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Autism and Neurodiversity

Recorded Jul 8, 2020

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AudiologyOnline.com Course #35457

- [Woman] And at this time it is my pleasure to introduce to you a presenter that is new to AudiologyOnline. She's gonna be presenting Autism and Neurodiversity. We welcome Dr. Diane Treadwell-Deering who has been the medical director of the Swank Autism Center at Nemours duPont Pediatrics for the past 2 1/2 years. Formerly she was an associate professor at Baylor College of Medicine and she worked at Texas Children's Hospital in a variety of positions throughout her almost 30 year tenure. We welcome Dr. Treadwell-Deering and thank you so much for being with us today. I'll hand the mic over to you now.

- [Diane] Well thank you for that very kind introduction. I'm very excited to have an opportunity to talk about this topic with you all. Let's get started. So here you've got a chance to look at some of my disclosures. Some of the information you've already heard about me. Give you a chance to look at that. And here's some more information about disclosures. But I do wanna spend some time talking about what I consider to be an important concern about my potential biases in presenting this conversation today. I'm trained in the medical model because I'm a physician. I belong to medical organizations and I'm the medical director of an autism clinic and I think that when we think about neurodiversity, which may be considered perhaps antithetical to the medical model, there may be legitimate worries that I could be biased towards a medical conceptualization of autism and therefore biased against the neurodiversity vantage point. I'm keenly aware of that and when I prepared this presentation I tried to take a very scientific and objective approach. I wanted to acquire knowledge through thorough examination of information. I wanted to consider it carefully. I'm a pretty skeptical person, I'm pretty critical when I look at information. I want to apply logic and reason in order to develop conclusions. I think that my personal clinical practice has given me lots of information but that it's only the information that applies to my own practice. So in order to have a very broad-based understanding I need to look at information in addition to my own personal practice experiences. In some way, because I'm a medical professional, because I took what I consider a scientific approach, I looked for information in very very specific ways. I use databases that

include peer review journals, sponsored by professional organizations such as psychologist, psychiatrist, speech and language pathologist, pediatricians, a variety of different groups. I also looked on the web. I searched for autistic self-advocates as a way to get other information. I referenced a book authored by Steve Silverman, a leading proponent of neurodiversity. I've attended some lectures by him. I have some collaborative working relationships with autistic people and family members of autistic people. I try to gather information from a broader way of resources prior to this presentation. I'm keenly aware that we all come to every situation with biases and potential biases. The group of people that I see in my clinical practice is a subgroup of autistic people. It does not represent autistic people in general. And I hope that our conversation today reflects my attempts to be very broadminded in thinking about this topic. Prior to kind of talking about these learning outcomes I'd like our first poll, in order to get a sense of people in the audience today. I think that many people, many things can apply so please check all that do apply.

So I think again it looks like most of us work with autistic people and a fair number of us have a close relative. I want to disclose to you all that I do not have a close relative with autism and that I would categorize myself as a person who works with autistic people and as a person who has friends, I have friends with autism and I have co-workers with autism. So let's go onto the next slide and the learning outcomes. I always hate this 'cause I have to mention, or I have to make three of them, but maybe there's more learning outcomes and that you'll be able to learn other things in addition to these. Let's hope that at least we manage to cover these three outcomes in terms of thinking about the application of the term neurodiversity as it applies to autism spectrum disorders. To think carefully about the different terms, disease, disorder, disability, differences. And to think about the models, both the medical model and the neurodiversity models as they apply to the autism spectrum. I think that it's helpful to begin with a really brief history of autism, so that we can put some of this conversation into context. Autism was first described by a child psychiatrist, Leo Kanner, from Baltimore, Maryland. He reported a series of 11 children in his clinical case load in a

journal which in 1943 there was a journal that was named "The Nervous Child", which I think seems kind of concerning and upsetting to us nowadays, to imagine that that would be the name of a journal. Nonetheless his explanation for these children was that they were subjected to a cold and distant style of parenting which caused their autism. And this explanation was in line with prevailing explanatory theories, psychodynamic theories of psychiatry and psychology at the time. Some of his writings did hint at biologic and genetic factors. He did indicate that the parents of his children had milder manifestations of what was more fully apparent in their child. And today I think we might think about that observation from a genetic standpoint and think about genetic anticipation and parents having broad autism phenotype, but subsequent generations having more significant manifestations of a disorder. Hans Asperger who is an Austrian pediatrician reported on a series of his patients in 1944.

