

**Autism Report: “Unapologetic, unrelenting in pursuit of trying to find all the pieces of the autism puzzle.”**

**Interview with Dr. Walter Zahorodny Director of NJ Autism Study, Associate Professor at Rutgers.**

**Host: Wayne Rohde**

Wayne began by describing his experience with autism and how his 24 year old son Nick is affected. The focus of his talk with Dr. Zahorodny was autism prevalence and how it's monitored.

**Zahorodny:** *The system calls itself ADDM, Autism and Developmental Disabilities Monitoring Network.*

<https://www.cdc.gov/ncbddd/autism/addm.html>

*That's the system that the CDC established in about 2000, 2001 in order to create an autism monitoring system in the United States.*

*That occurred because they were attracted to study autism prevalence in New Jersey. Families living in Brick Township identified what they thought was a cluster of autism, a really high, unexpected level of autism.*

*The CDC did a thorough investigation, and when they did that, they realized that they really had no frame of reference. No one had really studied the prevalence of autism in a modern, epidemiologic sort of fashion.*

*The findings the findings in Brick Township were three times higher than expected. They said autism in that town was about six per thousand, 6.7 per thousand. That was quite a bit higher than what people had written about and the way it was described in medical textbooks and references.*

*New Jersey is a very interesting state because it's very densely populated and it's very diverse. We have a wide array of difference race and ethnicities living here and a very wide spectrum of wealth, really poor people all the way to the most poverty level communities.*

*We were really curious, that is my colleague Frank Desposito and I, were curious why is was, that in our practices at the New Jersey Medical School, we were seeing more and more children with autism.*

*I hadn't been in practice that long, but when I was in graduate school I was clearly aware of autism, but autism was what we would call a rare disorder.*

*It was perplexing to us to see why children with autism and their parents were coming to different specialists if it was such a rare disorder. We competed to join the ADDM Network.*

*The way ADDM Network was figured was based on a kind of typical academic grant writing process. They didn't choose the states strategically. They said, what states would be interested in doing autism monitoring using our approach, and could you do it? Could you get access to the health records and education records?*

*That was their model for doing autism case finding. [It] didn't focus on interviewing or diagnosing children, rather it went to evaluating the already available medical and health information and the school-based information.*

*The thinking was children with autism, by the age of about eight, are likely to be known because they've been to different specialists and been diagnosed possibly, most likely they thought. Or at the very least, they would be known and helped through their special education system.*

*The special education system comes into prominence when the child is three years old. A child with some difficulty learning based on a parent report can get evaluated, and in New Jersey those evaluations are very comprehensive. They involve a lot of specialists assessing the child from their different area of expertise.*

*I knew that we probably could have access to that information, and that the information would likely be high quality because New Jersey is a state which spends a lot on educational services.*

*I knew, having lived in New Jersey most of my life, that the public education system is comprehensive.*

*So we competed, and luckily, we were in the right place at the right time, and we started doing surveillance with the ADDM Network starting with the 2000 surveillance study year.*

*The Network back then was six states. These were states that were interested in conducting surveillance. They all should have had access or did have access to education records and health records.*

*We joined because we knew that there was more autism than people were thinking in New Jersey, and we wanted to be involved in the best way to identify if that's true and to describe the children who had autism.*

### **8:33**

*Autism is very heterogeneous. Some kids are impaired in many different ways or have learning problems and have other issues. Other children on the spectrum may have less disability or less evident disability, but we knew that nonetheless we wanted to be as accurate as possible in identifying them, counting them and then comparing them.*

*The CDC system had never been tried outside of Atlanta. That is this process by which you review children's health and education records, submit them to a panel of experts to get to the prevalence rate, but they did it there successfully, and then they applied the model to at first six states and then over time to more and more states that joined the ADDM Network.*

*The ADDM Network was unique and important because it allowed states, many different states, to use the same definition of autism, the same way of identifying who the children were who had autism across many states and in a very systematic and consistent way.*

*The CDC, I thought, had done a good job in figuring out that one couldn't just depend on children who had a diagnosis because some children with autism don't get a diagnosis until much later.*

*They had a good process by which, not only would you find those kids who had a diagnosis, but you could identify and count and characterize the children who had all the aspects of autism, but hadn't yet sustained a diagnosis from a practitioner.*

