

**Autism Spectrum Disorder: Overview, Screening,
Diagnosis and Treatment Planning**

Tiffany Hodges, PsyD, BCBA-D
Associate Vice President, ABA/Autism
Optum Behavioral Health Solutions
Debra Katz, MD
Senior National Medical Director
Optum Behavioral Health

Dr. Elizabeth Albert: Hello, my name is Dr. Elizabeth Albert. On behalf of Optum Health Education, I would like to welcome you to today's activity, "Autism Spectrum Disorder Overview, Screening, Diagnosis and Treatment Options."

Before we begin, I would like to review a few items. A Question & Answer Session will be held at the end of this presentation. Questions may be asked via the Type Your Question Here field to the right of the webcast.

Upon conclusion of the webcast, the post-activity evaluation, credit claiming, and certificate of attendance will become available. To receive continuing education credits, these materials must be completed by no later than November 18.

Finally, this webcast will be recorded and will be posted as an On-Demand webcast. Check optumhealtheducation.com on October 25 for more details.

I would now like to welcome Drs. Tiffany Hodges and Debra Katz. Dr. Hodges is Assistant Vice President, ABA Autism with Optum Behavioral Health Solutions; and Dr. Katz is Senior National Medical Director for Optum Behavioral Health. It is with pleasure that I welcome Dr. Hodges and Dr. Katz.

Dr. Debra Katz: Hello everybody, I'm Dr. Debra Katz. I'm a board-certified child adolescent and general psychiatrist. I have worked in partnership with Dr. Hodges leading all of our initiatives associated with autism spectrum disorder and I've been at Optum for 20 years. Dr. Hodges.

Dr. Tiffany Hodges: Hi. Good afternoon and good morning, everyone. I'm Dr. Tiffany Hodges. I am a psychologist and also a board-certified behavior analyst by background. I've been here at Optum for about 14 years and prior to that was in the field doing psychological evaluations and other treatments for individuals on the autism spectrum.

We're so excited to be here today to talk to you a little bit about autism, which is a passion for both of us.

Before we get started, just as a quick note, neither of us have anything else to disclose. We're both here from Optum to share a little bit more about our knowledge here with autism.

Our goal today is to really review the symptoms and behaviors associated with an autism diagnosis, talk a bit about autism screening tools that can be utilized, and then talk about when autism screenings can be done along with other comprehensive evaluations, and also talk about some of the importance of neurodiversity and people-first language. So we're excited to get started.

Dr. Katz: I'm going to start speaking. I think we want to level set, you know, what's happened in the field of neurodevelopmental disorders – it used to be called just

developmental disorders – an oversight kind of terms have been used which is neuroatypical and neurodiverse. People who don't have learning or challenges or intellectual challenges were neurotypical. These words are used, they're really not pejorative, they're person-first and they're used to describe people that have atypical development, intellectual development and cognitive abilities. They're often used to refer to individuals on the autism spectrum, have ADHD, and I'm going to get in, on the next slide, to name a few of the other disorders.

You know, these terms are used to support the differences, strengths, and abilities of persons with autism spectrum disorder, ASD, ADHD, and other developmental disorders always using person-first language and always really focusing on what the individual can do, not what they can't do.

Next slide. So here is a visual with the neurodiversity title in the middle. And on the left side, you can see some of the diagnoses that were pretty common for all of us. ASD is autism spectrum disorder; ADHD, attention deficit hyperactivity disorder; Tourette's Syndrome; obsessive compulsive disorder, OCD. And on the right are some of what we used to call or are also cognitive disorders or learning disabilities. Dyspraxia is when it's hard to approximate things or it's almost like being a little clumsy. Dysgraphia is having trouble with handwriting. I've always been accused of having dysgraphia, of course, being a doctor. Dyslexia, which is reading problems, word finding, switching letters; and dyscalculia are those, of course, problems with doing math.

What is Autism?