His work was really largely ignored until Lorna Wing, who was an English psychiatrist, suggested the term Asperger's syndrome. I think it was in a paper in 1976. But not until the 1980s did this notion of Asperger's really flourish. Its relationship to more classic autism has always been controversial. It appeared in the "Diagnostic and Statistical Manual" fourth edition. It got removed in the next edition in 2013, we'll talk a little bit about the DSM in a couple of slides. But in many ways it was kind of autism that was not associated with cognitive impairment or with language delay. Bruno Bettelheim greatly influenced the field of autism from the 1940s through the 1970s. He was born in Austria as well but did most of his work in the United States. He himself was a Nazi concentration camp inmate. He became a psychology professor at the University of Chicago and towards the end of his career he was at Stanford. He was the director of a residential school for emotionally disturbed children. He is credited with coining the term refrigerator mother. He compared life in a concentration camp to the life of a child with autism and squarely placed the blame for autism on the child's mother. Next Bernard Rimland who is an American psychologist who had a son with autism. He's credited with helping folks move from considering autism as an emotional disorder to a brain disorder, but he had some ideas about interventions that included mega dose

vitamin therapy, especially vitamin B6, which has not really shown good evidence for efficacy in subsequent research trials. Andrew Wakefield has also had an impact. A British physician, he published a paper about the association between MMR vaccinations and a very specific type of enterocolitis that led to autism, and he had a huge impact in the anti-vaccine movement. Subsequently his studies were found to be fraudulent. He was found to have some conflict of interest. He was associated with some law firms that were going to sue the companies that had made vaccinations and so subsequently his work has been discredited. Nonetheless he continues to have a following of people who feel that there's an association between their children getting vaccinated and the development of their autism.

So why is there a medical model of autism causation? Tons and tons of research have been done looking at a variety of different kinds of factors and I think that there's, research shows multiple biologic and physiologic risk factors that typically the amount of risk is relatively small but is apparent and meaningful and significant. Interestingly both advanced maternal and paternal age are associated with a slightly increased risk of autism as are both short and long inter-pregnancy intervals. A variety of maternal infections during pregnancy. Babies who are small for their gestational age, babies who are large for gestational age and babies born preterm have a slightly higher increased risk of autism. Other factors have some, they're less well established risk factors but they are also, support biologic and physiologic etiology. And this includes family history of autoimmune disorders, prenatal air pollution, pesticide and antidepressant exposure and birth by cesarean delivery. Why is there a medical model? Genetics. Autism has the highest heritability estimates of any developmental disorder, somewhere between 70 and 90%. There are three main areas of evidence that support a genetic etiology of autism. One looks at twin studies and looks at identical twins who share identical DNA sequences and fraternal twins who are related as closely as any sibling pair, versus the rates of autism in the general population. If one identical twin has autism the likelihood the other twin has some form of autism is somewhere in the realm of 70 to 90%. Family studies look at the rate of autism in first

degree relatives of a person with autism and compare that to the rate of autism in the general population. And within families it's a much higher rate. If you look at a variety of rare genetic syndromes the association with those syndromes and autism is higher than in the general population. Not only is there genetics, there's epigenetics, a field of genetics that looks at DNA modifications that is not a part of the DNA amino acid sequence. There are three very specific syndromes that are highly associated with autism and all are caused by epigenetic dysregulation. And this is Fragile X, Rett syndrome and Angelman syndrome. Certain pathophysiologic factors, when you look at a group of people with autism, seem to show some evidence. So when you look at a group of children with autism there's a larger proportion of them that have larger head size and that larger head size seems to be related to early brain overgrowth. There are differences in connectivity and hypoconnectivity across brain structures.