*I hadn't really appreciated that before joining the ADDM Network. To me, autism was a very striking neurodevelopmental disorder, and I knew that most of the time you could identify it or see it in children before the age of three, let alone eight.*

### **10:51**

*I thought by age eight every kid with autism would have been diagnosed. I said, gee, their approach is a little different; it's more demanding than what I had expected. I thought I could just access through some sequence of available information, data bases and the like, how many kids were diagnosed with autism.*

*But their idea was more sophisticated, and it involved identifying children using a special scoring process and experts who were familiar with autism, using that in a consistent way.*

*I was surprised because, indeed, we identified about another 20 percent, another one in five children with autism who had all the characteristics of autism according to the definition, but who had not been diagnosed. That was a surprise to me.*

**11:59**

*The other surprise was, and we agreed to do this over time—it wasn't just a one off, it wasn't just for the 2000 study year. We were committing ourselves to doing this over time, at least for five and they thought possibly even 10 years.*

*I wasn't so sure that it would be necessary to go through many cycles of autism surveillance because **I thought that autism was like intellectual disability or cerebral palsy or epilepsy. That is, once you estimate, the prevalence doesn't go up from year to year.***

*If you were to ask how many children have intellectual disability, it would be very much like what you would expect to hear 10 years before or ten years later. I thought autism was like that too.*

**13:04**

*Some number of children, and I thought it was higher than rare. I didn't think it was two per thousand, but **I had no idea that the count or the prevalence would increase.***

***I thought, well, the CDC will wake up after we do this two or three times, and they'll say, hey, you know what, autism was higher than anyone had expected. It's at this level.***

*And at first you might find some disparities based on wealth or race. Poor people might not get identified early or minority people might not get identified early, but then you'll just be reporting the same thing over and over.*

**14:00**

*I was definitely wrong. **Not only was autism prevalence higher than people thought, but over time, as we continued doing surveillance, it was clear that it increased.***

*Now when we did our first report, the one for the 2000 study year, New Jersey's rate was about one percent, 9.9 per thousand, which like one percent. And the rest of the Network was within the range of .5 to .6 per thousand. So we were higher than the other states, but we understood that the quality of the information in New Jersey records was probably better than in other states.*

*We were better, I think, at case finding because we have pretty rich education records and a decent number of specialists who see children with developmental disabilities, including autism. We were likely to have a higher rate based on that.*

*Afterwards I said, now that we've learned that the rate could be as high as one percent, everyone will be alert to the fact that this is really an important question or public health phenomenon.*

**15:32**

***When a childhood disorder reaches the one percent level, it's an important, significant disability or disorder. It affects many children.***

*I really thought that, over time, we would be finding, okay, New Jersey's rate continues to be one percent, and the other states' rates had increased to the level of one percent.*

*Over time, even in states with poor or less high quality information, over time awareness of autism would increase, and it would improve in those states. And lo and behold, I suspected, when we do—if anyone should do this at the ten year point, we'll find that autism is one percent everywhere. And it was one percent in New Jersey early on because we had better access to information and the information was of a high quality so we were more accurate.*

***So in reality, we kept tracking autism, and each time we looked, autism increased. We did not find a consistent one percent levels in autism. They kept increasing, and they kept increasing across the other Network states too.***

*In states like New Jersey—Minnesota joined the Network, I know you're from Minnesota now. I know Minnesota joined the Network later than we did, but Minnesota and New Jersey are somewhat similar in the sense that they have well developed special education systems and high level practitioners in the region. I would think that we'd get to similar rates.*

*But when I looked at New Jersey, Minnesota, Georgia, Arkansas, Arizona, Missouri, any of the other Network states, until very recently, New Jersey was always the state with the highest rate or the highest prevalence estimate.*

*We kept, I would say, 25 to 30 percent higher than the average, than the other states in the Network over time.*

**18:08**

***That was perplexing. Perplexing because we don't really understand what's driving these rates.***

*The CDC created a system which would, I think, reliably capture all the true cases of autism, even those without a diagnosis without being misled by false cases.*

*So the system is very detail oriented and rigorous and requires a lot of manpower and hours of analysis and comparison.*

**18:45**

***It is a highly robust and accurate system. We could really identify no specific reason why autism prevalence increased, not only in New Jersey, but in every other state in the Network.***

***And it increased for boys and for girls. It increased for white, black, Hispanic, Asian children. It increased across every state.***