Next slide. So what is autism? What I really want to say it's a complex neurobiological disorder. It used to be broken out into all these different disorders. And through the DSM-5 and the work of the American Psychiatric and Psychological, they've made an umbrella phrase called autism spectrum disorder. The onset is usually before the age of three. There's a range of abilities and disabilities. Intellectual disability you can have children who are severely cognitively impaired or kids who actually test out on the gifted and talented.

There will be social impairments how they relate to other people, respond to social cues, unusual behaviors or stereotypies, which I'll get into, communication abilities and disabilities, and impairs in the limits of everyday functioning. And that is probably the most important line here, okay. We're all a little bit different, but where it matters is if it impairs our ability to function in this world.

And autism spectrum disorder is a lifelong disability. And we adapt, we can learn new skills; but once you have it, you have it. There's no cure for autism.

Next slide. So what are the hallmarks, the essential features of autism spectrum disorder? Persistent impairment and reciprocal social communication and social interaction; restrictive and repetitive patterns of behavior, interests, or activities. As we said, symptoms present from early childhood and they limit our ability to function every day.

Next slide. So the DSM-5 is the so-called, you know, I don't know, thesaurus bible for psychiatric mental health disorders and there has to be present criteria in the area of social communication or social interaction and these restrictive, repetitive patterns of

behavior. They must be present in early development, they must impair function, and, as we stated before, often they cannot be explained by other disorders.

You will hear a little bit later from both Dr. Hodges and myself there are many disorders that are comorbid, which means occur at the same time with autism spectrum disorder and the severity levels are 1, 2, or 3.

Next slide. So what do we mean by social communication and social interaction deficits? So what does that mean? They're unaware of other people's feelings. They could be with someone who's sobbing and crying and they pay no attention. They don't like try to calm- What do little kids usually do? They'll put a hand on you although you can see in their eyes that they're having some empathy.

They have problems identifying and explaining their own feelings. Lack of joint attention. They don't want to share activities, interests, or play time with anybody else; they don't have any changes in their facial expression; they lack the initiation of social interaction; and they're not used to the reciprocal conversation. Like little kids will go up to each other and they start babbling and talking back and forth. Individuals on the spectrum won't pick up on those cues and talk back.

I find often that they may not understand jokes or, in fact, they may have jokes that no one else understands. They may not understand sarcasm, flirting behavior, any kind of the social nuances that we know. And they may not even respond to their own name.

Next slide. And there's also deficits in nonverbal communication. I'm going to jump ahead a little bit and let you know that often parents talk about the first thing they notice

is speech problems. The kids aren't talking by the time it's expected to start repeating words, one- or two-word phrases. So usually it's the communication disorders both verbal and nonverbal are the first things that parents notice when they're concerned about the development of their child.

Many individuals on the spectrum have poor eye contact. They don't have any smile. They could be looking at something when a usual interaction would be a laugh or a smile, they don't do that. They don't understand the normal cues of nonverbal communication or body language or gestures. They can't tell if you're feeling anxious or you're feeling like they're in your space, they won't realize that. They'll get right in your face and even if you gesture, they won't know that you want them to back up.

They don't point, they don't gesture. Poorly integrated verbal and nonverbal communication. And just I want to highlight here every child that has autism spectrum disorder is one child with autism spectrum disorder. Every child is different and they can manifest symptoms all different times and in different ways. And, you know, as I said, they're poorly integrated verbal and nonverbal communication.

Next slide. They have difficulty in social interactions, maintaining and developing friendships, especially those that are appropriate to their developmental level. They have trouble adjusting to behavior in different social contexts whether it being going from home to school, to the ballpark, to a family social event, going out to dinner. They have difficulties in sharing imaginative play. One of the hallmarks of childhood is imaginative play – playing school, playing doctor, playing superheroes. A lot of these children may not be able to participate or don't participate because they don't know how

to really expand on their imagination. They often don't initiate interactions, don't respond appropriately to others, and they don't sustain. They prefer to be alone and some individuals don't have a lot of interest in really talking or being with other people.

