can see that if you fit a curve across this, I don't recommend that you do this necessarily. You know, just because you can get your data together and do an analysis like that, it doesn't necessarily make sense to do.

But they did. And they found that it looks like there really is a, you know, over time, an increasing trend in terms of the prevalence estimates in this worldwide literature. So then, ASD meets the criteria for a public health problem. It's got, its frequency has been increasing, it has lifelong aspects to the impairments that individuals who are affected have. Its costs are significant. An estimate for the United States of \$90 billion per year in 2000. It might be preventable. We don't really know. You know, we really don't understand the ideology to know whether it's preventable or not. People have certainly raised a variety of different hypotheses as to what might be associated with ASD. We do see disparities, and generally speaking, children of lower SES are more likely to be identified at older ages. And we certainly could remedy that kind of a disparity. What we do know is that early and intense intervention tends to improve outcomes. Although there are a variety of different interventions that have been developed, and they aren't all as effective as we might like. But children need to be identified in order to receive those kinds of interventions. And then in terms of public interest, it's obviously increasing. You know, the fact that this is a condition that's been on the cover of Newsweek four or five times in the last several years would be an indication of that. So then, how has doing the surveillance been beneficial? Well, this is a diagram for the model they have in Utah, that shows how they link this up. And they have connections both between their major medical education facility, the health department, both MCH and Children with Special Healthcare Needs, and the State Office of Education, and they have all of these linked together, and working together in this particular program, they were able to

access information from school sources and made a significant contribution to the overall prevalence estimates that they found. They also have collaboration across a variety of different programs within Maternal and Child Health, particularly linking with other special healthcare needs programs and birth defects, newborn screening, newborn hearing screening, but also linking, you know, the ability to link their information with other data sources that have a bearing on maternal and child health as well. One of the things that they did in Utah, I'm actually working on a similar study to this. I don't have results yet. But I've linked our records with birth certificates and generated a random sample of controls, and I'm going to do a similar analysis to what is being reported here. You know, they found a, you know, an excess risk of ASD among males. They also found some other things that, you know, they're interesting. I don't know what they mean. You know, an increased risk of, you know, or let's put it like this. Cases of ASD had significantly greater likelihood of being delivered breach, compared to the controls. They also were significantly more likely to have been delivered by primary cesarean section. These are just associations. I definitely wouldn't want to say that there is any causal relationship. They also found that children with autism were slightly smaller in terms of birth weight. About 140-gram difference. Again, I don't know quite what that might mean. They were more likely to have had assisted ventilation. I'm not sure quite what that means either. But, they didn't find any associations between autism and parity, autism and prenatal care, autism and entry into prenatal care. Those kinds of things were not found. And this, I think is, you know, in the Utah collaborative medical home

project, they have information specifically about autism, so they're trying to make those kinds of links as well. In terms of pediatricians and family practitioners who screen for behavioral and emotional problems, it's around 80% for pediatricians, a little less than 60% for family practitioners. They did a survey—in fact Judy sent me a draft of the paper that they did about that, to try to understand, you know, where they should focus their energies in terms of, you know, improving knowledge about developmental assessment. And then in terms of how many are familiar with screening tools specifically for ASD, they found, you know, of this 80% of pediatricians, while less than half of the pediatricians were actually familiar with, specifically with ASD screening tools, and virtually none of the family practitioners were. So again, there are some opportunities in terms of that.