Typically this is found in animal models of autism and there are some anatomic brain differences that seem to occur, again, in animal models. There is frequent co-occurrence with intellectual disability, speech and language disorders and learning disabilities, all I think that support the notion of medical factors that are highly associated with many cases of autism. But it's not the entire answer. We still don't know specific causes for every case of autism. I wanna talk a little bit about the DSM story because I think, again, it impacts how our society has kind of come to understand autism, how professionals think about autism and about how families of people with autism have been given information in ways that I think shape their perceptions of the disorder. The DSM stands for the "Diagnostic and Statistical Manual of Mental Disorders" and you can see that it's gone through several iterations over time. It's a handbook that's authored and published by the American Psychiatric Association. It contains descriptions, symptoms, other criteria for diagnosing mental disorders. The very first iteration was actually a collection of statistics about psychiatric hospitalizations and the number of hospitalizations and the reasons for hospitalizations across the country. It is used by healthcare professionals, educators, a variety of people across the country. Some of its benefits are that it provides a common

language. It allows for some consistency and reliability in how we talk about different disorders and this can be useful in terms of supporting research and helping kind of determine treatments. It reflects evolving theoretical frameworks and as I've said it was originally modeled after army statistical manuals and it talked mostly about kind of rates of hospitalization. In DSM-II in 1952 autism was considered a form of childhood schizophrenia and it was not until the third edition which didn't occur until 1980 that autism was listed as a separate disorder on its own, with three specific categories of diagnostic criteria. In the next iteration, DSM-III revised in 1987, the concept was broadened with the introduction of the term pervasive developmental disorder not otherwise specified. I think this was, from my standpoint, not a very helpful term because it felt like it was not very specific. It referred to people that had many aspects of autism but didn't meet strict criteria.

And so not to be pejorative about the term but it felt like kind of a waste basket. It wasn't very clear what that term meant and how it helped describe people who were given that diagnosis. In the DSM-IV that came out in 1994 and then the 2000 text revision, the category included five specific conditions. Autism, PDD-NOS, here is Asperger's, childhood disintegrative disorder and Rett syndrome. In 2013 DSM-5 was published and it was, prior to it being published there was a great deal of work by many many work groups who used a much more empirically derived categorization and based on that they moved from five specific conditions into a new conceptualization of autism as being a spectrum disorder. So classic autism, PDD-NOS and Asperger's were removed entirely from the DSM and were taken out of the official nomenclature. Childhood disintegrative disorder and Rett syndrome were redefined and moved out of autism and moved into different categories. So here is the current diagnostic criteria for DSM-5 Autism Spectrum Disorder. And, again, I think it's a descriptive diagnostic criteria and clearly somewhat subjective. So persistent deficits in social communication and social interaction across multiple context manifested by difficulties and deficits in social emotional reciprocity. Demonstrated in non-verbal communicative behaviors. And leading to difficulties in developing, maintaining and

understanding relationships. It's accompanied by restricted repetitive patterns of behavior and manifested by a variety of things. The stereotypic repetitive motor movements. Arm flapping, finger flicking, body rocking. Use of objects or speech such as delayed or immediate echolalia. Insistence on sameness, inflexible adherence to routines and rituals. The highly restricted fixated interests that are abnormal either in intensity or focus or both, and then the inclusion for the first time in very specific issues about sensory input, hypo or hyperreactivity to sensory input or unusual interest in sensory aspect of the environment. The symptoms are present in early development but the disorder may not be recognized until later in life and in many people is not recognized until adulthood. Partly because of the variety of and the variability in symptom manifestation. And many people may have some types of issues but not be identified as being on the spectrum until adolescence or until adulthood. I think this next item which, D, is a very very important item to think about.

Symptoms cause clinically significant impairment in social, occupational or other types of functioning. If these differences or difficulties or whatever you describe them as, if they don't cause clinically significant impairment you don't have a disorder. And I think that's an important distinction to kind of think about when we talk about is something, does something actually qualify as a disorder. If it doesn't cause impairment it's not a disorder. Again in the official diagnostic criteria the disturbances can't be better explained by intellectual disability alone. There are many many common features that accompany autism and in order to have a good understanding of any individual, specifiers should be delineated so that people can understand, fellow professionals, clinicians, educators, can understand more about the specific person, with or without accompanying intellectual impairment. With or without accompanying language impairment. Is there an associated known medical or genetic condition such as Fragile X syndrome or Angelman syndrome? Is there another neurodevelopmental or behavioral disorder? Does this person also struggle with depression or anxiety or ADHD? A feature of catatonia which is a motor symptom that is characterized by immobility and stupor, was added to DSM-5. Personally I'm not sure if it's gonna be