Next slide. This is important. They often exhibit restrictive, repetitive patterns of behavior of interests. Of course, if you remember the movie *Rain Man*, okay, he had what was called autism spectrum disorder, autism, and his was with numbers and he had repetitive behaviors and he had to watch, remember, Judge Wapner and what was it, his court. That's an example. Or motor movements like you can see hand flapping, you can see pill rolling, or anything. Or I had a patient once that always had to hold in their left hand a little round ball and a toy car.

And actually some of it is self-soothing. It's the way that they keep themselves because what often happens to a child or a person with, they have so much sensory information going in, they have a hard time discerning them and processing them, so it's a way for them to self-sooth.

Aside from hand flapping, you can see kids that spin around, toe walking, and the repetitive use, as I said, of holding or having the same objects.

You can also see if you look in the illustration on the slide, there have been kids who go into rooms and they have to play with the light switch on and off, on and off, and that's not uncommon. We see a lot of that.

Next slide. Excessive adherence to routines. Often children on the spectrum have very ritualized things. They have to brush their teeth only after they comb their hair. Any

disruption in the routine is going to throw them off and many will tantrum. They "No, mom, I can't have breakfast until X, Y, Z is done." So it's very regimented. They like routines, they like ritualized patterns of verbal and nonverbal behavior, and they are often resistant to change.

So one of the things that we often talk about in treatment and help with parent education is about how to prepare kids to be able to make those transitions. How to prepare your child to transition from the house into the car because there are many kids who cannot easily go into the car. And as I said, extreme distress. Amazing tantrums happen and upset with teeny, little changes in the environment.

Next slide. And I said highly restricted and fixed interest-specific activities. So you may meet a youth who knows every detail about every World War II medal or a child who knows every statistic about baseball since Mickey Mantle started to play and will recite them and actually will engage you that way. That's the first thing they say to you. They want to start talking about what's familiar with them. Or they have a strong attachment or preoccupation with unusual objects, and they have really preservative interests. I mean just can go on and on and on about the same thing.

I had a child also that all they could talk about was early American History and the Civil War and the War of Independence. Now that person had great communication, but that's all they would talk about. And it was really hard at times to redirect and that was part of the treatment, which will be in our second seminar.

Next slide. And hyper and hypo-reactivity to sensory input. If you remember, and I hate using Dustin Hoffman in *Rain Man* he had times when he would start rocking when it

was too loud, when his brother was talking loud or the stimuli was too much. Often kids have hypersensation in smell, in touch, in taste. Taste is a very common one. Lots of kids on the spectrum we have to do a lot of work because they won't eat certain foods because they don't like the texture, they don't like the taste. Or I mean we've met individuals who say, "I'll only eat green food." I mean it's a lot of work and a lot of the treatment is about helping them be able to adapt and expand to what we would call a normative environment.

Sensory seeking. They are kids that will lick, will touch, will jump, smell. There are kids that want to smell every object around them. Fascinating with lights, like I said with the light switch; an indifference to pain, heat or cold, or oversensitivity. Lots of times you may see kids out in the community who are wearing headphones which helps to protect them from the overstimulation of the sound.

Next slide.

Dr. Hodges: So I want to spend a little bit of time talking about what autism can look like with some examples with our itty bittys. One of our goals here is to make sure that we're getting children diagnosed young. Early intervention is really key. So one of the big parts here is to figure out what are those symptoms we can look for in our really young population of kids?

So when we think about typical developmental milestones, some of these children may not meet them and some key ones are things like not responding to their name. So when you have a little one and you say their name, hopefully, your goal is that they're looking towards you towards that name and children on the spectrum may not.

Other things are examples like if mom or dad or some other caregiver is holding that young child who's in that toddler phase, right, 12 to 14 months, and they look up and go, "Hey, look at the airplane," you're typically developing child is going to turn and look up at that airplane. But children who are on the spectrum or at risk for that may not.

Those pretend games like Dr. Katz talked about that imaginative play is so key for our little itty bitty kids. And even young ones as young as 18 months should be doing some of those basic types of pretend things like feeding a doll or trying to shave like dad in the mirror. Those are types of pretend things that you may see even young children do. And if that's missing, it's sort of a risk factor to continue to look if there's other concerns within the autism spectrum disorder.