I'm going to skip that. They've also tried to develop ways to collaborate, you know, with parents and families, and again, working closely with the autism Council of Utah, a parents' support group as well, and working on increasing public awareness about ASD with public service announcements, newsletters, various print media brochures, working with news media, and so on. And then this is an article that was in the Salt Lake Tribune right after the report was published. And again, you know, the future challenges that basically are very similar to the ones that I've already discussed, some of the things that are challenges have to do with health sources, you know, there are issues about HIPAA. In Utah, they've made ASD a reportable health condition. Doesn't mean that they necessarily expect all the cases to be reported. But, it makes it easier

for them to be able to access health sources, having it be a reportable condition. I mentioned FERPA, the Family Education Rights and Privacy Act, which governs some access to health information. Many of the autism surveillance projects were able to get waivers from FERPA for their projects. And in fact in Utah, they were able to get that. I was not able to convince the Department of Education in Alabama that the project should get a waiver. I'm thinking that now that we have data, and can show them what it looks like, we're going to, we actually have an appointment to go back in about a week and renew that discussion. And hopefully it will change. Okay. And then they came up with an estimate of the cost for doing the surveillance, and it worked out to about \$50 per child and the cohort that they were studying. But we also have to think about how much it costs to do an actual assessment of a child who is identified as potentially being on the spectrum. And for a comprehensive assessment, it can cost \$500 or more. It's, again, usually a multi-disciplinary assessment. It takes, you know, several hours and so on. Okay. And then they've also, with some help of a healthy economist, estimated some of the costs. You know, the lifelong cost per child with ASD estimated at \$3 million. Sounds like a lot. But by the time we're, by the time of my children are my age, who knows what the average income will be. You never know what these numbers actually mean. But it is significant. Okay, and then we have some references, which I'm going to skip too. And just, I've just got a couple more slides here about the West Virginia Autistic Spectrum Disorders Registry. And in West Virginia, they've also made ASD a reportable condition. They have a legislative role on this. And as of

January 1, 2004, ASD as a reportable condition of childhood, this is a copy of the diagnostic reporting form that the expectation is that anybody who makes a diagnosis of ASD will complete one of these and it will be sent to the registry, which is again, housed at Marshall University. And so you can see what kind of information they have. They've got what instrument was used, and what was the diagnosis, and, you know, some of the details about that, and then a little bit of additional qualitative information that can be reported as well.

If you're really interested in this, I think I actually have a Website. Well, yeah, right here. If you want to actually look at the website and look at the form in more detail, you can just go to marshall.avu.wvasdr and see that as well. So, I've rambled along for quite a while here without letting you guys ask any questions. Does anybody have a specific question? Yeah?

UNIDENTIFIED SPEAKER: I'd just be interested in knowing your opinion as to what potential the recently enacted combat and office (inaudible) holds, what promise you think it might hold for answering the questions on, two questions particularly. Causation and intervention.

RUSSELL KIRBY: Yeah. Well, you know, I haven't looked at all the fine print of that particular ad. But I think it's, I think it's going to be beneficial in focusing on, you know, federal concern about autism. I'm not sure quite what's going to happen in terms of the funding mechanisms as a result of it 'cause I don't think

that bill actually specifically made the appropriations. But it lays the groundwork for appropriations to be made across a variety of different federal programs. And, you know, what I haven't heard actually, and I don't know whether maybe Michael might have some information, or somebody from MCHB and a special needs, but whether there's anything in the Combatting Autism Legislation specifically targeting MCHB, I don't know. But that would, it would be nice to create an environment where we had that, but I don't know if that's been the case so far.

UNIDENTIFIED SPEAKER: One subsidy thing that I know it does is that enacting legislation requires each governor to name a lead agency in the state to interact with the federal government regarding provisions of the law. And to (inaudible) personal funding, which (inaudible) to the legislation at present. But at least (inaudible).

RUSSELL KIRBY: Yeah. I can tell you though, you know, I know the people around the Autism Society of America and there are several other major advocacy groups, and they are chomping at the bit to get appropriations, and will certainly be banging the doors of Congress real soon.

UNIDENTIFIED SPEAKER: I agree with that. And I do think the focus is a national attention, more than the (inaudible).

RUSSELL KIRBY: Mm-hmm. Yeah?

UNIDENTIFIED SPEAKER: When there is a collaboration between the public health departments and education as far as the surveillance, do they only use the primary diagnosis that comes from the schools?