included in DSM-VI because it's not a very common finding. I wanna switch around and kind of think about kind of words that we use and I think that folks in the neurodiversity movement have really refocused us on really being thoughtful and careful about words that we use. How do we define words and do we have a common definition for words? What do words imply and the importance of really thinking about how language not only reflects how we feel about things but how it also shapes how we feel about things. I think it's very important to think are we using the best term to describe something that really is accurate. And do terms that we use, do they evoke pity. Do they imply something about worthiness or value? And I think in particular this delineation of autism into high-functioning and low-functioning and I have to be honest, I have used those terms myself in certain situations as a shorthand of describing people with autism who have intellectual ability and verbal communication ability, versus people that do not. But I think that those terms can mean and imply certain things that are not accurate and don't communicate accurately things that we want.

Oftentimes I've worked with families who've been told that their child's high-functioning and then they're confused when their child does not meet the expectations that they had for their child but they said my child's high-functioning, why is my child having these difficulties. I think the terms also kind of imply how we should respond to people that have autism. Diseases need to be cured. That's what doctors do is they cure diseases or they treat diseases, and earlier on there was a parent organization that was called Cure Autism Now. But as an organization chose to change their name as they came to a different understanding of the focus that their group was gonna be involved in. Disorders need to be fixed. Disordered phones, disordered toilets, you fix them. And you don't really think that there's much positive about a disorder. Over time words and terms can acquire meanings that may be pejorative but were not initially associated with the term. So the terms I have here of moron, imbecile, mentally retarded and intellectually disabled are terms, they are nomenclature that were used to describe the same condition over different periods of time. And so moron was a medical term used to describe people we now describe as intellectually disabled. Over

time the word was co-opted by general population and was used in disrespectful and insulting ways and then was rejected by professionals. The same thing with the term imbecile and mentally retarded, and perhaps some day we'll also be intellectually disabled and we may move to another term in the future. I think Simon Baron-Cohen who is a psychologist at University of Cambridge in England, his professional career's been devoted to autism and he's made incredible contributions to the field, has thought very carefully about neurodiversity. He's talked about and delineated these very specific terms. I'm not sure that everybody has the same exact feelings of about what these words mean. This is how he feels these terms have been used and what these terms imply. That disorders talk about a person with a disorder's unable to function. And I suspect I, as an individual, differ slightly from him about this but it's important to recognize for many people this is what that term means. Disability is a different term. It talks about not being able to function in one or more area. It implies a need for support and intervention.

Differences don't necessarily have any implications about ability to function or wellbeing but may just refer to a typicality relative to a population norm. Diseases have a biomedical mechanistic cause that becomes known through research and testing and should be very very specifically used this way to, I think, make it clear what we understand about a condition. But what do these words mean and how are they experienced by people to whom they are applied. Does it mean you need to fix or cure? Does it mean that you need to prevent? Does it mean that there's nothing positive? Many people on the, autistic individuals dislike the word spectrum which they feel bleeds into neurotypicality and doesn't delineate them as a separate group of people in comparison to people who may need different levels of intervention. As a clinician I don't like spectrum because it doesn't help me as I try and help families understand the person in their family and what to expect over time and what will happen in the future. And I actually think that most of us, as individuals, it seems that life is somewhat easier or more clearcut if things are more black and white. You're either pregnant or you're not pregnant and those are two very different conditions with

very very different outcomes. And so any time we talk about a spectrum I think it leads to some lack of clarity that feels somewhat confusing. Many autistic individuals liked the term Asperger's and they liked that differentiation and they felt that it described them and separated them as a special group of people. I wanted to talk a little bit about kind of, again, I think some ways we use words that people on the neurodiversity movement have helped brought to the forefront. And this is do we talk about people first or do we talk about disability first. Do we talk about identity first? A study that was done in the UK in 2016 with regard specifically to autism looked at person first language, a person affected by autism, a person challenged by autism, a person with autism. That way of thinking about autism was preferred by medical professionals, family members and friends. I want to tell you that as a medical professional who did the bulk of my training in the 1980s, this was, using person first language was really really highly emphasized as a sign of respect.