***And we were maintaining the same system, the same definition, the same case finding.***

***Now some states didn't have the same access, the same quality of information as New Jersey. There were some states in which the investigators could never look at their education records, which would of course limit their accuracy and completeness.***

*The education system is where the kids with autism get the most intervention and the most diagnostics, and if your state can't look at education records, guess what? You're underestimating a lot.*

*I was not concerned so much that New Jersey's rate was higher. I knew that we didn't have any specific toxic fears or contaminants. I didn't really have any idea about us having any environmental risks that were different. I just knew that we were good at case finding.*

*We kept the system going from 2000 through 2016, and in the 2016 cycle, as you mentioned, we already were aware of the shift from DSM-IV to DSM-5 criteria for autism, and we essentially did the whole surveillance using both definitions of autism.*

*The DSM-IV definition, you will recall, allowed for the recognition of specific types like autistic disorder, pervasive developmental disorder, Aspergers. They had well specified criteria, of course, to sustain that or to achieve that diagnosis.*

*DSM-5 got away from the idea of there being specific types of autism, and starting 2013—that's when the DSM-5 came into action—we've had this concept of ASD, autism spectrum disorder.*

*People had different levels or impairments due to autism spectrum disorder, but people stopped using those terms from DSM-IV.*

*The DSM-5 criteria are a little more narrow. I'm not going to go into the reasons why, but the number of specific features required and the pattern of required features is more stringent under the DSM-5 definition.*

*As you pointed out, people were questioning and interested in understanding **would the prevalence rate or estimation be affected by this shift from one to the other.***

***We did that in that report, we did it in the 2014 report. We did it in the 2016 report. The difference was about 10 percent, 10 to 11 percent higher prevalence under the DSM-IV criteria.***

***No doubt about it.***

**22:49**

***The DSM-5 criteria are a little more stringent. I'm not surprised that the yield, that is the number of identified cases was slightly lower.***

*It was slightly lower across the states but not so significantly as you would think.*

***There was a shift going as well because the DSM-5 criteria in the 2016 study year was less than the difference identified earlier.***

***Practitioners are probably shifting in some subtle way how they describe autism, that is how they detail it in their reports. Therefore they probably, on some level, get to a DSM-5 diagnosis a little later.***

***It's harder to get the DSM-5 criteria before the child is four because the DSM-5 criteria requires some appreciation of how the child relates to other children.***

***There are many circumstances when, before the age of four, you don't have objective information about that.***

***Some kids stay at home. They don't go to daycare. They don't go to preschool. The family has no frame of reference. Maybe it's their first child or whatever. There are many circumstances which make it difficult for that criterion of their social interests in peers to be satisfied.***

*That's what I really thought was being affected, not so much how many children have autism at age eight, but how many get diagnosed by age four.*

***In the world of the prevalence estimates of the ADDM Network, we've only seen increases.***

***Throughout that DSM-IV period, only increases. When we shifted to the DSM-5 definition, we also only see increases.***

***We now have a report, the most recent ADDM report only references DSM-5, and still the rate is higher than previous cycles of the Network.***

***The other thing I would like to add is that the ADDM Network method from 2000 to 2016 provided a lot of information and review, a lot of information about the characteristics of the children with autism.***

*We could report many interesting aspects, and I think that made the system worthwhile.*

*The system was very expensive and time consuming. It took us two years to complete a cycle, one study cycle of surveillance.*

*The process of the ADDM Network involves reviewing the information of every child born in a specific year, who lives in your region through developmental health centers, like medical centers and clinics, and through the special education system.*

*In New Jersey we have a four county surveillance region that encompasses over 30,000 children per cycle. We tend to focus on eight year olds, so these would be 30,000 eight year olds.*

*So there's a huge amount of information—*

*When we started this was all done by going to the school districts, and we have 76 school districts in our region.*

*Before you set foot in the door of a school, you have to satisfy many state level and local level criteria.*

*And then we have about a dozen clinical centers that we review information from.*

*So it's a huge amount of information that ultimately gets filtered down to cases that have some indication of possible autism. That might be approximately a third to a half of all the reviewed cases. Then go through like a scoring and analytic process by autism experts.*

*They use the CDC DSM criteria to not only see which cases have autism, but also what are the characteristics of those individuals who have autism.*

*We track only does the child have autism, but other co-occurring conditions are there? What was the pattern of evaluation and detection and diagnosis?*