RUSSELL KIRBY: Okay. Well, what we actually do in terms of doing the surveillance is, you know, the FERPA waiver allows the Project abstractors to actually, you know, abstract the entire special-education record, which will include whatever evaluation was actually done to determine, you know, if the child was eligible for a particular exceptionality. And so it's not just using the information, you know, at the, you know, the summary level, but again, using that as a resource to look at in relation to other clinical evaluations that we might have found.

UNIDENTIFIED SPEAKER: Now, that's good.

RUSSELL KIRBY: And see, a lot of schools, a lot of schools actually have school psychologists, either on contract, or possibly in a large school district on their staff, who might do these evaluations. But because it's covered as part of the child's educational record, without the waiver, we're not able to look at those. Whereas, if they went to a developmental psychologist for example, and it's a

clinical visit, you know, then, you know, under our project, with our, of course, we have IRB and all that, we are allowed to look at those records.

UNIDENTIFIED SPEAKER: And that's good because I'm starting to see a couple of the families I worked with in Missouri, the school districts are wanting to change the primary diagnosis from autism to MR as they're entering high school and on.

RUSSELL KIRBY: Mm-hmm. Yeah. Well, the interesting thing I've been noticing in Alabama as December 1 counts is that we are actually seeing a decline in the number of children with MR exceptionality over time in the younger ages. And some increase in autism. But not a completely natural, but the other thing to point out is, a lot of the kids, as I think I showed a chart about this, but a lot of the kids who are in special-education who have an autism diagnosis, according to our criteria, are not in the autism exceptionality. You know, they could very well be in speech and language or MR or some of the others as well. Did you have a question too?

UNIDENTIFIED SPEAKER: Yeah. My question is how does Aspergers play into all of this in terms of is it included in your definition of autism, and that (inaudible)--

RUSSELL KIRBY: Yeah. It's included in our definition of autistic spectrum disorder.

UNIDENTIFIED SPEAKER: But do you put it in the exceptionality category?

RUSSELL KIRBY: It depends. I think it depends. I think it--

UNIDENTIFIED SPEAKER: Is that state by state or--

RUSSELL KIRBY: Well, there are federal criteria, but how they get applied varies a little bit from state to state.

UNIDENTIFIED SPEAKER: 'Cause the other thing that (inaudible) it's my understanding that in Arizona, a (inaudible) pledges given a diagnosis of Asperger, (inaudible) look at our school records. They won't do this.

RUSSELL KIRBY: Yeah. Well, ironically actually, Arizona had one of the highest in terms of the proportion of all the records that were found only in school sources. Arizona had one of the highest, something like 90% of all the cases. Now they were just looking in the Phoenix metropolitan area, and, you know, I don't know whether there is a unified school district for the area, but, you know, there's a lot of complexities that enter into that. Other questions? Okay, we've got a few more minutes. And, if I can convince my computer to behave here, we're

going to play a game. Okay? And we're going to play a game called Autism Jeopardy. Okay. All right. And, you know, it's, it's not intended to be a competitive game. However, I do have some prizes. They're not, and I'm not allowed to have these prizes myself because they're candy, and I'm diabetic, so I can't eat them. But we have Tootsie Roll pops and we have Easter mints that, and I have a lovely assistant who's going to help me with this as well. But how this works is as follows. You know, it's going to be Jeopardy and you always have to phrase your answer in the form of a question. Okay? And, what I'm going to need is, if you think you know the answer to the question, I'm going to try to call on the person who was the first one to put their hand up, okay? And don't be bashful. It's, you're not going to lose anything if you're wrong. Some of the questions, most of the questions are questions that I covered in the lecture, but not all. Some of them require a little bit more specialized knowledge of autism. Some of them require more specialized knowledge of where we are right now, which is the federal capital region. Okay? So what we're going to do is we'll play this game. And I need you to help me both to help me spot who puts their hand up first, and then if they get it right, we need to toss them a piece of candy. Okay? So here's our five categories. We have autism epi facts. You know, the narrow interest in dates. CDC developmental disabilities, surveillance history, Who's Who in Autism, and then BD facts, or fiction. And I am not going to promise that the application's going to work perfectly all the way through because it's sort of degraded over time. But hopefully it will. So, I guess, I'm going to let you pick the first category.