Again I think the medical profession often used shorthand and shorthand terms and so we would be on rounds and it wouldn't be uncommon for someone to say "Hey, did that gall bladder in room 17, did they go to the ICU last night?" And that kind of notion of identifying a person as their disorder was considered disrespectful and not humanistic and not fully embracing the biopsychosocial paradigm that really, I think, is the best of medicine. And so I remember being very very much criticized if we ever identified someone by their disorder and not as a person with a disorder. On the other hand some people feel like person first language implies that there's some kind of normal person inside waiting to get out, and many people in the deaf and blind communities have rejected person first language and prefer disability first or identity first language instead. Many but not all autistic people prefer identity first language. Jim Sinclair who is a well known self-advocate for autism is very very clearcut and in 1999 wrote that an autism person could never and should never attempt to separate themselves from their autism. That he feels that it's an essential core aspect of self-hood. He talked about positive adjectives going before the noun and I personally put a question mark in here because he talked about beautiful children, successful athletes,

that positive adjectives go before the noun and in the same way he wanted autistic people to know that that was a positive adjective. I'm not sure what to make of that because I personally use negative adjectives, I think I describe people as naughty children or disrespectful children. Although I do have to admit that sometimes when I try and soften terms I might use the word, the person first word and then kind of describe some of the things a person with autism, a person challenged by autism. And again that notion is are we over-identifying a person as his or her or their condition and for some people they want to identify themselves as their condition and for some people it doesn't seem to be comfortable for them or necessarily accurate to them based on their own self-identification. So now, finally, I'm getting to the word neurodiversity halfway through our conversation.

So diversity as a word is strictly defined as a variety, as variability, but I think over time terms like cultural diversity and biodiversity have come to mean and imply different things. In terms of biodiversity, I think that there's a recognition that we can't overvalue any specific aspects of our ecology and that truly, systems that don't value diversity will come to an end and will become extinct. When it comes to things like cultural diversity I think that we've come to understand that and recognize the value in differences, not just in accommodation or a tolerance but a celebration of differences leads to a fuller and more rich understanding of things. And how to think then about neurodiversity as it's applied not just to autism but other neurodevelopmental disorders I think is our challenge for today. It's a term that's attributed to Judy Singer, she was an Australian social scientist who has autism. It was first found in an article in "The Atlantic" in 1998 so it's a term that's been around for more than 20 years. The term is often coupled with the other term or the opposite term of neurotypicality which is a term that I sometimes personally dislike because it feels like then there's the us versus them, there's the neurodiverse versus the neurotypical. And that it can, again, deny the lack of nuances that I think are important for us to fully appreciate each unique individual. The term has been used differently in these 22 years. It's had different meanings, different groups have used it in different ways and it has changed over time.

There is not a monolithic neurodiversity movement that has just one way of thinking and one way of understanding. So let's talk a little bit about the different ways the term has been used and continues to evolve. For some people it refers to a very specific social justice movement. For many people autism is a difference not a disability and actually can be described as a cultural movement. Dawn Price-Hughes sees it as somewhat similar to the deaf community. Joyce Davidson highlights that there's a very very specific communication style amongst people with autism. It's been aided very much by the internet which is a very very different kind of form for interaction and much more autism compatible than in person, more typical social environments. If you think about autism as a cultural movement it means that there are group specific rights and that there are needs to accommodate autistic individuals. Some people think about using the social model of disability.

Again some people think all of the disability of autism is caused by society's response to it. Some people have a more measured approach that at least some of the disability of autism is due to society's response rather to any intrinsic factors to autism. Society becomes responsible for enabling individuals to live and thrive within that society. The goal is not to change or fix people with autism but to accommodate and support the autistic individual. Thomas Armstrong in an editorial in 2015 in the ethics journal, the ethics part of "The Journal of the American Medical Association" went to a pretty extreme position that since there's uncertainty about this kind of critical threshold between normal human variation and things that are pathology, that we should throw away and not even concern ourselves with the notion of discerning normal from abnormal. I think that's a little bit extreme and I don't think it's a model that actually ends up being helpful. But it certainly I think challenges us to kind of think about where do we draw a line and where do we think that there's uncertainty versus certainty. Many folks think about that normal human difference or normal forms of human variation such as eye color and hair color should be applied to atypical neurodevelopment. In contra distinction to neurodiversity there's this thought about neurotypicality and I wanna think a little bit about it and I wanna talk a little bit about it.