*What were the placements of the child? Children who qualify for special education have different eligibilities and receive different programs. And if they enter the clinical health system, these children sometimes get treatments*

*like pharmacotherapy, drug therapy, like you said your son was prescribed something for ADHD I guess. Some Ritalin would have been in the picture for attention.*

*So we get that information, and it gives like a really deep picture of not only how many kids have it, but how impaired are they or how affective are they. What are the problems that are either addressed or not addressed.*

**29:26**

*So the system, I thought, was great, but time consuming. I'm pretty sure when the CDC had to report and justify, the reports would have stood on their own, but a frequent criticism was that the system is always a couple of years behind.*

*Why does it take so long to track autism?*

**Wayne then asked Dr. Zahorodny if it would make a difference if the ADDM Network surveyed the entire state of Minnesota and New Jersey instead of just a select few like they're currently doing. Would it be a more accurate picture of the true rate in that state? 31:30**

**Zahorodny:** *I thought about this a couple of times when we first started doing surveillance, that is the first 2000, 2002, 2006.*

*We have four counties. I looked at the county level to see whether there were differences. Theoretically there should be no difference because they're all in the same county, served by the same education systems and clinical centers.*

*There were differences, but they were not what I would call significant or meaningful.*

*But in 2016 when my colleague and I looked, we did find a very striking set of differences such that some counties had way higher prevalence than other counties.*

*In fact, Ocean County—*

*So in New Jersey we cover four counties. Essex, Hudson and Union are all contiguous, side by side, and they're in northern Jersey, right across from New York City. So they're in the heart of the New York City metropolis.*

*And our fourth county is Ocean County which is, as you would guess, down the shore, about 70 miles southeast of the rest of the surveillance region. This is a growth area. People used to live in Ocean County seasonally, for the summer, but the year round population was small until about 30 or 40. Maybe 30 years ago, people started to move and housing developed for people to live year round. Now some of the largest school districts are in Ocean County.*

***In Ocean County in 2016, while the overall New Jersey estimate was 3.2 percent, we found that the prevalence of autism was already over five percent in Ocean County.***

**33:52**

*I hadn't ever anticipated that. It was an unexpected finding. If you had asked me four or five years ago, how would you change, would you expand your system or shift it or contract it, I would say I would keep doing surveillance in Essex, Union and Hudson County because that's where we did it. We have a clear baseline. We have many years of experience there.*

*And that area, I think we understand it demographically, but I would drop out Ocean County because their rate was not really much different back say, in 2010. It was out of our region. We had to send researchers down there. Why do it if their rate wouldn't add anything? Or their information wouldn't add anything?*

*It was sort of a middle class region too. So we had other middle class regions. Why should we— maybe we should be more parsimonious, maybe we should just stick to those three counties.*

***Had we made that decision, we would not be in a position of identifying, in fact there's a whole county in the New York metropolitan area in which the average range of autism is five percent. We have in that county a school district, it's the largest school district in New Jersey, and the rate of autism there is seven percent.***

***We published a paper about that last year. It came out about the same time as the CDC report.***

***So, on the one hand you have the CDC report saying autism prevalence in the United States looks to be about 2.3 percent. That's what it is overall or average in the Network, and we're publishing a paper in New Jersey that says, hey, but there are very significant areas in which the rate is much higher.***

***It's not just a suburban thing. We also then looked at Newark, which the state's largest school district. It's a large urban district. Largest city in New Jersey is Newark. It's predominantly low income and minority. And their rate, that is the rate of autism in Newark, was five percent.***

***Is autism prevalence five percent in the United States?***

***I don't know, but I know it's five percent and higher in many places in New Jersey.***

***And I suspect that New Jersey is just the leading indicator. We will have and already are seeing that some states are showing prevalence—***

***Even in the ADDM Network report, California's reported for the first time. For the first time a site in San Diego joined the ADDM Network, and their first time doing surveillance, they identified the rate of four percent.***

***San Diego, California, four percent.***

***Newark, New Jersey, five percent.***

***Toms River, New Jersey, seven percent.***

***One in five towns in New Jersey, in our region, have a rate of five percent or higher.***

***This is where autism prevalence is.***

***If I were to say someone invited me a couple of weeks ago to talk on autism in 2022.***

***I said we don't really understand different about the risks or causes of autism, nor do we have better treatments, but certainly there's a lot to learn and to appreciate about how high the prevalence is.***