UNIDENTIFIED SPEAKER: D.C. Facts or Fiction from (inaudible).

RUSSELL KIRBY: All right, so we'll click on that. Wait, that's not right. Okay. Oh. Okay, I knew this was going to happen. I'll find it. I'll find it. D.C. Facts or Fiction for a hundred is right here. Okay? Okay. So this, okay, there's an answer right, I didn't even get to say it. But it's an upscale neighborhood in the DC area that can't be reached by the Metro. And it has to be as a question.

UNIDENTIFIED SPEAKER: Where is Georgetown? Because they left it out of Metro.

RUSSELL KIRBY: That is correct. Where is Georgetown? Okay? Okay, now we'll see if the game goes properly from here.

UNIDENTIFIED SPEAKER: I used to work there. Right, at (inaudible).

RUSSELL KIRBY: Right. So, so give her a prize. And you could pick the next question. And maybe it will be one you don't know.

UNIDENTIFIED SPEAKER: Autism epi facts for 100 please.

RUSSELL KIRBY: Let's see if this works. That does. Okay, so this condition is the most common special-education exceptionality among eight-year-old children

with an ADDM diagnosis of ASD. What is, anybody? In fact, anybody? Most, most common exceptionality among children with ASD? Did I say here?

UNIDENTIFIED SPEAKER: What is speech and language?

RUSSELL KIRBY: What is speech and language? Let's see if that's what it is here. It's actually autism is the most common. Yeah. It's for 100. They get harder, actually. Okay, how about if we do autism epi facts for 200? Okay? So this one is, this condition is the most common associated DD among children with a diagnosis of autism. That, that (inaudible).

UNIDENTIFIED SPEAKER: What is speech and language concerns?

RUSSELL KIRBY: What is speech and language concerns? Okay. I'm not sure that's going to be right. What do you think? Speech and, what's that?

UNIDENTIFIED SPEAKER: Yeah. (inaudible).

RUSSELL KIRBY: What's that?

UNIDENTIFIED SPEAKER: Social concerns.

RUSSELL KIRBY: Social concerns. Okay. Well, it's actually (inaudible) is the most common. Okay, we're gonna, you know, don't all you guys leave, 'cause I'm not taking the candy home. So I expect you guys are going to take that anyway. So we'll do 300, okay? Okay. So, this one, you had to be really paying attention to the information about the Metropolitan Atlanta program as to which developmental disabilities are monitored only by Metropolitan Atlanta. Remember, in addition to autism, the conditions that might be monitored are cerebral palsy, epilepsy, mental retardation, hearing impairment, and vision impairment. Yeah?

UNIDENTIFIED SPEAKER: What is epilepsy?

RUSSELL KIRBY: What is epilepsy? That's not quite right. Actually, actually there is one other site that does, but there are two of these conditions that are only monitored by Atlanta. Anybody want to take a guess? Okay, yeah?

UNIDENTIFIED SPEAKER: MRCE?

RUSSELL KIRBY: MRC, no. Okay. It's actually vision and hearing are the ones. Okay, well, okay, so, these conditions are the most common early childhood clinical diagnoses in children later diagnosed with ASD. What are--

UNIDENTIFIED SPEAKER: (inaudible). Speech and language?

RUSSELL KIRBY: Speech and language. Could be. Okay. It's actually usually more general than that. But, you know, I mean, I have a Top 10 list of the 10 best ways to misuse hospital discharge data. And one of the best ways to misuse it is to have another category that is the top of the list. And it would be better to have that broken down for sure. Okay. In the interest of time, let's do some of the dates. Okay? So, the Austrian psychiatrist, Hans Asperger first characterized this disorder in what year?