This paper in 2019 which was, looked at a number of self-identified autistic vloggers who had discussed and mentioned and talked about neurotypicality on their sites. Looking at this analysis of these, of 39 different vloggers, neurotypicality was conceptualized in several different ways. So some of these folks thought about being neurotypical as an accomplishment, it was a goal. It was something that they were proud of accomplishing, that it was something that they'd strived for. And again it was a source of pride. Some folks talked about neurotypicality as a masquerade. That they would pretend they could mask, they could fit in. That they would try to be neurotypical. It may or may not be worth the effort, it may or may not be something they did in different kind of contexts and situations. Some of the folks really felt that it should never be something that they should try and accomplish and that it was a denial of their true self. And that they felt like it was never their goal. One common feature though is that all of these vloggers talked about neurotypicality as something that was very exhausting. It took a lot of effort, a lot of very concerted, very purposeful behavior on their part to accomplish. It did not come naturally at all by any stretch of the imagination. I think that a group of folks, again, I think in 2019, looked at kind of a strength-based approach to autism.

Again I think something that the neurodiversity movement has helped us realign our thinking that not only are there difficulties for some people with autism but there are clearly advantages as well. And in this paper there was a report of 28 semi-structured interviews with a very selected group of autistic adults. Half of the group had not been identified with autism until adulthood and I think that that probably then talks about that this was a very specific sub-population. Only six people in the group were identified as having, or employed. Most of the people who identified strengths also indicated that these strengths or advantages of autism could also be weaknesses, depending on the context. But frankly speaking I think that's true, not just in autism and not in just the particular strengths that they identified, but is true about many many characteristics and traits that we all have. They all indicated that the ability to modify these behaviors, to use these strengths in certain contexts, was very very important.

Most of the people in this particular group did not identify autism as an illness or a disorder but as a difference. And here are the list of things that they identified as autism advantages. The ability to hyperfocus. Good attention to detail. Having a very good memory. They identified themselves as being very creative, as being honest and loyal. Having great empathy for animals and other people with autism. And I think that as we look at this list we can understand that these features could be extraordinarily helpful in some circumstances but perhaps not always helpful and not always functional. Gillespie-Lynch and her group in 2017 really challenged us to think about autistic adults as autism experts. One of the things that she pointed out is that many autism experts who were responsible for thinking about interventions and treatments and supports and accommodations, did not have autism themselves and perhaps were not listening carefully enough to those with autism who are able to express their own needs. An online survey of reaching out for folks with autism found a group of people who were mostly unemployed, mostly self-identified as autistic and willing and able to participate in an hour long interview. One of the things that I think of as an essential and a very very important feature that I think has impacted me and the way I think about caring for people with autism, is that interventions for autistic people are not necessarily aligned at all with their own needs and self-identified goals. Especially obviously with autistic adolescents and adults.

Again this group had a high proportion of people that were diagnosed in adulthood and they often were very relieved to receive the diagnosis. They felt that it was helpful to them to understand their own life experiences but they definitely didn't view it as a disability. On the other hand many of the adolescents in this survey felt that they were struggling and did desire to be normal in some way, in some definition. Most, but not all, felt that autism was not a disease and most were okay if others wanted a cure but they themselves did not. They especially felt that individuals with autism who had intellectual disability and who were not able to verbally communicate, who had difficulties with aggressive behavior, that they may want a cure but that that was not the autism that they experienced themselves. Some reported their autism presented a

significant struggle. A substantial minority indicated support for a medical model. A substantial minority saw merits to both the medical model and the neurodiversity model. Almost all of them talked about using and masking their autistic traits but that this was very very effortful and very taxing. Perhaps not tasking but taxing. And that it was not, that one of the significant difficulties was how difficult it was to maintain a more neurotypical set of behaviors when in public, when at work and when in school. But must these models compete and I think Simon Baron-Cohen has been, has written very very eloquently about this. And I think I very much endorse his ways of thinking about this, that it's not an us versus them. The heterogeneity of autism spectrum disorder that I have seen in my clinical experience over my years of practice lends support to the notion that some forms of autism are a disorder, some are a disability, some are a difference.