**38:30**

**Next Wayne asked Dr. Zahorodny about his comments on the increases in autism in Michael Smith's film, Autism: The Missing Piece. Is there an increase in the number of children with severe autism? Are we trying to normalize autism while ignoring severity?**

**Zahorodny:** *So severity and complexity are important and kind of critical aspects of the person's intervention and prognosis, I would say.*

*The network does monitor also the children's intellectual capacity or ability. Kids have IQ testing. And a child can have autism and have intellectual disability or could have borderline disability or could have average or above average IQ.*

*People are never quite sure that severity necessarily coincides with intellectual disability, but I would think that that's an important assumption to start with. That is, a child who has an IQ below 70, intellectual disability and autism requires a much more complex and demanding program, educational program, than a child who has higher levels of ability.*

*So over time, we've seen some shifting in the proportion of children who have autism with intellectual disability and without intellectual disability.*

***My colleague and I have a paper actually now that's under consideration for publication, and we have seen a pattern that both have increased. Children with intellectual disability and autism have increased, but children who have autism without intellectual disability have also increased.***

***If I might simplify, it's about—the number of children who have both has doubled since 2010, both disabilities, but the number that have autism without intellectual disability has gone up five fold.***

***The proportion of children who have autism without intellectual disability is much different than it was even 10 years ago. A greater portion of those kids on the autism spectrum have IQ above 70. IQ above 70 however isn't like a panacea or an indicator of good outcome. There's another 20 to 25 percent of children who have autism who have borderline ID, borderline intellectual disability, that's IQ between 70 and 84.***

*That means that the child has difficulty learning in a lot of different domains, and definitely does need intensive special education. **So those children have also increased over the period.***

*So we're in a situation where, is the glass half empty or half full? From my counting, more than half of the children, **close to 60 percent of all children have either borderline intellectual disability or intellectual disability with autism.***

***Is that good or bad?***

*Well that's hard to say. It's neither good nor bad, but definitely the group of individuals, children with autism that don't have intellectual limitations has increased a lot in the last decade.*

***We also have information about severity of impairment due to autism.***

***This doesn't get published by the ADDM Network, but some of our researchers are looking at this data in New Jersey because it is also an indicator of how much, how intense the levels of care or service needs are.***

***A child with severe impairment due to autism may have even good or excellent intelligence, but still have many intense deficits and problems that call for a lot of support.***

*I do know that autism severity is misunderstood by many people. Many casual observers of autism feel, think that we've only become better acquainted with children with mild impairment, and that that's the reason that autism prevalence has increased.*

*...We are finding more children with autism without intellectual disability, but that's not the only characteristic that makes for a positive outcome or a positive prognosis.*

*The picture has to be elaborated with the individual's specific pattern. Every kid's pattern is going to be slightly different, **but definitely the number with what we would have called Aspergers Syndrome is not the largest. It's not even an increasing aspect of the autism phenomenon, in fact.***

*It's not that we're just picking up those smart, but socially inept people. That's not what autism spectrum is. Even the DSM-5 diagnostic criteria specify that the individual has some significant impairment that impede their everyday functioning.*

*That is in play for even what we call mild autism, impairment that impedes your everyday functioning.*

**Wayne then brought up efforts by the media to normalize autism by showing characters in shows who have only mild forms of the disability.**

**Dr.Zahorodny:** *It's an unfortunate mistake by which some people equate being socially uncomfortable or socially anxious or less proficient socially as being the same as autism or autism spectrum disorder.*

*If you're not impaired in your everyday functions, you're not on the autism spectrum that I'm studying. You may have features of autism. Lots of people have features of autism, have characteristics, but that doesn't equate to the disorder ...*

**Zahorodny went on to describe a graduate student from Harvard who worked with autistic people and who then announced that she actually had autism too.**

**50:33**

**Wayne next asked the really important question:**

***What are your concerns about the ever-increasing numbers?** I've got a good friend, Anne Dachel, who writes for Age of Autism, and she writes a ton of articles reporting on special education budgets just exploding because of that.*

***I've got a news report here from ...Hasbrouck, New Jersey, "Special education costs are almost 25 percent of the school budget."***

***That's more of the rule across the land than it is in certain areas. Special education budgets are exploding. Where are we heading here?***