UNIDENTIFIED SPEAKER: What was 1944?

RUSSELL KIRBY: Okay. We have a correct answer. Nineteen forty-four, yea. Okay. Do you want to pick another category?

UNIDENTIFIED SPEAKER: Who is Who in Autism ASD History (inaudible).

RUSSELL KIRBY: Okay. He was the first physician in the United States to be identified as a child psychiatrist, and his book, Child Psychiatry, was the first English language text looking at psychiatric problems of children. And we did talk about him, but not about this in the lecture. So who is, okay. Well, we talked about Asperger, but there was another guy who was important in the history of autism too.

UNIDENTIFIED SPEAKER: Dr. Kanner?

RUSSELL KIRBY: Dr. Kanner. (applause). And just as a bonus question, what year did he make the first characterization of autism?

UNIDENTIFIED SPEAKER: What was 1943?

RUSSELL KIRBY: Nineteen forty-three. Okay. Yeah. Yeah, maybe we should do another date. Since she knows, want to do 200?

UNIDENTIFIED SPEAKER: Sure.

RUSSELL KIRBY: Okay. Okay, so the first Metropolitan Atlanta Developmental Disabilities Prevalent Studies focused on this birth cohort. It's a little bit of some trivia. It's probably not that important. Do you know?

UNIDENTIFIED SPEAKER: Nineteen ninety-two?

RUSSELL KIRBY: Nineteen, it's not actually 1992. It's a little earlier than that. Do you know? No?

UNIDENTIFIED SPEAKER: The first ones?

RUSSELL KIRBY: Yeah.

UNIDENTIFIED SPEAKER: It was three to 10-year-olds in the United States.

RUSSELL KIRBY: No, it was actually earlier. It was actually 1975 to '77. And they were looking, they were looking at a wide range of ages. Okay. How about we'll do D.D. Facts or Fiction for 200, okay? Now, these are all screwed up. See, what happened, (inaudible) well, what happened is when I, you know, I had a different version of the game--

UNIDENTIFIED SPEAKER: Right. You had D.C. Facts probably.

RUSSELL KIRBY: That's correct. I had Arizona facts. And so I copied these, I copied them from another, okay, facts and figures for 200. Okay. So, this region of Virginia in which Crystal City is located was part of the original District of Columbia. What is--

UNIDENTIFIED SPEAKER: What is Alexandria?

RUSSELL KIRBY: What is Alexandria? Is it Alexandria or is it Arlington?

UNIDENTIFIED SPEAKER: Arlington.

RUSSELL KIRBY: Arlington. Let's see what it says here. And it's actually Arlington County, which includes, you know, it's this little--

UNIDENTIFIED SPEAKER: Alexandria's down there.

UNIDENTIFIED SPEAKER: it's this little piece that's Alexandria, it's this--

RUSSELL KIRBY: Alexandria, it's this--

UNIDENTIFIED SPEAKER: I think he should get it.

UNIDENTIFIED SPEAKER: Give him the candy.

RUSSELL KIRBY: Okay, give him a piece of candy. Okay. Okay. These are all screwed up. We've got to go back, we'll get the next one here too. Yeah, this is what they call a beta test version of the game. And we found out that I needed to test it a little bit more closely. Okay. So recently, I might not know that Michael's going to know the answer to this. What was the name of that team that left after the 1971 season? Back there?

UNIDENTIFIED SPEAKER: Senators.

RUSSELL KIRBY: Who were?

UNIDENTIFIED SPEAKER: That's right.

RUSSELL KIRBY: The Washington Senators. Okay. That's right.

UNIDENTIFIED SPEAKER: Is that the second generation?

RUSSELL KIRBY: Okay. Who said that?

UNIDENTIFIED SPEAKER: So, is that the second generation?

RUSSELL KIRBY: Okay, so what do you think is the answer to this question here? What was the name of the previous major league team in Washington, D.C.?