We talked about avoiding eye contact and that trouble understanding other people's feelings.

Now as you have an individual age, so even though we can look back and be able to see that symptoms were present before age 3, sometimes individuals may not be diagnosed with autism until we're in middle or even high school, times when the social demands really become far more complex for that individual to navigate. So when we talk about things like that, we're thinking about maybe giving unrelated answers to questions, right. Someone was trying to talk to them and they go off on a different topic. When everything is very black and white and that difficulty understanding teasing and even flirting behavior, like Dr. Katz mentioned earlier, those can be sort of cues as we move into that adolescent phase of life.

One of the other things that I wanted to mention here too was that sometimes children on the spectrum can have not only those unusual behaviors but sometimes dangerous behaviors too. So Dr. Katz talked a lot about tantrums, and when we think about children, children have tantrums, right. I've got three of my own. We all went through tantrum phases. But children on the spectrum, those tantrums are longer and more intense than we would see in a typically developing child. But they can also have things like self-injurious behavior, so head-banging or pinching themselves. We can also see those types of aggressive behaviors towards others in the forms of hitting, and biting, and kicking. So sometimes those behaviors are showing up due to that inability to communicate what they're looking for. Sometimes it's related to sensory concerns but those are also things that can co-occur with that diagnosis of autism.

The other thing I wanted to chat about before we move on to our next slide is one of the criteria within autism is that all the symptoms that they're displaying are not better accounted for by an intellectual disability. And intellectual and developmental concerns can certainly co-occur with children on the spectrum and do so commonly, in fact, but we need to ensure that those social communication challenges that the individual is displaying are below what would be expected for their developmental level. So as we talk more about diagnosis and evaluation, we'll chat about that more in detail.

So as I was starting to say, autism can co-occur with other disorders and this is pretty common. So your individuals with autism are actually unlikely to just have autism; there is often something else that's going to co-occur with that diagnosis. We're going to talk about sort of the behavioral things that can co-occur, behavioral health diagnoses and then medical diagnoses.

So on the behavioral health side, one of the most common things is ADHD, so attention deficit hyperactivity disorder, and this is a fairly common comorbidity. Some estimates range from maybe 50 to 70% of children can have both an autism and an ADHD diagnosis.

We talk about communication challenges so that speech can be delayed, both their ability to speak and express their language, along with understand it, so more on the receptive side.

The intellectual disabilities research kind of varies here in terms of how often there's a comorbid intellectual disability. Some older research was supporting that it was maybe between 50 and 60% of children with autism also had an intellectual disability. Newer research actually lowers that down to maybe 20 to 30% having kind of a true intellectual disability and then another maybe 20 to 25% having a borderline intellectual disability.

Differentiating here between an intellectual concern and autism can be difficult. If we think about someone with a severe or profound intellectual disability, it can be challenging to determine if those social communication skills, like Dr. Katz was talking about a few slides before, are really lower than that child's, you know, mental age that they're functioning at due to their intellectual disability.

We're really looking in those circumstances that a child who has intellectual disability without autism should still be able to show things like joint attention, you know, showing attention towards something, directing their attention; you know, that socially appropriate eye gaze. When we see autism and an intellectual disability co-occur, that child with autism won't have those types of skills.

We also see anxiety and depression can co-occur for individuals with autism and almost half of individuals will have either anxiety or depression comorbid.

We also include in here things like trauma. So research on trauma is still emerging but certainly we understand that children with an autism diagnosis are at an increased risk for exposure to traumatic events, so really determining and evaluating if there's a trauma-related disorder is important when there's an autism diagnosis.

If we kind of look over to the other side, we start talking about things on the medical comorbidities that can occur here. So one of the most common ones that people think about is seizure or an epilepsy disorder. Almost just under a third of children with autism also have some sort of seizure or epilepsy. It's really important to make sure that we're evaluating for that as part of an autism diagnosis.