And that there's not really a very unifying way to think about autism that I think is successful. I think the medical model at its best and the neurodiversity paradigm both support a biopsychosocial model. I have to be honest that the biopsychosocial model was very very appealing to me and one of the things that led me to go into psychiatry is because of how very highly emphasized that was for me during my training. I have to admit now that the model of 15 minute med checks does not lend itself to the biopsychosocial model at all and is not medicine at its best. I think both the medical model and the neurodiversity model can endorse services aimed at improving subjective quality of life and wellbeing of autistic people, if only we listen carefully. I think that the neurodiversity paradigm has had multiple positive impacts and this slide is not an all-inclusive list, make no mistake about it. And I think the longer I look at this and the more I think about it, I think there are more items that I would put on this slide. I think, again, thinking in a respectful and humanistic way towards autistic people is an important contribution I think of the neurodiversity paradigm. A much much greater emphasis on strengths and a strength-based model and on helping people not fix things that they don't want fixed. If it's not broke don't fix it. And being very very thoughtful about what it means to mask and how to support masking if that improves

function, or if it's a goal of a patient or a client is something that's very important. I think that greater appreciation of word choices is very important in thinking about how individuals like to be referred to. Using the terms that they are comfortable with is respectful. Again developing intervention and support that align with the goals of autistic people. Accepting, including, protecting differences is an important job for all of us in society and for those of us who work with people with autism I think informs our role as important advocates and is something that we need to continue to think about. There are concerns and criticisms of the neurodiversity model. That doesn't mean the model should be discarded. It means that models and ways of thinking evolve. Natural variations are not always benign and are often associated with diseases, disorders and disabilities, not just differences.

So the fact that things occur naturally, cystic fibrosis occurs naturally but it's not benign. Fragile X syndrome is a natural genetic variation. It's associated with incredible pathology, much distress, medical disorders. Not having clearly defined normal does not mean that we can't delineate things that are, for the lack of a better word, not normal or at least areas that we need to focus on to support, research treatments, interventions, supports, as indicated. The neurodiversity model may work well for some autistic adults, especially those with strong cognitive and language skills but it does not work for all autistic individuals. And thinking about who could and can and should speak for the entirety of this spectrum is a very important thing. I, as a person who treats mostly people under the age of 21, continue to believe that until proven otherwise, parents are the best advocates for their children and that we are a strong team when we work together to set goals for their children. This is a diagram that I found in my internet search and it really really resonated for me. I don't necessarily agree with every specific point on it but I really really liked the way it was delineated and it was posted by an individual who goes by the term the Bearded Behaviorist and he's got a lot of different kinds of things on his website, but this particular way of thinking about autism as a large circle, perhaps including people that it's just a neurotype, it's just differences, and then there being a subcategory within that larger

group that includes people that might be considered and best considered as people who have a disorder. And I got his permission to use this model, again because I found it a really helpful model and something that I think made sense to me and I hope makes sense to other folks. This is, this top part of the slide is the bottom part of the schematic on his website but I couldn't get it to fit into one slide well. And, again, I've obtained his permission to use this in this presentation in addition to many other presentations. I just wanted to kind of remind folks of what that biopsychosocial model was. In terms of thinking about the unique interconnection of a variety of factors, biologic, psychologic, social, environmental, cultural, that impact each unique individual human being and that as practitioners we do intervene with unique individuals. As policymakers we think about groups. As practitioners we think about individuals.

And we have to be able to think about both models and many different ways of thinking about folks. So now I'm kind of to the end of my talks and I wanted to finish up just briefly talking about this particular slide. This quote is inscribed on the wall at the front entrance of the Nemours Enterprise Headquarters. The Nemours Healthcare Enterprise is supported by a legacy from A.I. duPont who was a rich guy back in the day. And I think it's been very fulfilling to work in an organization for whom this is the culture. That it's the duty of everyone to do what is within his or her power to alleviate human suffering. There's a picture here of A.I. duPont and his third wife Jessie Ball, who was responsible for actually implementing his legacy. Below is a picture of the hospital where I currently work and it is on the grounds of the Nemours mansion and estate which is also pictured in this slide. I'd like that to kind of be a lead into our second poll question. And I'd like to get some feedback from you all in terms of kind of how you conceptualize autism and what are maybe important ways to kind of think about autism. And I'm really really good about checking all that apply because I think, again, having different frameworks and conceptual frameworks kind of help us kind of understand what we're looking at best and when we find ourselves clinging to one very specific viewpoint I think, I suspect we are often not seeing things fully and accurately.

And I suspect that many of you felt this way before this talk. But I hope that at least you learn some information about, specifically about autism and the evolving ways of thinking about it and addressing it as an important issue for many children and adolescents and adults. So I would like to open it to questions at this point.