UNIDENTIFIED SPEAKER: It's the second one I've learned from you in two years.

RUSSELL KIRBY: Yeah.

UNIDENTIFIED SPEAKER: Washington Senators.

RUSSELL KIRBY: Washington Senators. So--

UNIDENTIFIED SPEAKER: Last year in Miami, it was Bill (inaudible).

RUSSELL KIRBY: That's right. That's right. And then of course, the question of when and where were the Washington Nationals moved? Well, only time will tell. But, they certainly have a history. Let me just see if I can find the, since we're doing these, we'll do the D.C., wait, we need to do this one here. This one's a good one here. Okay. Why won't that come up? Okay. So, the presidential library of only one US president is located in the D.C. area. Who was—and I'll give you a hint-- President Bush, the first one, his is in Texas, and President Clinton's is in Little Rock, Arkansas. But there's one presidential library, and also, not very many presidents have presidential libraries. But there is one that's in the DC area. And I had to make these harder as we go. So.

UNIDENTIFIED SPEAKER: This is a hard one.

RUSSELL KIRBY: Anybody want to take a guess?

UNIDENTIFIED SPEAKER: Bush.

RUSSELL KIRBY: And it's not Bush. Yeah. Are you talking about the current president? Yeah, that's possible. Yeah.

UNIDENTIFIED SPEAKER: Woodrow Wilson. Couldn't say it.

RUSSELL KIRBY: How did she know that?

UNIDENTIFIED SPEAKER: Because (inaudible)--

UNIDENTIFIED SPEAKER: She cheated.

RUSSELL KIRBY: Oh, you cheated. Oh. Okay.

UNIDENTIFIED SPEAKER: No candy for cheaters.

RUSSELL KIRBY: All right. We can, you know, we're running out of time, but let's just do a couple others. Another one here. In what year, what academic year did autism become a specific exceptionality for special education? And I might give you credit if you're close.

UNIDENTIFIED SPEAKER: It was in the early-'90s.

RUSSELL KIRBY: It was in the early-1990's, that's right.

UNIDENTIFIED SPEAKER: (inaudible).

RUSSELL KIRBY: It was actually 1991. But there wasn't any data until 1992.

UNIDENTIFIED SPEAKER: I was gonna say (inaudible).

RUSSELL KIRBY: Yeah. Yeah. Okay, and then, another one here, okay, now, okay, what year did--

UNIDENTIFIED SPEAKER: We already got (inaudible).

RUSSELL KIRBY: You already have that?

UNIDENTIFIED SPEAKER: Rain Man. What is Rain Man?

RUSSELL KIRBY: But, yeah, well, Rain Man's the name of the movie, but when was the movie--

UNIDENTIFIED SPEAKER: (inaudible) the date.

RUSSELL KIRBY: You know it?

UNIDENTIFIED SPEAKER: Nineteen eighty-eight.

RUSSELL KIRBY: Nineteen eighty-eight? I think I'm, I think, I'm hoping I have it right, yeah, 1988. And then you already answered the bonus. So we're, okay. And then we'll maybe do one more that, okay. And this is the significant date in Adam Cadre history that has been a problem for us. Okay, and there's nobody here from the group that, it's not likely anybody's going to know this. But that was the date when CDC's FERPA Memorandum of Understanding expired, meaning that the past year they haven't been able to go to school records. Well, anyway, if you're interested in this, you know, I've actually made several other games. I have a Maternal and Child Health Programs and Policies game that my students get to play at the end of the semester. And also one for GIS, and who knew, and I, actually, I think I made one for Record Linkage too. But anyway, I appreciate your attention. I hope that I've given you information that's useful and also that you know how to contact me and my colleagues if you have other questions. And I want to thank you for your attendance. Yeah?

UNIDENTIFIED SPEAKER: I do have another question. You know, you mentioned the appearance of our Thirsting for Knowledge interventions that aren't—