I think back to a young child that I worked with and we were concerned he was having a seizure because his eyes would go back and forth, and we were concerned that was a type of seizure and had him evaluated. Turns out it wasn't seizures; it was actually repetitive behavior for that young man, but it was really important to be aware of the fact that a seizure disorder could be in place.

Sleep disorders also occur in almost half of children with autism, often related to difficulty falling asleep and waking up in the middle of the night. And think how challenging this can be for a parent to worry that their child with autism may be waking up and moving around the house in the middle of the night.

Feeding-related issues, food-related challenges, as Dr. Katz mentioned, some of that can be related to texture or even color issues but there's a lot of research out here, and this is another broad category, so research is somewhere between 30 and 80%. It's a really big range of individuals with autism have some sort of food issue, whether that's being really selective about their food intakes; sometimes it's sort of inappropriate mealtime behaviors or unhealthy eating habits.

Other things within this list there's often common comorbid genetic abnormalities that can happen with an autism disorder along with gastrointestinal issues. Sometimes that's related to the food issues. Sometimes it's a separate issue that's in place.

So as you can see, right, autism occurs, and we've sort of gone over the diagnostic criteria there, but autism so often co-occurs with other conditions that it's important to really consider that as we start to talk about evaluation.

Prevalence of ASD

Before we jump to evaluation though, let's talk a little bit about prevalence rates.

So the CDC actually updated the prevalence rates for autism earlier this year. So we're now at 1 in 36 children is diagnosed with autism. And I slow down to say that because I think about my own kids in classrooms where they have 20, 30, 40 kids in their classroom and especially as we get into middle and high school that means most children are in class, right, with someone who's diagnosed with an autism spectrum disorder. My guess is many of you hear today can think about someone you know or

someone you know who knows, right, someone in your life who has a family member with autism.

Autism occurs across all racial and ethnic and socioeconomic groups. Boys are nearly four times more likely than girls to have autism. You know, there's that when we look at autism, we know there's not one cause of it, but there are genetic factors; and I think sometimes that contributes to that 4:1 ratio there for boys versus girls.

When we think about that sort of no one cause, no exact cause of autism is known, we are starting to see that there's factors that have been identified as risk factors; things like those genetic complications, maybe challenges or complications at birth. The CDC is actually working on some studies to continue to look at those risk factors.

The other thing that's really important to talk about here is autism can be diagnosed really reliably by two and even younger now, and it's great to see some technology continuing to come out to try and reliably diagnose autism even younger by looking at things like that eye gaze, that socially appropriate eye contact because early intervention is really key. It's important to get services in place as early as possible to help make as many gains as that child has the capacity to do. It can help reduce the overall cost of managing the autism as a diagnosis as well.

We can't talk about autism without talking about their families and their caregivers. So taking a broad step back not just autism, but when we talk about children under the age of 18, 19% have some sort of special healthcare need. And when that happens within the family, now you have a caregiver that's twice as likely to need to utilize their mental health services as well due to their own challenges with anxiety and depression.

Learning that you have a child with an autism diagnosis or any diagnosis can sometimes come with a period of grief and balancing the different activities that you need to be engaged in – the therapies, coordinating services, navigating school services, right, all the different things that have now sort of come into the life of that family – you know, means that that caregiver may struggle with some of those emotions and anxieties that now exist a bit more frequently in their lives.

And an interesting statistic we came across as we were putting some of this together is that a third of caregivers sometimes reported having to stop working so that they could care for their individual in their family who had this diagnosis. It really speaks to the level of complexity of treatment and the needs that these young people may have. So it's important if we're working with a family who has a child or an adolescent or even a young adult diagnosed with autism to not just pay attention to that individual but the family as a whole and talk about their whole holistic needs that we can put into place to support them.

Developmental and ASC Screening

All right, let's switch gears a little bit and talk about screening for autism. So autism often is found, most likely, at that pediatric well visit, right. We're dragging our kids to the pediatrician often when they are young and there are screenings that occur as part of that pediatrician visit that occur routinely throughout those early childhood visits.