- [Woman] Thank you so much for sharing with us your wealth of knowledge. We are going to welcome any questions or comments for Dr. Treadwell-Deering. We do have one question here from Julie. Julie asks what intervention strategies do you recommend for those with ASD or hyperacusis. And do you find that those strategies used for neurotypical populations are as effective for those with ASD.

- [Diane] I think one of the things that's really kind of helpful is that even people that don't have autism may have some of the same issues that people with autism do. So hyperacusis, that really extreme sensitivity to auditory input, people have that who are considered neurotypical and, again, that notion of do we learn something from people with autism and hyperacusis that can be applicable to people in general. I think that's always hopefully the goal. If you learn something about a small area it's applicable to a larger group. I think that when we think about most of those kinds of sensitivities and, sensory sensitivities, we look to our occupational therapy colleagues in particular who have been I think most instrumental in looking at some of those things. What are the environmental manipulations that we can use? Is it using headphones, noise canceling headphones? Is it using light dimmers? Is it changing environments? Is it providing sensory environments that can be utilized across the board for the population in general? Can we create sub-environments that are helpful for the autistic individuals within the larger population? And I think one of the things that we find is that there's not one answer that meets everybody's needs and requirements. That we have to be very creative, we have to be willing to try a variety of different things. What works for one person doesn't work for everybody. And I do find that some things that I think of as being helpful in folks that we've learned that are helpful in folks with autism, we do now use in the more general population. I think of things like weighted blankets and

compression vests that may have been originally used just with folks who also had autism are also things that we find very very helpful in neurotypical people. The kinds of swaddling we do in normal infants is a sensory kind of thing. And some of us need to, want to, benefit by that continued kind of sensory input as we get older. Sure. I think that it's, we don't need to kind of think about this purely in this is pathology versus that some of these issues, maybe in less intense forms, exist in those of us who we might identify as being neurotypical.

- [Woman] And we have time for one more question. We have a question from Kevin. Kevin asks would you be able to describe the essentials of the UK survey one more time. Dr. Treadwell.

- [Diane] There were several surveys that came from the UK and one of them was around how people like to be, how people like to be referred to. And I'm not sure if that's the survey to which you're referring versus another survey, I'm really sorry. If Kevin can kinda help be more specific I'd love to address that. I do wanna really quickly 'cause I see, I hope I'm not mispronouncing Rochna's question about a hearing assessment mandatory for children who are undergoing an assessment for autism. I think that many children with autism who don't appear to respond to verbal communication, they don't respond to their name, that oftentimes it is very very important to get a hearing assessment. Many young children who have multiple infections, otitis media and sequelae of those infections, have hearing difficulties and that may impact their language development. And so we always wanna make sure that that's not the explanation for speech and language delay and not the explanation for a child not responding to their name. When that's corrected we expect to see a significant change, that the child will respond and that their language will, development will improve and if it does not or when it does not that's again one of the things that makes us concerned that perhaps it's autism that's responsible for the child's behavior.

- [Woman] And yes, and Kevin did clarify. He says how would people prefer to be referred to, that's what he meant, from the UK study.

- [Diane] So the thing is is that, the problem is is that it wasn't, there wasn't a vast majority that were one way versus the other. And that has been an issue for me because when I speak to a group of people I don't wanna offend anybody and I want to be as inclusive as possible. And sometimes I ask the group prior to starting a conversation how would you best like me to talk about this topic. And sometimes I think I slip. When I write things it's easier for me to be careful and thoughtful. Do I write about autistic people? Do I write about people with autism? Am I talking to a group of parents? Am I talking to a group of individuals with autism? And obviously I'm often talking to a group of people from different backgrounds. And, again, when I talk to individual patients and families I try and put a note in my medical record, again I'm that medical professional and I have a medical record. I put a note how does this person like to be referred and try and kinda follow that if possible. And sometimes I don't. I mean sometimes I'm really really busy and I'm looking through a chart very rapidly before I walk into a room and greet a family. I try and I'm not always successful.

- [Woman] Thank you so much Dr. Treadwell-Deering for being with us today. We hope that everyone has found this as a valuable resource and we wanna thank Dr. Treadwell-Deering for her time and expertise. This will conclude today's webinar. We hope that you have a great day, thank you so much.