***We're going to get to the point where we have a tsunami coming. We've got to figure out something, right?***

**54:13**

**Zahorodny:** *It seems like the best information I'm familiar suggests that somewhere in the range of one in five children have some learning issue, problem or deficit.*

***The most quickly expanding group is those children with autism.***

***Next most frequently occurring are children with ADHD.***

***I spoke about intellectual disability, but many individuals with autism, I would say within the range of 35 to 50 percent, also have ADHD.***

*This is a very complex, not monolithic, very heterogeneous, difficult to understand and difficult to intervene with disability.*

***When we say that five percent of the children in our region have autism, I think that's a fair metric for anticipating the future scope or perimeters of care for adults, adolescents and adults.***

*The vast majority of children improve, but the vast majority of children with autism maintain autism as a lifelong disability.*

***You're planning for at least five percent of the population to be disabled.***

***And we know one of the most regular statistics from the world of autism is that boys outnumber girls with autism by a rate of four to one.***

***We have already in Newark and in Toms River eight to 12 percent of boys in the public education system [that] have a lifelong disability or most likely a lifelong disability.***

***I'm not an economist, but do you choose to project five percent or 10 percent as a realistic metric for how many people will need significant, maybe lifetime support?***

56:51

***Wayne followed this talking about what this will mean for the military. Is this going to be a national security issue?***

***Why is this not a public health crisis? We've been demanding that for years. Why is this not ringing bells with our federal government as a public health crisis?***

***Zahorodny:*** *For some combination of reasons, the public opinion, the predominant public opinion and to some extent the expert opinion, is that autism prevalence, increasing autism prevalence is a consequence of better awareness and better recognition, and that it's not a true increase.*

***That's a big mistake I'd say.***

***When our first prevalence findings came out in 2007, these were the first two ADDM Reports, came out in 2007. Within six months in New Jersey, the legislators had voted a panel of seven autism laws into effect to enhance education, create a registry, stream for autism research. And autism prevalence was only one percent.***

***Now it's, in New Jersey, I would say, a good guess is four to five percent. There is no next panel of autism legislation.***

***Politicians are not responding because I think they have accepted for the most part the red herring interruption that autism has always been around***

***If you increase your perception of what autism is to include people on the Bachelorette, at Harvard University and actors with Academy Awards then you don't really see it as a problem.***

*You start seeing it as, well; autism is an aspect of humanity.*

*Well, yes, it is. In some very real way, it is, but I'm not studying the tenth of a percent who are Aspergers-like.*

*I'm trying to learn something about the 65 percent who have real moderate to severe autism and who have trouble every day, either going to school, learning efficiently, advancing interpersonally, advancing socially, improving their likely outcomes.*

***I'm concerned with the large number of kids, whether you call it 2.6 percent or 3.6 percent or four percent this is a true public health phenomenon and crisis which we cannot act on until we acknowledge.***

***How can you progress against a problem you don't even acknowledge?***

***In a way we've taken steps backwards from where we were 20 years ago, because if I said this affects one percent of the population, and autism is like this, people paid attention.***

***...And the other phenomenon, we have yet to understand what's driving autism increases.***

***Better awareness cannot be expected to carry 200 percent increase.***

***Better awareness accounts for maybe 10 to 15 percent of the increase in cases, not the vast majority of cases.***

***So what is it in, I hate to say this, our environment which is making it so much more likely for children to get autism.***

**1:01:15**

***We don't know anything about that.***

***And in fact I would say everybody knows about the ADDM Network because every two years we publish prevalence estimates, but the CDC has in fact been studying autism risk factors and autism causes and triggers since 2000.***

***First in a multi-state network called CADDRE ... Guess what?***

***Look at those findings and let me know what's been discovered about the things that are triggering high rates of autism.***

***Wayne asked about the impact of long waiting lists for diagnosing autism.***

***Zahorodny: I would say this is perhaps one of the most important ways in which state level information or data could be useful.***

***It is incredibly different from state to state as to how many practitioners diagnose, how prepared the school systems are, how much intervention is considered normal or average or appropriate.***

***Very dramatic differences.***

***One of the things that my group does, other than autism surveillance, is promoting autism detection. We want to identify autism between 18 and 36 months of age so that the child could get the benefit of early intervention program services.***

*I can't tell you how frequently I'm insulted by the comments that people make, that it doesn't matter. Why identify children early when you can't get them diagnosed until a year or two years later.*

*Even if they're diagnosed, it makes no difference.*

*It does make a difference.*

*If you don't think that early detection matters, you're very mistaken. There are many, many interventions. The earlier they start, the greater the likelihood of them being effective.*

*There's a socioeconomic gradient to these things. If you're from the richest third of the population, you get evaluated earlier, and you're much more likely to get early intervention services.*

*Also wealth is related to diagnosis.*

***If you're not wealthy, if you're in the bottom third of the population, you're not going to get evaluated by a professional before 36 months. You're not going to get diagnosed before 48 months. You're not going to get comprehensive services when you're in the school system, and you definitely don't get services before you're 36 months.***

***These are wealth-based disparities. They shouldn't exist. I know we're not yet an equal society, but this is one of the most practical ways in which we can change.***

***There is a mandate through the IDEA laws and covers all states for early intervention services.***

***We must have universal autism screening before 36 months and after 36 months.***

***Many school districts are looking for ways to help, but they're looking for tools, and some of the tools are missing.***

***Better awareness is only meaningful if it leads to early detection and correct intervention.***

***I'm a big proponent of autism awareness, autism acceptance too. But I want to do something. I want to take actions that will help somebody and the best ways, our group has determined, we could make a difference, is by promoting early detection of autism.***

***It varies tremendously across states***

***The most recent CDC report, the one that reports on study year 2018, is very interesting in that for the first time, they're not really concerned with autism prevalence. They're not really reporting. If you read carefully, you'll find out that they changed the methodology, and they're not really concern with what is the true prevalence of autism.***

***They're really beginning to show differences by state, across states, in diagnoses.***

***One thing that maybe nobody understands, maybe through your podcast people will begin to appreciate the fact that the CDC no longer—and the ADDM Network—no longer does active population surveillance.***

***We're not trying to find all the cases of autism. That's the old system. I would call the old system ADDM ONE. You're trying to find all the true cases.***

**ADDM TWO, it's not identified that way, but the 2016 report is the beginning of ADDM TWO, and what's reported there are "diagnosed with autism."**

**"Diagnosed with autism" is incomplete because, in a state like New Jersey, we still know that they are 20 percent undiagnosed. And it's a metric that is biased.**

**1:07:52**

**People from low income communities are more likely to go undiagnosed, and they're going to go unappreciated by the new method.**

**The new method, the ADDM TWO method, is good in that it's beginning to shine a light on the fact that there are differences from state to state. Even something blunt like who's diagnosed**

**Wayne: Will it lead to under reporting?**

**Zahorodny: Yes, definitely.**

**In states which have high access to information, like New York, sorry, New Jersey, California...the current report underestimates by about 20 percent.**

*It makes no difference probably for states which don't have access to school records or where the systems are very underfunded, at least half of the states are in the southern tier, and they underfund education.*

*They detect late. They diagnose late. This may be, in an interesting way, the public's opportunity to see that there are those crude differences from state to state. Not that this involves true prevalence, but it does show that some states have good resources, probably like California, New Jersey and Minnesota. And other states have weak resources for children with autism.*

**... For some reason, none of the media picked up the fact that in this most recent report, identified, that is diagnosed autism, in San Diego is already 4 percent among four year olds. 1:10:01**

**That means when the less impaired individuals are detected later, that their rate is going to be quite a bit higher.**

**1:10:26**

*...Less impaired [get detected] over time. If you have good intellectual ability and decent language, you don't get diagnosed until later. Even, I'm a clinician too ...in New Jersey, every couple of months I see a child who's age seven, eight, nine with autism who's never been diagnosed and been in the school system since age five.*

*If this is happening in New Jersey, it's definitely happening throughout the United States.*

**Wayne asked Zahorodny what he would do if he could do one things about autism.**

**1:11:11**

**Zahorodny: Identify the environmental factors that can be changed that affect who gets autism and how many kids have autism.**

**We don't understand what the trigger is.**

*If we do that, what could be more constructive than seeing the prevalence of autism decline?*

*What if we could see autism go back to being one percent prevalence disorder or half a percent, instead of four or five percent?*

*I guess if I were to do one thing, it would be to identify the environment trigger that can be changed.*

*If I could do two things, the second thing, I would have universal autism screening from 18 months, every six months.*

Finally Wayne remarked to Zahorodny that when it comes to finding the “environmental trigger” “the CDC isn’t interested in studying that.”

A point Zahorodny didn’t challenge.